

INTERNATIONAL

Epilepsy News

GLOBAL CAMPAIGN IN LATIN AMERICA



European Epilepsy Day in Strasbourg





Rome Congress now on the horizon

It has been a busy few months for IBE since the last issue of IE News. While the end of a year can mark a period of slowing down and reflection, for the Bureau it was a time of great activity as we prepared for the important events taking place in 2011, IBE's Golden Jubilee Year.

First up was European Epilepsy Day (EED), plans and preparations for which started in mid-2010 when Gay Mitchell MEP kindly agreed to host the event on IBE's behalf, supported by ILAE. EED will be celebrated on the second Monday of February each year, which coincidentally fell on Valentine's Day this year. Almost 50

representatives from IBE member associations in Europe celebrated 14th February in Strasbourg in advance of the terrific events in the EU Parliament on the 15th, which you will read about in this issue. I would like to thank all those who were involved in EED, those who were with us in Strasbourg, as well as the member organisations who arranged terrific activities at national level. The enthusiasm of all made the launch of EED a wonderful success! With annual epilepsy days now taking place in several regions, IBE and ILAE are hoping to announce the creation of an annual International Epilepsy Day in the next few months!

The 29th International Epilepsy Congress is now on the horizon and I hope that we will be able to welcome at least one representative from each IBE member association to Rome, which will be the

highlight of our jubilee celebrations. One of the most interesting events will be a special gala dinner to highlight those exceptional people who have been awarded with Ambassador for Epilepsy Awards since they were introduced soon after IBE was founded. And have you seen the new changes to the IBE website to highlight IBE's Golden Jubilee?

Finally, I would like to highlight the new IBE/ILAE Joint Task Force for research and advocacy in Europe. This group will focus on both social and medical research opportunities in Europe and will also promote advocacy activities throughout Europe including European Epilepsy Day.

All the best,
Mike Glynn
President



EDITORIAL TEAM

Editor: Carlos Acevedo
carloredoacevedo@yahoo.com

Co-ordinator: Ann Little
ibedublin@eircom.net

Regional Sub Editors:

- ⊙ Noeline de Goede (Africa)
- ⊙ Tomás Mesa (Latin America)
- ⊙ Lisa Boylan (North America)
- ⊙ HV Srinivas (South East Asia)
- ⊙ Robert Cole (Western Pacific)

Advisors:

- ⊙ Mike Glynn
- ⊙ Grace Tan
- ⊙ Abdulaziz Al Semari
- ⊙ Shunglon Lai
- ⊙ Susanne Lund
- ⊙ Janet Mifsud
- ⊙ Vinod Saxena
- ⊙ Mary Secco
- ⊙ Anthony Zimba
- ⊙ Nico Moshé
- ⊙ Emilio Perucca
- ⊙ Sam Wiebe

ISSUE 4 - 2010

International Epilepsy News is the quarterly newsletter of the International Bureau for Epilepsy (IBE) and is circulated to IBE members, supporters and other subscribers in more than 120 countries. All enquiries to:

International Bureau for Epilepsy
11 Priory Hall, Blackrock,
Co Dublin, Ireland.

E: ibedublin@eircom.net

T: +353 1 210 8850

www.ibe-epilepsy.org

All rights, including moral rights, reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, without the prior permission in writing from the publisher. The Editor reserves the right to edit content for reasons of space or clarity. The views expressed in this magazine are not those of the publisher. Articles covering medical aspects of epilepsy are not intended to be taken as advice. They are not intended to replace medical care.

INTERNATIONAL RELATIONS

ECOSOC

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

WHO

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

SPONSORING PARTNERS

IBE acknowledges the support of its partnering sponsors listed below. Please contact us if you would like to learn about sponsoring opportunities with IBE.

Gold Partner

- ⊙ Dainippon Sumitomo Pharma Co., Ltd

Silver Partners

- ⊙ Eisai Europe Limited
- ⊙ GlaxoSmithKline
- ⊙ UCB Pharma

Other Partners

- ⊙ Cyberonics



Welcome to the newlook IE News

It has been a great and delightful summer here in the Southern Hemisphere, but it is now ending and, of course, the holiday season is also coming to a close.

First of all I would like to welcome you to this new design of IE News. We have made a few changes that I hope you will like. In this first issue of the new look magazine, I would like to announce that we have some excellent material for our readers, including a special report on the first European Epilepsy Day, which was celebrated on the 14th February in the European Parliament.

There are also reports on the congress in

Melbourne last October, including the Outstanding Persons with Epilepsy awards.

I would also like to congratulate Mrs Lynn Savill and Dr Simon Shorvon who have been honoured for their special dedication in the field of epilepsy. Still on the subject of awards, we highlight the winners of the Excellence in Journalism Awards, which have just been announced.

Harry Meinard is going to interest us with some further fascinating details about IBE's history. It is very important to read reports about activities at national level around the world and in this issue we have news from Brazil, Colombia and Italy. I would like to invite you to submit news from your association that we can include in the next issue.

In this number we also publish the results of the Excellence in Journalism Awards.

These are very appropriate awards, which encourage journalists to use correct terminology when writing or reporting on epilepsy.

You will find that the tables have been turned on me in this issue, as I am interviewed on the great strategic plan, which has been developed in Latin America in the framework of the Global Campaign against Epilepsy.

Finally, we encourage all readers to join IBE's Photography Competition; we give a small reminder to arrange this year's dues payment and, in doing so, ask you to remember those less advantaged by making a contribution to the Solidarity Fund.

Best wishes,
Dr Carlos Acevedo

Contents

- 1 President's Message
- 2 Editor's Letter
- 4 A new report about something great
- 6 Another report about something new
- 8 Story sent by our member in Africa
- 8 Report and interview about someone
- 9 Pictures from a recent congress
- 11 More Pictures about something
- 12 Another report
- 13 A sample story
- 14 More reports
- 14 Special mention about something new
- 18 Another story



Melbourne Memories

A busy year of regional congresses came to an end with the 8th Asian & Oceanian Epilepsy Congress in Melbourne in late October. The city and its people provided a warm welcome to delegates and the Scientific Committee, co-chaired by Simon Harvey (Australia), Shih Hui Lim (Singapore) and Shunglon Lai (Taiwan) ensured a terrific congress program. The main congress topics:

- Depression and Epilepsy
- Prevention of Epilepsy
- Predictors of Outcome of Epilepsy
- Epilepsy and Driving
- lent themselves to discussion of the social problems faced by people with epilepsy, their carers and healthcare providers. This was a very welcome aspect to the overall programme providing another opportunity to increase community awareness of epilepsy in order to change attitudes and to help reduce stigma.

Taking advantage of the opportunity, to coincide with the congress, the Epilepsy Foundation of Victoria hosted a Service Practitioners Forum immediately before the start of the congress, which was attended by 44 staff members epilepsy associations from all parts of Australia as well as from New Zealand. The full day meeting discussed topics of interest to all and also provided the platform to share knowledge and experiences of best practice.

Epilepsy & Society

The special program for people with epilepsy titled *Epilepsy & Society* was a highlight of the congress with 234 delegates attending. Organised by the IBE Western Pacific Regional Committee supported by the South East Asian Regional Committee, this was one of the largest attendances at such an event.

The major highlight of this day was the presentation of the *Outstanding Persons with Epilepsy* awards. This was the 5th time that these awards had been presented since they were first introduced during the 4th Asian & Oceanian Epilepsy Congress in Nagano, Japan under the guidance of Dr Park (Korea), Dr Marshall (Taiwan), Dr Kubota (Japan) and Dr Mehndiratta (India). The idea behind the awards is to encourage people with epilepsy not be

embarrassed or ashamed of their condition and to fight to overcome the heavy culturally defined stigma and discrimination that exists in the region

Recipients of the award in Melbourne:

- Dr Michelle Bellon, Australia
- Ms Cindy Li, China
- Ms Li Ying Yi, Hong Kong
- Ms Kavita D Shanbhag, India
- Mrs Noriko Fukui, Japan
- Mr T Munkh-Aldar, Mongolia
- Dr Mike Hills, New Zealand
- Dr Ronald Magbitang, Philippines
- Ms Shih-Min Li, Taiwan

There excellent presentations during the Epilepsy & Society program. Graham Scambler from University College of London presented a keynote address on epilepsy and stigma; popular Australian television sports presenter and past Australian Rugby League captain Wally Lewis, spoke movingly, and not without a generous dollop of humour, of his own experience of epilepsy spanning more than 20 years.

New Chinese Term for Epilepsy

An item of special importance was the news on the change of the Chinese term from epilepsy, which Anchor Hung explained. In Hong Kong, the Chinese (Cantonese) word had caused much suffering to the persons with epilepsy, labelled 'crazy' or 'insane' because of the old term, where the Chinese 1st character 'dian' meant 'crazy'. This had resulted in epilepsy being regarded as a mental illness.

The new term is a simple description of the biological nature of the condition, referring to 'brain'. This small change in the Chinese character now shows the condition to be neurological, thus instantaneously reducing the stigma burden. This was a monumental achievement as there are strict laws in place regulating the Chinese language and which are difficult to change.

Following on the Hong Kong, the Korean government has also changed the word for epilepsy to a more suitable name.

Regional Committees Meet

Regional congress provide a great opportunity for IBE Member associations to meet

and such was the case in Melbourne, with meetings of the South East Asian Regional Committee and the Western Pacific Regional Committee. There was a very good representation of IBE members at each of these meetings giving the opportunity to report on activities at local level as well as to formulate plans for joint activities moving forward. The meetings were followed by a joint meeting of the two regional committees and the chance to relax thanks to a very pleasant Cocktail Reception. Thanks are due to Robert Cole, Dr HV Srinivas and their committees for making these meetings possible.

Particular thanks are due to Robert, Denise Chapman and Graeme Shears who worked hard over a long period of time to make sure that the Epilepsy & Society programme was the success. They certainly succeeded!

Poster Exhibitions

The huge scale of the Melbourne Congress building gave us a great opportunity to showcase the work of IBE members in the region. An exhibition of Members Posters demonstrated the tremendous scope and diversity of activities carried out by epilepsy associations in the region. Almost thirty posters lined the walkway at the congress centre and were much admired by delegates.

We are now planning an extra special poster display in Rome!

Promising Strategies Showcased

Since its creation in 2005, the Promising Strategies Program of IBE has supported more than 30 project around the world. In Melbourne we showcased the projects that IBE has funded in the South East Asian and Western Pacific regions since the program began with another poster display. This was enhanced by an exhibition of the craftwork created by the Seahorse club in Shanghai, which received funding to create an artists studio in the last round of funding. Thanks are due to Dr Ding Ding, who was kind enough to bring to Melbourne framed pictures, beadwork, calligraphy and clothwork created by the people with epilepsy who are supported by the club in Shanghai.

8TH ASIAN OCEANIAN EPILEPSY CONGRESS

21–24 October 2010
Melbourne, Australia



1 Denise Chapman (Australia), Secretary of the IBE Western Pacific Regional Committee, chats with Hubert Barennes, a French doctor working Laos.

2 Anchor Hung, Hong Kong, explains the change to the Chinese word for epilepsy.

3 Mrs Ms Li Ying Yi, Hong Kong, receives an Outstanding Person with Epilepsy Award from Mike Glynn, IBE President.

4 Robert Cole (Australia), Chair of the IBE Western Pacific Regional Committee with Man Mohan Mehndiratta (India) Vice Chair of the IBE South East Asia Regional Committee.

5 Participants attending the Service Practitioners Forum, hosted by Epilepsy Victoria.

6 IBE Members from the South East Asia and Western Pacific regions attending a joint meeting of the committees.

7 Presentation of the Outstanding Persons with Epilepsy Awards.

Since when have you been working in the field of epilepsy in Chile?

I first joined the Chilean League Against Epilepsy in 1983 and became a member of its board in 1987. Subsequently I had the opportunity to start developing plans and participate in activities related to quality of life of people with epilepsy in Santiago, the capital of Chile. At that point in time the Chilean League was only active in Santiago. In 1988 I became President of the association.

In that the same year we managed to bring all local and regional Leagues in the country under the umbrella of the Chilean League and a national association was founded. Its membership included doctors as well as non-medical professionals and people with epilepsy. In 1998 a national association, ANLICHE, was founded, which became a Full Member of the International Bureau for Epilepsy in 1999.

A new epilepsy association, the Chilean Epilepsy Society, with the participation of the most important epileptologists in Chile, was founded in parallel in 1988, and became the ILAE representative in Chile. Both the Chilean Epilepsy Society and ANLICHE, like the Bureau and the League, are working closely together and the Presidents and Secretary-Generals of each organisation are also members of the sister-organisation.

Before that we had worked only at national level; membership of the international organisations literally opened borders for us.

What did this development mean for you personally?

During the 23rd International Epilepsy Congress in Prague in 1999 I was appointed by Philip Lee, then IBE President, as the Chair of the new Latin American IBE Regional Committee. Soon afterwards I became involved in the ILAE/IBE/WHO Global Campaign Against Epilepsy.



Main photo: Carlos Acevedo with his wife Keryma against a backdrop of Santiago de Chile. Right: Hanneke de Boer asks the questions

"membership of the international organisations literally opened borders for us"

The most important event that followed from this was the organisation of the 1st Latin American Epilepsy Congress, which was organised by the IBE Latin American Regional Committee and the ILAE Regional Commission with the involvement of PAHO and WHO Headquarters. The Regional Declaration on Epilepsy was developed and the now annual Latin American Epilepsy Day was inaugurated on 9 September 2000, when the President of Chile read the Declaration to all participants. Since then six further Latin American Epilepsy Congresses have been organised by the IBE Latin American Regional Committee and the ILAE Regional Commission.

Would you consider this to be the start of GCAE activities in the region?

One of the main activities carried out under the auspices of the campaign in the Latin American region was the successful Demonstration Project in Brazil, which was completed in 2005. In addition, sessions on Global Campaign activities in the region were organised at each regional congress.

Have there been any recent Global Campaign activities in the region?

During the past few years involvement of PAHO in the region has increased to a great degree with the arrival of Dr Jorge Rodriguez, PAHO/AMRO Regional Advisor for Mental Health and Neurological Disorders. Dr Tarun Dua, WHO was also involved. Recent activities include:

- In 2008 the Latin American Regional Report on Epilepsy was launched in Honduras;
- A workshop on epilepsy was organised, which also led to the initiation of the Demonstration Project in Honduras;
- A further workshop on Mental Health and Neurological disorders, including epilepsy, took place in Santiago, Chile.

During the 6th Latin American Epilepsy Congress a meeting was organised involving stakeholders in the region: IBE and ILAE Presidents, Latin American IBE/ILAE vice-presidents, representatives of the Global Campaign and of PAHO with the aim to develop a strategic epilepsy plan for the Americas.

Activities in the PAHO Region

Carlos Acevedo

In conversation with Hanneke de Boer



The aim of this plan is to have epilepsy included as a health priority for the next 10 years by the regional leadership of PAHO, which involves the Ministries of Health of all member states in the region. This would be the first time that epilepsy was considered a priority in the 100 years of PAHO's existence.

In the months between November 2010 and February 2011 several drafts of this strategic plan have been prepared and circulated in North-, Central- and Latin America. This activity was co-ordinated by Dr Rodriguez of PAHO, Marco Tulio Medina - Honduras (ILAE Vice President Latin America) and myself (IBE Secretary General and Vice President Latin American Regional Committee).

During this period five meetings have taken place (in Argentina Chile, Guatemala, Honduras and Panama) organised by PAHO with important contributions from the ILAE North American Regional Commission. At present the document

is being circulated within PAHO for an internal review. The PAHO Director will assess the document in March and it is to be expected that she will approve it. However, the Director may make some recommendations, which will have to be dealt with. The working group will have a final review in order to do so.

Finally, the document will have to be translated into English, Portuguese and French and should be posted on the PAHO website and available to all by the end of April. In September, during the Annual Meeting of all Health Ministers from the Americas, which will take place in Washington DC, the document will, hopefully, be approved.

It is usual for a procedure for approval such as this to take a minimum of at least a year to accomplish. However, in this case the entire process went extremely fast and took just four months, thanks to the determination and enormous efforts of all those involved.

What is the significance of this strategic plan document and the importance of its approval?

I believe the significance is threefold:

1. The entire process in developing the document strengthened the relationship between PAHO/AMRO and IBE/ILAE;
2. This procedure and this document may be a model which can be used in the other regions of the world;
3. The document will lead to a commitment of all countries in the region to develop a national plan for epilepsy, based on the national realities. All countries will be obliged to submit an annual progress report to PAHO/WHO. This entire process was initiated under the auspices of the Global Campaign and followed Goal 4 of the Strategic Plan of the Campaign's Taskforce: *to increase partnerships and collaboration with other organisations*. This process involved the following two necessary actions:

- Organisation of a regional meeting during a regional congress.
- Development of an action plan and setting up a task force in each country, comprising the Chairs of the IBE Latin American Regional Committee and the ILAE Regional Commission, the local representative of PAHO and a delegate of the Ministry of Health.

We have done just that and now we are keeping our fingers crossed and hoping that it will work for the Americas and, if it does, for all regions of the world!



Finally,

after some years of discussion and six months of frenetic preparations, European Epilepsy Day became a reality in Europe on the feast of Valentine, Monday 14th February.

To celebrate this great occasion, almost 50 representatives from 26 IBE member associations in 20 countries travelled to Strasbourg to participate in special activities on 15th February, organised by IBE

and hosted by Gay Mitchell, an Irish Member of the European Parliament (MEP). Using the theme 'The Many Faces of Epilepsy' European Epilepsy Day 2011 aimed to highlight to MEPs and European Commissioners:

- that epilepsy remains a hidden disease due to stigma;
- that it is a treatable disease yet up to 40% of people in Europe who have epilepsy do not receive appropriate treatment;
- that lack of treatment imposes a huge financial burden on

national health systems;

- that research and legislation remain key issues in improving quality of life of persons with epilepsy.

Two main activities had been planned, a Lunch Discussion and, later in the evening, a reception to mark the official launch of an exhibition highlighting the facts about epilepsy and the problems faced by people with epilepsy.

Speakers at the lunch discussion included Hanna Mathes and David Josephs, who spoke very movingly

European Epilepsy Day becomes a reality in Strasbourg



*The Louise Weiss building, one of the two main European Parliament Buildings in Strasbourg. Photo: Ann Little
Turn the page for more photographs from the launch.*

of their experiences of living with epilepsy and caring for a child with epilepsy, respectively. Many of the MEPs present remarked on how touched they were by these remarkable presentations. Other speakers included Alexis Arzimanoglou, a child neurologist from Lyon, France and Tarun Dua from the WHO. Gay Mitchell acted as host.

The Many Faces of Epilepsy exhibition was officially opened by EU Vice President, Edward McMillan-Scott, who excused himself from chairing a very important meeting

in order to do so. Although other commitments prevented his attendance, EU President Mr Jerzy Buzek sent a letter expressing his support for the initiative.

In addition, a small delegation attended very significant private meetings with Mr John Dalli, Commissioner for Health and Family Policy and with Mrs Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science. Throughout the day, IBE member representatives attended personal meetings with their national represen-

tatives in the European Parliament, providing the ideal opportunity for MEPs to learn about the difficulties faced by people with epilepsy in their own countries.

A total of 56 MEPs and two EU Commissioners participated in European Epilepsy Day - a figure of which other NGOs would be very envious! The launch of a European Advocates for Epilepsy special interest group was announced in Strasbourg, as well as a European Declaration on Epilepsy. We will bring you more news as these are initiatives are developed.



1



2



3

European Epilepsy Day Captured on camera

Cover Photograph: John Dalli, Commissioner for Health and Consumer Policy accepts a souvenir plaque from Mike Glynn. Inset: Maire Geoghegan-Quinn, EU Commissioner for Research, Innovation and Science, with Mike Glynn.

- 1 A very impressive line up!** Eighteen of the 56 MEPs who participated in celebrating European Epilepsy Day line up against a backdrop of the **Many Faces of Epilepsy** poster exhibition.
- 2 Meeting with Commissioner Dalli:** Attending the private meeting with Mr John Dalli, Commissioner for Health and Consumer Policy are, from left, Victoria Dimech, Member of the IBE European Regional Executive Committee; Janet Mifsud, IBE Vice President Europe; Nico Moshé, ILAE President; Commissioner Dalli; Mike Glynn, IBE President; Emilio Perucca, ILAE Treasurer; and Ann Little, IBE Executive Director.
- 3 The delegation arrives:** Arriving at the parliament are, from left, Richard Holmes, IBE/ILAE International Director of Meetings; Aisling Farrell, Vice Chair of the IBE European Regional Executive Committee; Ciaran Duffy, Enterprise Ireland; Tarun Dua (speaker), WHO; Sofia Kasradze, Georgia; Alexis Arzimanoglou (speaker), France; and Thanos Covanis, Chair of the IBE European Regional Executive Committee.



6



7



4 IBE Member representatives: Back row from left, Daniel Kiss, Hungary; Margaretha Andersson, Sweden; Caroline Morton, Netherlands; Anne Soehnel, Germany. Front row: Eva Teysslerova, Czech Republic and Helena Schwarz, Germany.

5 The Many Faces of Epilepsy: European Union Vice President Edward McMillan-Scott launches the poster exhibition, which ran in one of the principal walkways in the Strasbourg Parliament building from 14th to 16th February.

6 A group of Irish MEPs: Four of the nine Irish MEPs who attended the events in the Parliament, pictured with Mike Glynn. From left, Sean Kelly, Máiread McGuinness, Gay Mitchell, Mike Glynn and Jim Higgins.

7 A full house for lunch: The 70+ people who attended the lively Lunch Discussion are welcomed by Gay Mitchell. To his immediate left is Hanna Mathes, Germany, who gave a compelling account of her life with epilepsy. David Josephs, UK, also spoke movingly of caring for a son with severe epilepsy.

8 Rehearsal dinner: IBE members gathered for dinner on the evening of the 14th February, for final preparations in advance of activities in the parliament the following day.

9 Raising awareness with Finnish MEPs: Reetta Kälviäinen, Finland, speaks with Mr Hannu Takkula and Mrs Sari Essayah, two of four MEPs who attended the Lunch Discussion.



Thank You!

IBE would like to extend its very sincere thanks to all those who lent to the success of the first European. A little like the Oscars, there are so many people to thank, that we fear someone might be overlooked! First we must thank Gay Mitchell, who acted as host to the events in Strasbourg. Gay's assistant Gráinne Delaney provided an enormous level of support to the IBE office and also assisted in setting up meetings with Commissioners Geoghegan-Quinn and Dalli. We would also like to thank Jim

Higgins, MEP, who was Questar for the exhibition. European Union Vice President Edward McMillan-Scott opened the exhibition for us, excusing himself from another meeting which he was due to chair. For this we are also grateful.

Our Lunch Discussion speakers made a huge impression on MEPs attending, so thank you to Hanna Mathes, David Josephs, Tarun Dua, and Alexis Arzimanglou. We would like to thank all those IBE member representatives from 20 different

countries who made, at times arduous, journeys to be with us in Strasbourg. And we mustn't forget the many activities organised by IBE members at national level. A final thank you goes to the Commissioners, their members of cabinet and to the 56 MEPs, listed below, who agreed to private meetings, and who came along to learn about epilepsy and to meet with their constituents.

Thank You All!

COMMISSIONERS

Máire Geoghegan-Quinn,
Commissioner for Research,
Innovation & Science

John Dalli,
Commissioner for Health &
Consumer Policy

MEMBERS OF CABINET

Philippe Cupers, DG Research
and Innovation
Karl Freese, DG SANCO

MEPs

AUSTRIA

Ulrike Lunacek
Angelika Werthmann

BULGARIA

Iliana Malinova Iotova
Iliana Ivanova
Ivailo Kalfin
Andrey Kovatchev

Mariya Nedelcheva
Antonyia Parvanova
Kristian Vigenin

FINLAND

Sari Essayah
Satu Hassi
Ville Itälä
Anneli Jäätteenmäki
Eija-Riitta Korhola
Hannu Takkula
Sirpa Pietikäinen

FRANCE

Nathalie Griesbeck

GERMANY

Peter Liese

GREECE

Marietta Giannakou

HUNGARY

Andras Gyürk
Krisztina Morvai

IRELAND

Nessa Childers
Proinsias De Rossa
Pat the Cope Gallagher
Marion Harkin

Jim Higgins
Joe Higgins
Seán Kelly
Mairead McGuinness
Gay Mitchell

ITALY

Niccolò Rinaldi
Oreste Rossi
Giancarlo Scottà
Marco Scurria
Iva Zanicchi

MALTA

Simon Busuttill
David Casa
Louis Grech
Edward Scicluna

NETHERLANDS

Lucas Hartong
Lambert van Nistelrooij
Ria Oomen-Ruijten
Wim van de Kamp

POLAND

Filip Kaczmarek
Jacek Protasiewicz
Adam Siekierski Czeslaw

SLOVENIA

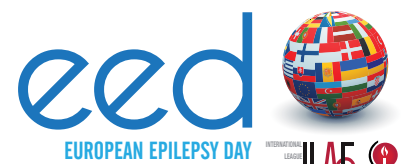
Tanja Fajon
Jelko Kacin

SWEDEN

Gunnar Hökmark
Alf Svensson
Marita Ulvskog

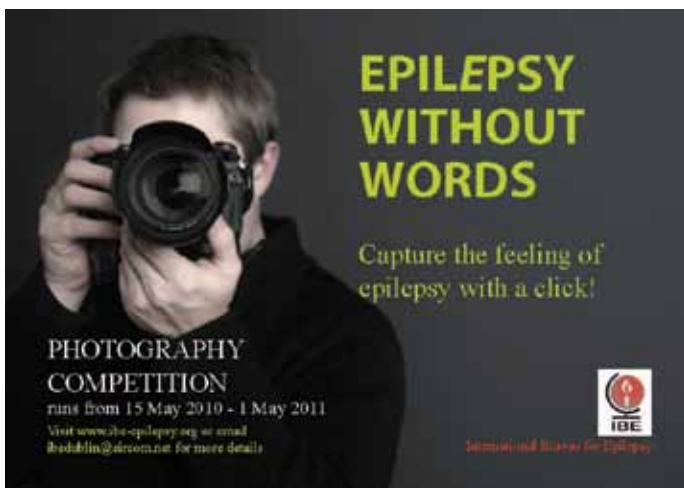
UK

Edward McMillan-Scott
Peter Skinner
Catherine Stihler
Keith Taylor
Glenis Willmott



The impressive courtyard of the Louise Weiss parliament building in which the European Epilepsy Day activities were held.

Photo: Michael Alexa



EPILEPSY WITHOUT WORDS

Capture the feeling of epilepsy with a click!

PHOTOGRAPHY COMPETITION
runs from 15 May 2010 - 1 May 2011

Visit www.ibe-epilepsy.org or email ibedublin@eircom.net for more details

IBE
International Bureau for Epilepsy

Don't Miss Out!

The closing date for entries to the IBE Golden Jubilee photo competition is now only weeks away.

With a prize fund of US\$7,000 this is a great chance for anyone with a camera (or mobile phone) and a good eye for a photo opportunity to win one of the six prizes on offer. All details on the competition are available on the IBE website

www.ibe-epilepsy.org/jubilee/jubilee-photo-competition.

An exhibition of Epilepsy Without Words will be mounted at the 29th International Epilepsy Congress in Rome at the end of August, when the prizewinners will be announced.



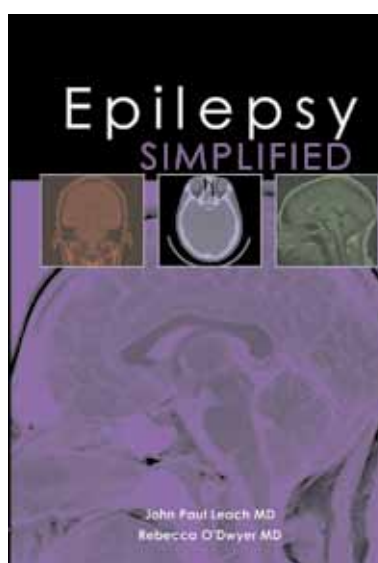
IBE sends its best wishes to Lynn Savill, who was awarded an MBE in Queen Elizabeth's New Year's Honours List, for her dedicated voluntary work for people with epilepsy. Lynn founded the Gravesend Epilepsy Network more than 30 years ago, when her daughter was diagnosed with epilepsy following an accident. The Member of the Order of the British Empire (MBE) is awarded to individuals for outstanding service to the community that merits public recognition. Lynn was presented with her MBE medal by Prince Charles.



Dr Simon Shorvon, University College of London, was recently awarded the William G Lennox Award for 2010. Dr Shorvon is a leading authority on status epilepticus and is also editor of the ILAE journal *Epilepsia*.

Dr Shorvon was among the first to conduct studies documenting the treatment gap for people with epilepsy in the developing world. Among many contributions to the field are his creation of the world's first MRI unit dedicated solely to epilepsy research; extensive research on antiepileptic drugs; and, studies of prognosis, mortality and life expectancy in epilepsy.

The Lennox Award is conferred by the American Epilepsy Society and the Lennox and Lombroso Trust for Epilepsy Research and Training.



Epilepsy Simplified

John Paul Leach MD
Rebecca O'Dwyer MD

ISBN: 978 1 903378 73 1
Published December 2010

This recently published book is intended to act both as a stimulus and guide for everyday management of epilepsy for all clinicians treating patients with this condition: neurologists, GPs, doctors in training, hospital pharmacists, primary care physicians, nurses and nurse practitioners.

John Paul Leach and Rebecca O'Dwyer, neurologists based in Glasgow and Washington, have produced this work to make the process of diagnosing and treating epilepsy as accessible as possible, and to debunk the myths around this common neurological disorder. Drs O'Dwyer and Leach have produced a very readable summary of their experience and knowledge, which will benefit both doctors and people with epilepsy alike.

Price: £30; US\$59.95; EUR 45; softback; 182pp;
To order: visit www.tfmpublishing.com



Harry Meinardi recounts more of IBE's history

Although the IBE was conceived in 1961 in Rome it was delivered at its first formal meeting on Thursday, September 4th 1965 in Vienna.

In 1965 IBE is still an informal organisation; however by 1966 a small office is established on the premises of the British Epilepsy Association (BEpA) at 3-6 Albert Place, London WC1. Mrs Isabel Little, formerly personal secretary of George Burden at BEpA, left BEpA to become half-time secretary of IBE and to take care of the day-to-day running of the office.

The next important step took place during the 10th World Congress of the International Society for Rehabilitation of the Disabled in Wiesbaden Germany.

There the first Constitution of IBE was agreed upon during a meeting on September 15th 1966 at the Schloss Hotel, Grünerwald. The following officers were elected:

President and Chairman of the Council:

- Mrs Ellen Grass, USA

Vice Presidents:

- Dr Amparo Arcaya, Chile
- Dr Mogens Lund, Denmark
- Dr Karl-Axel Melin, Sweden

Treasurer:

- Miss Irene Gairdner, England

Secretary General:

- Mr George Burden, England

In the Constitution, provision was made for each corporate member (a national state organisation or institution) to nominate a representative to the Council. The newly elected President gave the following message:

Presidential Message

"Lord, have mercy on my son, for he is an epilept and he suffers terribly; for often he falls into the fire and often into the water. And I brought him to your disciples, and they could not heal him." (Matthew 17: 15-16 Revised Standard Version of the Bible.)

These two simple sentences, written centuries ago, justify an International Bureau for Epilepsy, and point the direction for its programme.

First, mercy for the epileptic¹ is asked. Let this not be construed as maudlin pity, for pity alone fast burns out and achieves nothing. Further, handicapped² persons prefer to be respected for what they can do, rather than be accorded special privileges. Our mercy should find expression in skilfully planned rehabilitation, educational and vocational programmes that produce useful citizens.

Second, the verse points out "he suffers terribly." True, the convulsion itself seems tortuous to the beholder - often the stricken family - but the epileptic¹ is mercifully unconscious. His suffering comes later, during the days dreading the next attack and the shame of coming to. Even worse is the ostracism from school, from companionship, from employment and often from marriage. Affording relief from this suffering through an enlightened programme of social education is certainly a major province of the Bureau.

Third, Matthew says, "and they could not heal him." If one reads further, Jesus then explains why his disciples were unsuccessful and he himself shows them how to cure the boy. Clearly the medical management of seizures is the province of our ally, the International League Against Epilepsy. But jointly, we should encourage research and urge the training of many more specialists in neurology and epilepsy, so that the benefits of modern concepts of seizure control can extend throughout the world.

I have assumed the task of guiding the Bureau in these early years with great misgivings as to my worthiness to serve. I am consoled, however, by the zeal and enormous abilities of the officers who have graciously consented to work by my side. We shall count heavily on the guidance of the International League as well. We welcome your suggestions on programmes and procedures, and our sincere wish is that you will communicate with us fully and often.

With warm greetings.

Ellen Grass, President

Look Back with Pride
1965 - 1969

One of the special meetings at the congress in Wiesbaden was organised by IBE and its topic, appropriately, was Epilepsy and Insurance.

In Newsletter No 11 a profile of the elected president was presented by Irene Gairdner. In the following issues 12, 13 and 14 the profiles of the vice-presidents Mogens Lund, Amparo Arcayo and Karl-Axel Melin were sketched.

Extracting the 1965-1969 history of IBE from its Newsletters we notice that a standard item in these letters were reports about who came to visit the office. Such lists may have helped readers to realize who and where other persons interested in the care and rehabilitation of people with epilepsy were to be found. A similar function was served by reports of the peripatetic Secretary General George Burden. The most authoritative summary of activities is obviously his quadrennial report to the General Assembly. However, integral reproduction would cause this overview to exceed by far its permitted length.

The office of the IBE in its early days thrived because of the generous assistance of the British Epilepsy Association, which allowed their employee George Burden and his personal secretary Isabel Little to spend half of their time on IBE business. But now that IBE had been established it was time that it should also “hold up its own trousers”.

A grant from the International Society for Rehabilitation of the Disabled (ISRDI), made possible because of an anonymous donor in USA, created the financial situation in which this became feasible. Thus it was in the early months of 1966 that Mrs Isabel Little, who had wanted to relinquish her full-time appointment with the BEpA in favour of a part-time appointment, became the first salaried staff member of the Bureau on a half-time basis. Her appointment was reflected in immediate progress in developing the membership and in formulating a Constitution.

On 1st January 1969 George Burden resigned from the post of General Secretary of BEpA to remain half-time with that organisation as Director of their newly established Information Unit. At the same time he was appointed half-time Secretary-

General of IBE (receiving a salary commensurate with this). As IBE had started its activities as a guest of the BEpA it also moved in 1966 with that organisation from 27 Nassau Street, London W1 to its new location at 3-6 Alfred Place, London WC1, but from 1968 onwards IBE started to pay for space and services. In this period Mrs Little³, who was expecting a baby, resigned and Astrid Weld (presently Astrid Gregor-Weld) took over from her as full-time executive secretary.

To highlight how IBE fared in the period under consideration it is best to summarize the quadrennial report that was presented by the Secretary General to the General Assembly.

In its earliest years meetings organised by IBE were part of congresses of other organisations. In 1965 the meeting on Epilepsy and Driving Licences was held during the 8th International Congress of Neurology. In 1966 IBE met at the 8th Congress of the International Society for Rehabilitation of the Disabled in Wiesbaden; here the first Constitution of IBE was formally adopted. A special meeting of the Wiesbaden congress was held in Heidelberg and dealt with Epilepsy and Insurance. In 1967 the first independent European Conference on Epilepsy (called Institute following an American example) was organised together with the French ILAE chapter in Paris. In 1968 the 2nd European Institute was held in Dunblane, Scotland. (*H.M.: It is interesting to note that the International Bureau for Epilepsy, named its meetings “European”!*)

In 1969 IBE and ILAE both held their meeting/congress as part of the 9th International Congress of Neurology in New York.

Not only did IBE organise meetings: as part of establishing IBE as the international umbrella organisation of national organisations or individuals caring for the social aspects of epilepsy the Secretary General travelled widely. At the end of 1965 he visited Canada, the USA, New Zealand, Australia, Thailand, India, Greece and Italy.

In 1966 he took part in the launch of an Irish Epilepsy Association. In 1967 the Secretary General took part in meetings of the German League and of the joint

Austrian and Swiss sections of the ILAE. Furthermore he visited the Belgian social organisation called Les Amis de la Ligue Nationale Belge contre l'Epilepsie and a leaflet in Portuguese was prepared to assist in the setting up of an association in that country.

In 1968, assisted by a grant from the British Commonwealth Foundation, the Secretary General visited Nigeria and Ghana in January and again in December (when apparently he also other Commonwealth countries but these are not mentioned by name). In September the Secretary General took part in a seminar on Epilepsy in Africa, which was held in Marseilles.

Now with IBE well established it is good to remember that at first there were many doubts about its viability. In order to offer some insight into its growth the report to the General Assembly presented an overview of the increase in correspondence produced in 1965, versus the output in 1968, showing that the total output had more than doubled and in particular personal enquiries, advice and cases had quadrupled.

IBE membership at the time of the 1969 General assembly was:

- 22 National and State Associations,
- 21 Institutions
- 54 Individual Members
- 18 ILAE members (chapters) by virtue of the inclusive subscription agreed at the onset.

The report of the Secretary General also had a section “The Shape of Things to Come” which space does not permit to reproduce. However, in the next issue of this overview, you will be able to read about the The Shape of Things that Came in the period 1969 – 1973.

Notes:

1. While usage of the term 'epileptic' as a pronoun to describe a person with epilepsy was common parlance in the 1960's, such usage is no longer acceptable. The acceptable term is 'a person with epilepsy'.

2. Likewise, the word 'handicapped' is now also frowned on. It is preferable to say that the person 'has a disability'.

3. Isabel Little is still involved in the epilepsy field as a Vice President of the English charity Epilepsy Research UK.

EPILEPSY AT SCHOOL: TEACHING THE TEACHERS

Educational Plan of the Associação Brasileira de Epilepsia

Report by Laura Guilhoto

Children with epilepsy suffer prejudice at school which is responsible for much of the stigma in adult life. Teacher's knowledge about epilepsy can have a direct impact regarding school and social achievements and consequently, employment and networking in adult life. Despite the important role of educators, little research has been undertaken in this field anywhere in the world.

Brazil is the largest developing South American country with a population of 190 million.

Teachers play a fundamental role in the acceptance of diversity and the fight against discrimination, and as they are not well informed or trained regarding epilepsy, Associação Brasileira de Epilepsia (ABE), IBE's Member in Brazil, proposed an intervention program in elementary schools in Sao Paulo State, called "*Epilepsy at School: Teaching the Teachers*" - one of the programs selected for IBE Promising Strategies funding in 2008.

The program comprises a lecture with simple didactic visual resources on the following aspects of epilepsy:

1. basic aspects of brain anatomy;
2. definition;
3. causes;
4. epidemiology;
5. diagnosis;
6. treatment;
7. first-aid during a seizure;
8. psychological and social consequences;
9. false myths on epilepsy;
10. Global Campaign Against Epilepsy.

A questionnaire was developed by ABE experts with 35 true or false questions on the following:

1. Concepts, definition and causes of epilepsy;
2. Treatment and adverse effects of antiepileptic medication;
3. Epilepsy stigma;
4. Activities of people with epilepsy (PWE);
5. First aid during and after a seizure.

The questionnaire was presented to teachers before the lecture "*Epilepsy: Causes, Symptoms and Treatment*" given by a health professional from ABE (phase 1) and again afterwards (phase 2). The lecture was given either through classical live class (CC) or video-conference (VC).

Mean of correct answers in phase 1 in CC was 78% and VC, 79% and in phase 2 in CC, 86% and VC, 86%, reflecting increased knowledge in phase 2 in both strategies.

The areas with greater improvement in knowledge between phases 1 and 2 were, "First-aid during an epileptic seizure", followed by "Activities of PWE", and finally "Concepts and definition of epilepsy and its causes" and "Treatment and adverse effects of antiepileptic medication". In the topic "Popular stigma about epilepsy" there was a decrease in the number of correct answers after the lecture.

"Teachers play a fundamental role in the acceptance of diversity and the fight against discrimination"

The topics "popular stigma" and "first aid during seizures" had the lowest correct scores in phase 1 (CC+VC), 74% and 72%, respectively. The highest gain in phase 2 was observed in "First aid" and the lowest (0.1%), in "Popular stigma". There was a significant variation in "First aid" in CC, 41% compared to VC, 33%.

There was an overall improvement in knowledge after the lecture. The area most impacted was "First-aid during an epileptic seizure" which rose from 71 to 89% of correct answers between phases 1 and 2. This probably reflects the low knowledge of first-aid care in the general population due to stigma. Another area of great impact was "Activities of PWE", which had 88% of correct answers in phase 2. In these two areas the information was probably easier to learn because the principles were transmitted as true "rules" based either on scientific or legal aspects.

The topics "Concepts and definition of epilepsy and its causes" and "Treatment and adverse effects of antiepileptic medication" showed good improvement but somewhat inferior to the previous mentioned areas. This may reflect the broad range of definitions and treatment options for epilepsy.

The poor results in phase 2 observed in the topic "Popular stigma about epilepsy" may



Excellence in Epilepsy Journalism Awards 2010

Winners Announced

The winners of the 2010 Excellence in Epilepsy Journalism Award have just been announced.

The award, a joint initiative of the IBE and the UCB, aims to raise awareness about epilepsy across the globe by recognising journalists who have excelled in reporting compelling and informed stories that engage the audience on the topic of epilepsy.

IBE President Mike Glynn, an award judge, commented:

“This year’s Excellence in Epilepsy Journalism Award saw an increased number of entries, with the overall standard being particularly high. A total of 43 entries from 17 countries were submitted, ranging from messages of hope to moving personal accounts, which shows that the message on epilepsy is united across the globe.

“We congratulate and thank all journalists who submitted entries for their dedication to responsible and educational reporting on epilepsy.”

An independent seven-member judging panel, made up of media experts and people with experience of epilepsy,

were tasked with identifying responsible, original and informed stories that were well structured and researched, built on a foundation of responsible reporting and that gave a voice to people with epilepsy.

The winner of the Print category was Makiko Tatebayashi for her article *Let’s Know Epilepsy*, which featured as a seven-part series in the Japanese newspaper Yomiuri Shimbun.

Jessica Solodar was the winner of the Online category for her article *Seizures triggered by video games: Underestimated and undiagnosed* which was posted on the web-site epilepsy.com.

Winner of the Broadcast category was Niamh Maher, producer of the “*This Is Me*”, for her documentary “*Not Out*”, which was broadcast on Radió Teilifís Éireann 1.



Jessica Solodar (pictured above), award winner of the Online category.



The winner of the Print category award was Makiko Tatebayashi (pictured left).

have been caused by:

1. inadequate questions;
2. difficulties of health professionals to transmit information in a simple and direct way to lay people.

We also noted difficulties in understanding differences between the terms “to cause” and “to predispose” the occurrence of an epileptic seizure.

In conclusion, we observed that teachers in the Elementary Schools surveyed, had basic knowledge on epilepsy, which could be improved after the lecture. There were no significant differences between types of presentation (CC/VC), although CC was more efficient in teaching first aid during seizures. Popular stigma about epilepsy knowledge has not improved after the lectures and this subject needs further research and efforts for better understanding and action planning.

Support:

- International Bureau for Epilepsy (Promising Strategies Program 2008);

- Companhia de Seguros Aliança do Brasil;
- Secretaria da Educação do Estado de São Paulo, Brazil.

Acknowledgements:

1. Heloise Martins, Marcos Vidal-Dourado, Erika Almeida, Sueli Mesquita, Carlos Tavares, Katia Lin, Veriano Alexandre Jr., Elza Márcia Yacubian, Alzira Castro, Alice Masuko.
2. Adriana Mendonça, Maria Helena Martins, Marcos Galvez, Marluce Camarinho, Natalina Mateus, Rose Jurjuck.
3. Carlos Luque.

1. Associação Brasileira de Epilepsia (ABE, Oficial Brazilian Chapter of the International Bureau for Epilepsy)
2. Secretaria Estadual da Educação do Estado de São Paulo; Brazil,
3. School of Economics, Business and Accounting at the University of São Paulo, Brazil.

References

Guilhoto LMF et al. J Epilepsy Clin Neurophysiol 2010; 16(2):80-86.





Colombia Introduces Epilepsy Law

New legislation protects persons with epilepsy

Dear Friends

It's with great joy that I send you a copy of Law No.1414 of 11 November 2010 signed and ratified by the President of the Republic, Juan Manuel Santos. There is no doubt of the benefit of this law. Now we must regulate it, but it is a law and enforceable. Colombia has pioneered the world in introducing human rights legislation for the 800,000 people with epilepsy living in Colombia.

We will send this law document to Strasbourg, where the Court of Human Rights of the European Union and Human Rights Watch is based, so that people with epilepsy in Colombia will have an international court to which appeal, if our country does not comply with the law.

I ask you to promote this law and make it known to lawyers, judges, teachers, councilors, students, in fact, to everyone.

*With best wishes
Jaime*

This joyous message was sent to IBE at the beginning of this year by Dr Jaime Fandiño-Franky, who, together with his colleagues at FIRE and the Colombian League Against Epilepsy, had toiled for a long time to see the introduction of legislation in favour of persons with epilepsy in Colombia. It had been a long and arduous road and, on more than one occasion, impediments had appeared, just as the finish line was in sight. But, finally, it was time to celebrate as the law entered the statute books on 11th November 2010.

Pictured from left: Jaime Fandiño-Franky, Senator Manuel Virgúez, who was instrumental in bringing about the introduction of the new legislation in Colombia, and Roberto Cadavid, a lawyer who also worked on the campaign

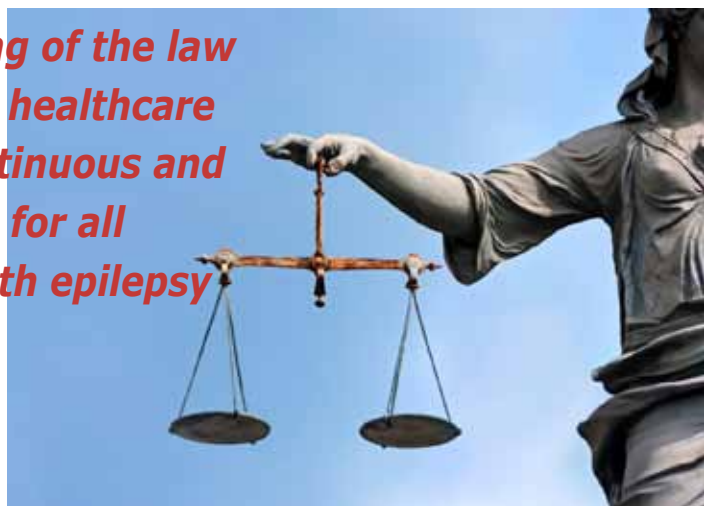
So what exactly will it mean for people with epilepsy in Colombia? The simple answer is that it will mean a lot - on the assumption that the law will be implemented correctly.

treatment, GP and specialised care, and access to support groups. Recognising the importance of the carer or family group, these will have access to education, as well as assistance in accompanying the person

The wording of the law states that healthcare will be continuous and permanent for all persons with epilepsy

The objective of the law is to guarantee the protection and care of persons with epilepsy. The legislation recognises that epilepsy is a chronic disease characterised by recurrent seizures and rules that safeguards be put in place to ensure comprehensive care to include education; prevention; early detection to prevent physical and mental complications; and diagnosis and treatment (including surgical intervention, medication, and rehabilitation).

The wording of the law states that healthcare will be continuous and permanent for all persons with epilepsy with the aim of identifying appropriate multi-disciplinary



with epilepsy in the role of guardian.

Rehabilitation is recognised as a process of limited duration, with a defined objective, directed at guaranteeing that the person with epilepsy attains optimal physical, mental, social and functional levels.

The law demands the absence of barriers that might prevent the person with epilepsy from receiving the necessary health and social services that would assist in his or her integration into quality family, social or employment environments.

The law prohibits acts of discrimination, in any form, against the person with epilepsy. It states that to complement the principal of solidarity, society in general, organisations, institutions, the family and, in addition, specialised national and international entities, will participate in joint activities to promote, educate and protect all persons with epilepsy.

The legislation states that the Colombian National Government will safeguard the dignity and human rights of all persons with epilepsy

More importantly, the legislation states that the Colombian National Government will safeguard the dignity and human rights of all persons with epilepsy and promote conditions to ensure equal rights for persons with epilepsy in laws, liberty and opportunities, without discrimination.

To achieve the objectives of this law, in particular to accomplish the principle of solidarity, health authorities will implement awareness programmes for the public, to promote education, prevention and

treatment and to guarantee the fundamental rights of persons with epilepsy.

The national government is legislated to establish strategies for international cooperation, in order to facilitate adoption of this law, and to implement mechanisms that will allow the development of strategic projects with other states to promote comprehensive treatment for persons with epilepsy, so that they can count on the power and technical assistance of ILAE, the Colombian League Against Epilepsy, the Foundation for the Rehabilitation of Persons with Epilepsy (FIRE), the national Academy of Medicine and Neurological, Neurosurgical and Paediatric Neurological associations.

The statute goes on to state that the Health Regulation Commission will be required to include epilepsy in its benefits plans, following the adoption of guidelines and protocols to ensure that medication and health services necessary for this condition are available. The Ministry for Social Protection will also be required to take the necessary actions to ensure that the objectives of the law are met.

Persons with epilepsy, without distinction, will have the right to life, to equality, to work, and to human and health dignity. Epilepsy will not be considered as an impediment to prevent integration and access to work, sports, or schooling in just and dignified conditions. Persons with epilepsy, their families and the community will have

the right to be sufficiently informed on the different aspects of the condition, and to receive accurate and detailed information, through all appropriate means.

Persons with epilepsy are protected against all forms of exploitation and discriminatory rules or abuse.

Young people with epilepsy, who are economically dependent on their parents, will have the right to benefits from the Health Service System. This will be of tremendous benefit to people with epilepsy whose families refuse, for whatever reason - be it stigma or poverty - to seek medical help and care for their child with epilepsy

The Ministry for Social Protection, in collaboration with the Ministry of Education, will design a special programme to educate GPs in the early detection of symptoms which could indicate a neurological condition such as epilepsy.

While much of the text of the law refers to the rights and protection of persons with epilepsy, there are also references to the obligations of persons with epilepsy to society. One of these states that a person with epilepsy who refuse to accept treatment prescribed by doctors will not be allowed to undertake dangerous activities that could be a risk to society.

It is, perhaps, too early to know successful or well implemented this legislation will be. But we can congratulate Jaime and his colleagues on their great achievement.

IBE-ILAE Task Force in Europe

The new IBE-ILAE Joint Task Force met recently in Brussels to lay down plans and objectives and to set its agenda for future activities.

This taskforce will serve as the political and advocacy arm of the IBE European Regional Committee and the ILAE Commission on European Affairs; promoting epilepsy care across the European region, defending the social integration of persons with epilepsy, and facilitating Epilepsy Research funding.


Its targets in the European Union and Europe will be: the EU Parliament and the EU Commission. The task force should also benefit non EU countries in Europe and contribute to Global Campaign activities throughout Europe.

The group is co-chaired by Mike Glynn and Emilio Perucca, with Aska Pitkänen serving as Secretary and Hanneke de Boer as Treasurer. The first tasks to be addressed are a review of EU funding opportunities available for research and the setting in motion of preliminary arrangements for European Epilepsy Day 2012.



From left: Janet Mifsud (Malta), Hanneke de Boer (Netherlands), Emilio Perucca (Italy), Mike Glynn (Ireland), Aska Pitkänen (Finland), Christian Elger (Germany), Michel Baulac (France) and Reetta Kälviäinen (Finland)




International Bureau
for Epilepsy
1961 - 2011
50 years focussed on epilepsy

 29th International
Epilepsy Congress 
ROME 2011
  28th August - 1st September