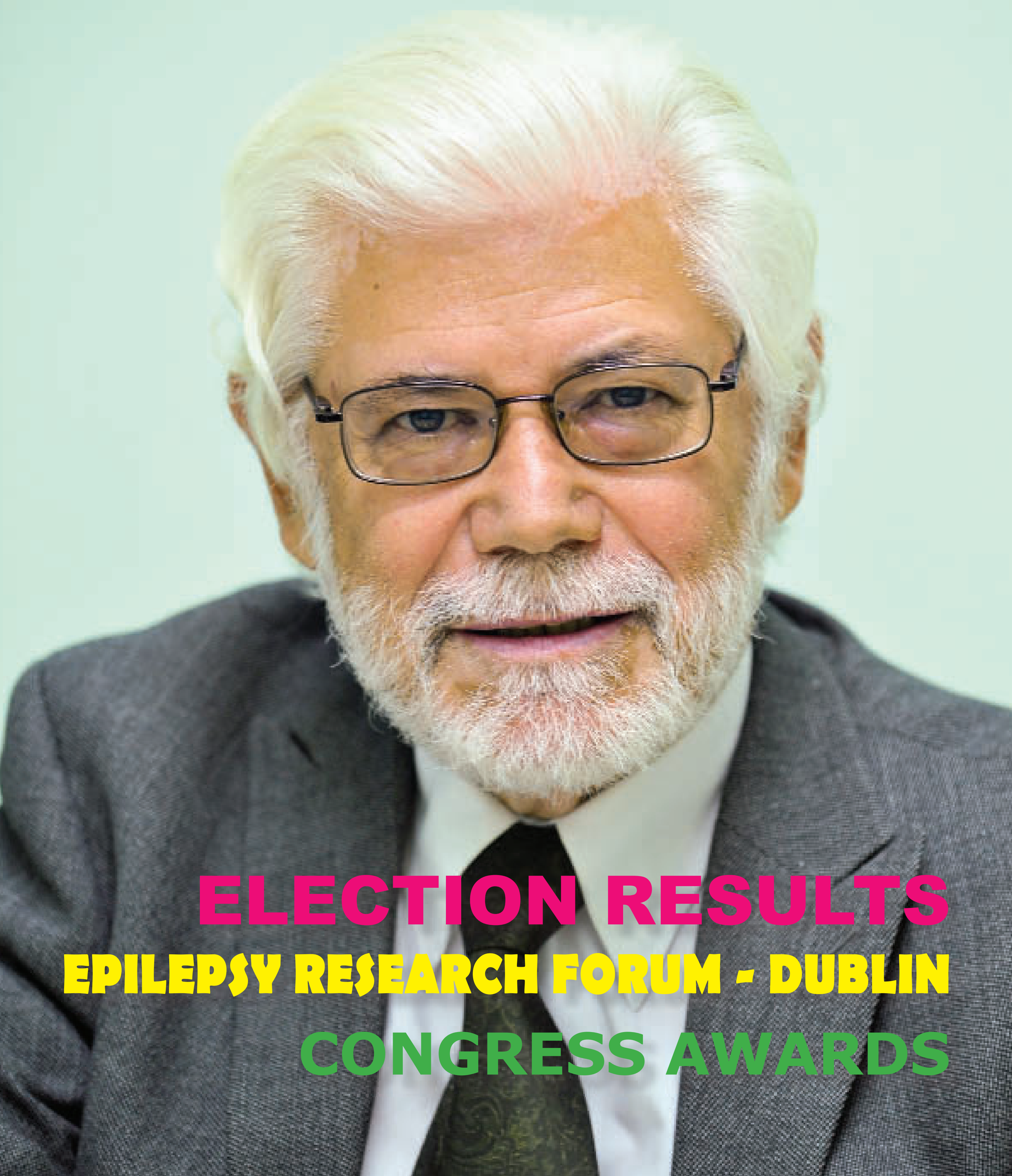
NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 4 2012

INTERNATIONAL Epilepsy News



ELECTION RESULTS

EPILEPSY RESEARCH FORUM - DUBLIN

CONGRESS AWARDS

Looking forward to a very busy 2013!

2013 has begun as another busy year for IBE with several activities planned or in preparation.

In February we celebrate the 3rd European Epilepsy Day (EED) - an event that has grown in stature since it was launched in 2011. A number of activities will take place in the European Parliament, during the week commencing 18th February, as part of EED 2013, organised by the Joint Task Force - Epilepsy Advocacy Europe.

Throughout the week, an exhibition of the Stand Up For Epilepsy photographs will be on display in a busy location that the MEPs pass several times each day. A special reception will launch the exhibition at which a young Hungarian gymnast, Veronika Mitykóm, will perform. The aim is to publicise the difficulties the 12-year old is experiencing in Hungary where she has been prohibited from competition and from gymnasia, despite the fact that her epilepsy is controlled.

A workshop on Prevalence & Costs of Epilepsy in Europe has the purpose of alerting MEPs to the need for accurate figures on prevalence, in order to plan for future epilepsy services at national levels. Finally, and perhaps most importantly, a private meeting will take place with Dr Tonio Borg, EU Commissioner for Health and Consumer Policy.

In May, a European Forum on Epilepsy Research - as part of the Irish Presidency of the European Union - takes place in Dublin. It is hoped that at least one representative from each IBE member association in Europe will attend.

In June we will celebrate the 30th International Epilepsy Congress in Montreal, when the new IBE committee begins its term of office; in August there is the 13th Epilepsy & Society Conference in Ljubljana, Slovenia to enjoy.

Already, two important future meetings are in planning. The 2nd African Epilepsy Congress will take place in South Africa in 2014 and the venue is expected to be announced shortly. The following year, in 2015, the 31st International Epilepsy Congress will be in Istanbul, Turkey. Spanning Europe and the Eastern Mediterranean region, this promises to be a meeting that will have significant impact for the region.

With best wishes to all

Mike Glynn
President

ISSUE 4 - 2012

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:

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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).

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A time to look back and to look forward!

This issue of the magazine demonstrates that time never stands still and that life rushes by at an incredible speed, so that, what is news one day suddenly becomes history!

First of all, although we are already in the second month of 2013, I would like to wish you all a Happy New Year.

The articles that we have for you this time are a great mix of the old and the new. Looking back, Harry Meinardi presents us with another excellent instalment of the history of IBE. In this, the 7th instalment, we have now reached the 1980's.

In the report on congress awards for Montreal, we can see the many decades dedicated by the recipients to improving treatment and care for people with epilepsy. No less so than Dr Juhn Wada, who has spent a life-long career working in the field.

Looking forward, we present the recently elected members of the next International Executive Committee, who will begin their terms of office at the General Assembly in June. I send each one my heartiest congratulations and best wishes for the next four years.

More future activities are the meetings and congresses that you can read about – the 30th International Epilepsy Congress in Montreal, the 13th European Epilepsy & Society Conference in Ljubljana in August, and the European Forum on Epilepsy Research in Dublin in May.

You can also enjoy the reports of Janet Mifsud, Shunglon Lai and Vinod Saxena who attended WHO sessions in Malta, Vietnam and Indonesia; as well as an article on a visit by members of APCE Bulgaria to the long established Chalfont Epilepsy Centre in London.

Finally, as it looks forward to a bright new future with a brand new name, I would like to send best wishes to the Irish epilepsy association, formerly known as Brainwave, which has just changed its name to Epilepsy Ireland!

Kind regards

Dr Carlos Acevedo
Editor

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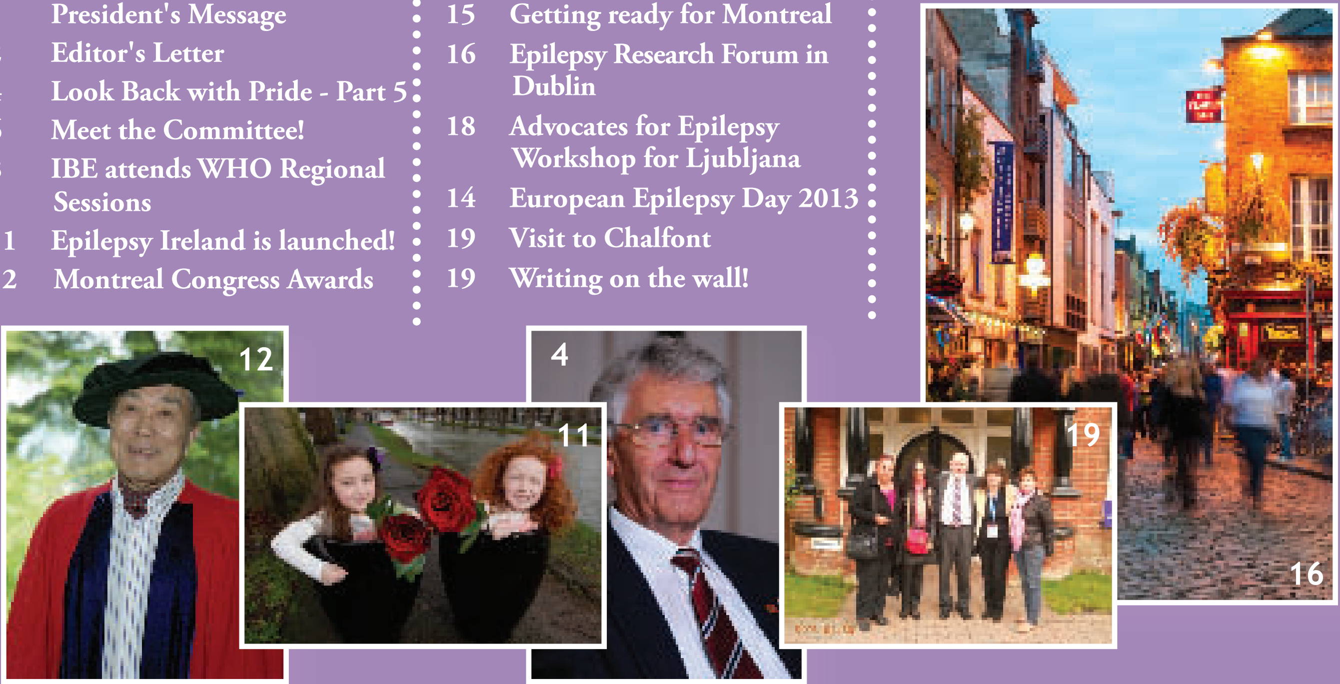


Harry Meinardi

presents the seventh instalment of IBE's history as reported in its newsletters

1982-1983

New associations, new technology and more!

April 1982: Francesco Castellano, in his turn as Chairman of EI, highlights proposals of the Planning Committee: an official journal on Social Aspects of Epilepsy; an audio-visual festival; an international information centre; an international handbook of epilepsy centres; new data and position statements about head injury; teratogenic effects of anticonvulsants; genetic factors; a worldwide system for reporting unfavourable drug effects; evaluation of the behavioural effects of drugs; standards of anticonvulsant drug level determination; workshops on education, self-help, employment, and minimal standards of medical care.

Although these plans may not have been realised as envisaged, surely we can say now that progress by and large has been along these lines.

July 1982: a book produced by the Commission on Antiepileptic Drugs titled *Epilepsy – Diagnosis and Treatment* will have 2,000 copies distributed in African countries, following an agreement with WHO. (Unfortunately there was no follow-up of the results of this agreement. Later experiences revealed that such actions did not always reach the subjects for whom they were intended). Jacqueline Beaussart-Defaye, from Lille, France, Vice President of IBE, reports how an organisation for research, care and prevention of epilepsy (GRINE), founded by the sociologist Jacqueline and husband neurologist Marc set up AISPACE in 1981, as an association of patients for the social rehabilitation of persons with epilepsy. This has stimulated the French League Against Epilepsy to establish a Social Committee in a number of regions.

The October 1982 issue, with opening words by Castellano, is filled with reports about awards and prize winners, new Ambassadors for Epilepsy and the 80th birthday of Irene Gairdner. It highlights the important role Irene played, since 1938, in lay organisations for epilepsy in the UK and how, in Rome, she and George Burden pledged the assistance of the British Epilepsy Association - BEA (now Epilepsy Action) in setting up IBE, of which she became the first Honorary Treasurer.

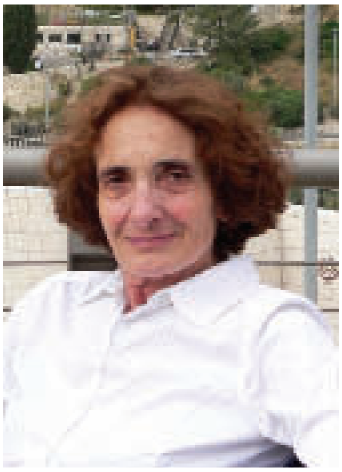
Irene Gairdner

Judith Manelis announces that the League and the Ministry of Works & Social Welfare of Israel established a centre to advise and rehabilitate people with epilepsy. Dorothy Gowans, from New Zealand, summarises the first 25 years of the New Zealand Epilepsy Association and the opening, in December 1981, of a lodge that will allow residents to cut the apron strings of home or hospital, as an intermediate step to full and independent living.

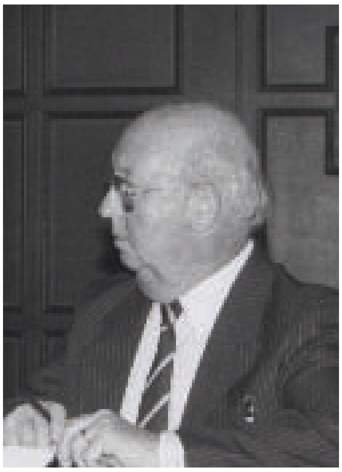
Ernst Rodin from the Epilepsy Centre of Michigan describes an electronic network whereby any university-connected user, anywhere in the world, can access through telenet data any participant and, as far as EEG's are concerned, coding forms can be filled out while the record is read and the form is translated into an English language report. The epilepsy centres in Denmark, Japan and the Netherlands are already connected. (In 2011 Ernst Rodin comments:

Look Back with Pride - Part 7


Marc Beaussart


Judit Manelis


Arthur Ward


Alec Aspinall

"The referred-to article represented the beginnings of the Internet without which today's society could no longer function. Digitization of data, their electronic transmission, and automated voice recognition, now are commonplace, with their attendant advantages and drawbacks. The latter have, as yet, not been fully appreciated but the 'outsourcing' of human work to machines is a significant factor in the global economic crisis we are currently confronted with. Our relationship with the 'labor-saving' devices we have created requires urgent attention because even patient care is beginning to be adversely affected. The proverbial genie is out of the bottle; we cannot put it back and must devise ways to prevent it from overpowering us.")

December 1982: The 14th EI-Symposium in London had an interesting program and was attended by 600 people. Financially, however, something went very wrong but, thanks to magnanimous creditors, a disaster was avoided.

March 1983: the Australian National Committee on Epilepsy, chaired by Robert Gourley, announced that National Australian symposia were to be organized every second year alternating with the EI-symposia. Furthermore an Annual Epilepsy Week was introduced, with the first from 22nd to 28th May 1983.

A Dutch medical anthropologist Corrie Gerrits describes finding, in Grand Bassa County Liberia, a prevalence of epilepsy of 49 per 1000, the highest ever reported. Political conditions in Liberia disrupted her assistance to people with epilepsy and a study of why there was such high prevalence.

The frontispiece of June 1983 announces four main topics: Religiosity in epilepsy (a topic again reviewed in 2008 by Devinsky and Lai); Employers attitudes; Self-help groups in the USA; and Monotherapy. The last paper is the fruit of requests from readers to pay more attention to the medical practice of treating epilepsy.

September 1983: "Medical Practice" deals with epilepsy and pregnancy. At the same time the president of ILAE signals the problem that medical literature is not always unanimous in its advice while the lay-reader cannot easily assess the author's competence.

An EI workshop is reported, organized by Marc and Jacqueline Beaussart in Lille, on "Evaluation of the expectancies of people with epilepsy and their families". The gist is that all three groups - people with epilepsy, those in direct contact, and the general public - need to be better informed. A Japanese student with epilepsy, Chihiro Kawamura, a volunteer in Epilepsy Movements, writes about her participation in a training course organized in the USA during the 1981 International Year of Disabled Persons and how that inspired her to apply for, and obtain, a job in the Japanese Epilepsy Association. (In 2011, she is associate professor at the Department of Social Work, Saitama Prefectural University. Although no longer staff, she is still member of the JES).

December 1983: Alec Aspinall explains how the adage of the BEA - that medical and nursing professions should be thoroughly acquainted with the social aspects of epilepsy - is put into effect.

Arbitrarily 50 years of epilepsy-surgery are reviewed; not a jubilee. (Penfield had started his work in Montreal 54 years earlier and in 1986 the Journal of Neurology, Neurosurgery and Psychiatry celebrated that 100 years ago the present era of epilepsy-surgery was initiated by Victor Horsley in London.) Arthur Ward, speaking at the 15th EI symposium, stresses the fact that only a small percentage of people with epilepsy who can be helped with surgery are thus treated, and that Europe, in particular, lags behind. (In 2011, at the 50th IBE anniversary, 10% of all posters at the 29th International Epilepsy Congress, concerned epilepsy surgery.)

MEET THE COMMITTEE!

Message from the Election Task Force

Following the close of the International Executive Committee Elections, we are pleased to introduce the newly elected members of the incoming committee, who will begin its term of office at the General Assembly, which takes place at the 30th International Epilepsy Congress in Montreal.

The Election Task Force would like to thank all those members who played an active part in the election process, in nominating candidates and in casting their association's votes. At the close of the balloting period, just less than 60% of eligible members had cast votes.

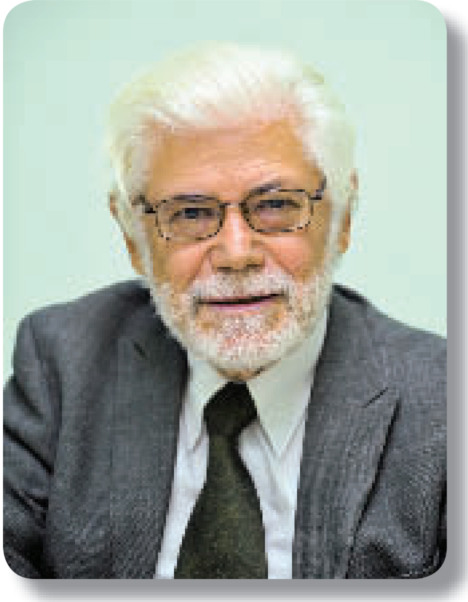
The Task Force would like to note its appreciation, in particular, to all those candidates who allowed their names to go forward for election and sends its congratulations to those who were elected and encourages all other candidates to consider participation in future IBE's activities.

The elections to fill places on the Regional Executive Committees are now underway and we ask all eligible members to play an active role in these elections.

IBE Election Task Force

Susanne Lund, Chair
Jerome Engel Jr
Mike Hills

January 2013



PRESIDENT 2013-2017
Athanasios Covanis
Greece

SECRETARY GENERAL 2013-2017
Sari Tervonen
Finland

TREASURER 2013-2017
Robert Cole
Australia

Structure of the International Executive Committee

The International Executive Committee comprises a President, Secretary General, Treasurer, Immediate Past President and seven regional Vice Presidents representing IBE's regional structures. In addition, three members of the ILAE Executive Committee sit as ex-officio voting members on the committee.

The President, Secretary General and the Treasurer form the IBE Management Committee which, according to the IBE Constitution, is authorised to make decisions in the name of IBE between meetings of the full International Executive Committee. Since members of the committee are located around the world, the Management Committee facilitates the taking of decisions, particularly in matters that require immediate attention.

Any decisions that would require policy change may only be taken by the International Executive Committee or by the General Assembly.

As is the case with the full committee, much of the work of the Management Committee is acheived through email or conference calls, with face to face meetings taking place not less than once each year. and more frequently when required.

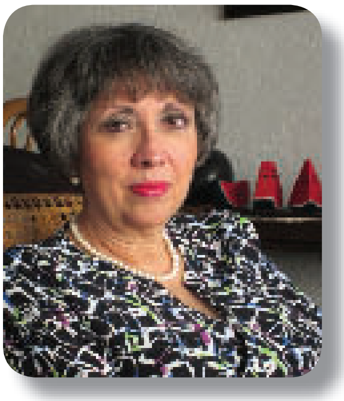
International Executive Committee 2013-2017

Mike Glynn (Ireland)
Immediate Past President

Anthony Zimba (Zambia)
VP Africa

Najib Kissani (Morocco)
VP Eastern Mediterranean

Janet Mifsud (Malta)
VP Europe

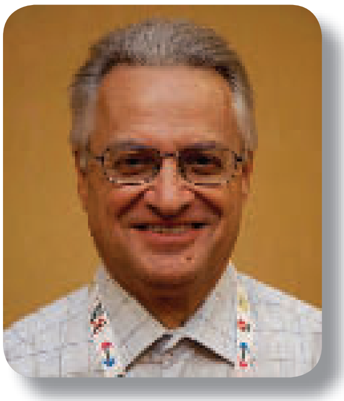


Lilia Núňez (Mexico)
VP Latin America

Philip Gattone (USA)
VP North America

Man Mohan Mehndiratta (India)
VP South East Asia

Ding Ding (China)
VP Western Pacific



Emilio Perucca (Italy)
ILAE President

Helen Cross (UK)
ILAE Secretary General

Sam Wiebe (Canada)
ILAE Treasurer

> *"The elections to fill positions on the Regional Committees are now underway and we ask all eligible members to play an active role in these elections."*
>
> *Election Task Force*

IBE calls on the WHO to prepare a Strategic Plan for Epilepsy in each region

Shung-lon Lai, IBE Vice President Western Pacific Region, was in Hanoi, Vietnam to represent IBE as an observer at an annual meeting of the WHO in the Western Pacific Region.

Janet Mifsud, IBE Vice President Europe, was the IBE observer at the WHO European Region meeting in Malta.

Vinod Saxena, IBE Vice President South East Asia, travelled to Java, Indonesia to act as the IBE observer at the WHO South East Asia meeting.

63rd session of the WHO Regional Committee of the Western Pacific

HANOI, VIETNAM

As our former President Susanne Lund stated when IBE was given Special Consultative Status in the Economic and Social Council of the United Nations in 2007 - "The important aspect of this is that we make epilepsy visible in the United Nations! When we address epilepsy within the United Nations we will create some impact. I see all this in a long-term view as a gardener sowing seeds, adding some fertilizer and water, tending them and seeing them slowly grow until eventually they are ready to harvest".

IBE and ILAE have worked in partnership with the WHO in the Global Campaign Against Epilepsy since 1997. The efforts of several IBE and ILAE Presidents and all others involved in the campaign has led to major achievements. In 2011, PAHO passed a resolution supporting the Strategic Plan of Action on Epilepsy (CD51/10) in the Americas. This action formally establishes epilepsy as a health care priority in that region.

In late 2012, through its working relationship with the WHO, IBE was invited to have a presence as an observer at the WHO regional meeting in WHO-Europe, WHO-Southeast Asia, and WHO-Western Pacific regions. This provided an excellent opportunity for IBE to express its wish to see epilepsy remain as a disease of major concern in WHO's mental health priority.

I had the chance to attend the 63rd meeting of the WHO Western Pacific in Hanoi, Vietnam last September. From the meeting agenda, reports presented and discussion, it was clear that the regional concerns included nutrition, violence and injury prevention, neglected tropical diseases, measles elimination, tobacco control, infectious disease (TB, HIV, malaria, polio) and non-communicable diseases (NCD), WHO reform, and finance. In respect of NCD, the major concerns include cancer, diabetes and hypertension. Although epilepsy belongs to the mental health section of NCD, yet not one word was mentioned about the disease.

Nevertheless it was good that we had the chance to present a short speech during the NCD session, as follows:

Mr. Chair, Deputy General, Delegates, Ladies and gentleman, Good Morning

The International Bureau for Epilepsy is very happy to be invited here as an observer and to have a time to present our concern. We wish to present: 'A Call for a Strategic Plan for Epilepsy for WHO Western Pacific Region'.

Epilepsy is one of the world's most common chronic neurological disorders. Approximately 50 million people have been diagnosed worldwide, 17 million of them in the Western Pacific region, with 950,000 new cases diagnosed each year in this region.

Key Message: **Millions of people in our region suffer from the disease**

Furthermore, the stigma attached to epilepsy is a barrier to social integration. People with epilepsy suffer not only from the disease itself - in our region they experience high levels of unemployment and are exposed to stigma and prejudice in school, marriage and insurance. Epilepsy disrupts every aspect of life and can impose physical, psychological and social burdens on individuals and families.

Key Message: **Millions of people suffer from the stigma of epilepsy**

It is important to note that, while scientific advances have improved understanding and management of epilepsy and up to 70% of people with epilepsy could be seizure-free with appropriate treatment, more than 70% of people with epilepsy in our region do not receive appropriate treatment.

Key Message: Epilepsy is treatable, but the treatment gap in our region is huge

In other WHO regions epilepsy has already been selected as a priority. In 2011, the Directing Council of the Pan American Health Organization (PAHO) passed a resolution supporting the Strategic Plan of Action on Epilepsy (CD51/10). This action formally establishes epilepsy as a health care priority in that region.

A call is thus being made for WHO Western-Pacific region to agree to the preparation of a strategic plan for an integrated response in order to develop lifelong programs for people with epilepsy.

Key areas to be addressed include:

1. Prioritising epilepsy as a major mental health disease that imposes a significant burden across the region and to focus on reducing existing treatment gaps;
2. Ensuring the availability of the anti-epileptic drugs considered essential for treating people with epilepsy, especially at the primary care level;
3. Assisting Member States in the preparation and execution of national epilepsy programs within the framework of their health policies, with a view to correcting inequities and prioritising the care of vulnerable and special needs groups, including indigenous populations;
4. Strengthening human resources as key to improving national epilepsy programs, through systematic training geared especially to personnel in primary health care; neurology; psychiatry, neurosurgery and neuro-paediatrics;
5. Encouraging Member States to ensure equal quality of life, including in education, employment, transport and public healthcare;
6. Promoting educational initiatives directed at the population to combat the stigma and discrimination suffered by people with epilepsy. In this we thank especially the Korean Government which changed the Korean symbol for Epilepsy from "Mad" to "Brain waves" in 2011.

Finally, regarding partnerships: working together, IBE and ILAE have undertaken key programs under the banner of its global campaign program 'Out of the Shadows' in China and Vietnam in partnership with regional WHO offices. A new partner program is due to begin in Vietnam.

We hope that our region can put "Epilepsy" as a priority in the mental health session of NCD and look forward to the future cooperation.

Report by: Shung-lon Lai

62nd session of the WHO Regional Committee of Europe

MALTA

Group photo of participants. Centre front is Malta Minister of Health. To his right (in black) is Dr Margaret Chan, DG WHO and to his left (in white) is Crown Princess Mary of Denmarkf the Crown Princess.

Over 400 delegates from 53 countries and 30 NGOs met in Malta in September 2012 for the 62nd Session of the regional committee for Europe.

The meeting was opened by the Prime Minister of Malta, Dr Lawrence Gonzi; her Royal Highness Crown Princess Mary of Denmark who is the Patron of the WHO regional office in Copenhagen; Zsuzsanna Jakab, WHO Regional Director for Europe; John Dalli, who, at the time was European Union (EU) Commissioner for Health and Consumer Policy; and Deputy Secretary General Yves Leterme, Organisation for Economic Co-operation and Development (OECD).

Dr Margaret Chan Director General of WHO, attended the full four day session, together with more than 28 Ministers of Health from various European countries.

The networks and contacts made during these meetings, both with WHO officials and ministerial delegations, were unique. It was also apparent that there was a lot of interest, in particular from the former

USSR countries, to have closer liaisons with IBE and ILAE.

The main agenda topics included the new European health policy framework, Health 2020; WHO reform and the global programme budget for 2014-2015; an action plan for healthy ageing in Europe 2012-2016; the Regional Office's country strategy; and a renewed strategy on geographically dispersed offices.

WHO Europe explained that there is a clear need to transform and update public health services in countries in the region, in order to take account of new challenges such as inequalities, the prevalence of non-communicable diseases and an ageing population. Key to this transformation is the need to invest in prevention and health promotion measures, which currently account for just 3% of health budgets. Focusing on prevention is a cost-effective approach to improving health outcomes. An action plan has been developed to complement and support the Health 2020 policy.

A written statement by IBE was approved and uploaded on the official meeting website and Dr Mifsud also had an opportunity to give a recorded oral statement in conjunction with the agenda item Health 2020, highlighting the need for a Strategic Plan for Epilepsy for WHO Europe.

She explained how epilepsy is one of the world's most common chronic neurological disorders, yet 40% of persons with epilepsy in Europe still do not receive such treatment. In addition, they experience high levels of unemployment and are exposed to stigma and prejudice with huge physical, psychological and social burdens for them and their families.

This is the right time for the WHO Regional Committee of Europe to make epilepsy a priority. Epilepsy has already been selected as a priority in other WHO regions such as the Pan American Health Organization (PAHO) resolution in 2011.

A call was thus made for WHO Europe to agree to the preparation of a strategic plan for epilepsy. This plan will prioritize an integrated response to promote the prevention of epilepsy, treatment of epilepsy and research on epilepsy. Such a plan can only be executed by facilitating the promotion of technical cooperation among WHO European Member States together with partnerships with key stakeholders and NGOs, in order to formulate the best possible response needed for the implementation of this strategy.

From left: Victoria Dimech, Caritas Malta Epilepsy Association and Member, IBE Regional Executive Committee Europe and Janet Mifsud, IBE Vice President Europe greet Zsuzsanna Jakab, WHO Regional Director for Europe

Report by: Dr Janet Mifsud

65th session of the WHO Regional Committee of South East Asia

YOGYAKARTA, INDONESIA

World Health Organization
Yogyakarta, Indonesia,
04 Sept to 07 Sept 2012

A Strategic Plan for Epilepsy for WHO South-East Asia was presented by us on invitation from WHO.

The first day of the Meeting was primarily for WHO and the Health Ministers of the 11 member countries. The following three days were taken up as Regional Committee Meetings.

The Director General of WHO Dr Margaret Chan; Regional Director Dr Samlee Pliangbangchang; Deputy Regional Director Dr Poonam Singh and about 100 official country delegates attended these meetings.

Significantly there were 10 NGOs who had the designation of being "in Official Relations with WHO". This included IBE.

The main purpose of our attendance was to present our strategic plan so that it becomes part of the official documents under active discussion with WHO. Four of the NGOs, including IBE - represented by Dr VS Saxena, were permitted to orally present their statements.

The preamble in the Strategy Statement was modified in tune with the requirements of this Region. It was highlighted that there was a large number of cases of epilepsy with the number increasing each year. In addition, the treatment gap was higher in the South East Asia region than in many developed regions.

The success in the PAHO Region was cited. The initiative of the European Parliament in approving a Written Declaration on Epilepsy; collaboration efforts of the WHO with IBE and ILAE in the Global Campaign Against Epilepsy "Out of the Shadows" and the WHO aided efforts in China and Vietnam were also cited.

The opportunity to present the Statement came to us late on the afternoon of the second day during the session on Non-Communicable Diseases.

I came to know that a Session was held in Yangon in April 2012 where Dr Vijay Chandra spoke about impact assessment of intervention through Primary Health Centres in epilepsy citing treatment gaps in four countries.

Both Myanmar and Bangladesh claimed drastic improvements, with treatment gaps of about 90% reducing down to single digits after intervention. Bhutan and Timor showed more modest improvements. It was mentioned that the spectrum of diseases in this Region is moving from Communicable to NON Communicable with 80% fatalities from Diabetes, CV diseases, Chronic lung conditions and Cancer.

WHO supports actions aimed at reducing exposure to risk factors; improving health systems; setting national targets with monitoring and promoting international co-operation.

The meeting provided a unique experience. Granted that the WHO machinery moves very slowly but perhaps this still remains the most effective international health cooperation mechanism.

Dr Vijay Chandra provided encouragement but some other officials from the Delhi Office were also very helpful. One fervently hopes that in a small manner this may turn out to be a new and major World outlook of epilepsy.

Report by: Dr VS Saxena

BLOOMING GOOD NEWS

Little rose buds, twins Hannah and Emma Boughton (age 6) pop up at the launch of the Epilepsy Ireland St Valentine's Rose Appeal and the introduction of Brainwave - the Irish Epilepsy Association's new name - Epilepsy Ireland. *Photo: Andres Poveda*

On February 7th 2013, Brainwave - The Irish Epilepsy Association became ***Epilepsy Ireland.***

"At a time when people are encouraged to speak more openly about epilepsy, we need to lead the way with a name that doesn't hide the condition we represent. By making our name shorter and simpler, we believe that the task of raising public awareness of epilepsy and eliminating epilepsy stigma will be easier to achieve," a spokesperson stated.

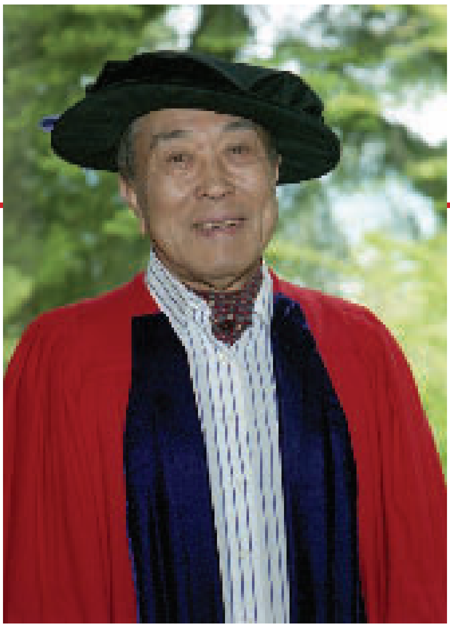
The word "Brainwave" was added to the original "Irish Epilepsy Association" more than 20 years ago in response to members' needs at a time when people with epilepsy were more likely to keep their diagnosis hidden compared to today.

In a recent survey, only 15% of people questioned were able to connect the name 'Brainwave' with the condition of epilepsy, according to the association. While its name is changing, the vision of Epilepsy Ireland "to achieve a society where no person's life is limited by epilepsy" will remain at the heart of everything it has been doing since the association was first set up in 1966.

2013 MONTREAL
23rd - 27th JUNE, 2013
30th INTERNATIONAL EPILEPSY CONGRESS

CONGRESS AWARDS

The IBE/ILAE congress awards are presented biennially at the time of the International Epilepsy Congress, to honour individuals who have made significant contributions, over a long period of time and at international level, in the field of epilepsy. There are three categories: Ambassador for Epilepsy - presented to a maximum of 12 recipients; Social Accomplishment, presented to one individual; and the highest honour, Lifetime Achievement Award which, as its name implies, recognises a lifetime of achievement of an individual.



Lifetime Achievement Award

This is the highest award bestowed by IBE/ILAE and is given to an individual to recognise his or her exceptional and outstanding personal contribution over a long period of time to activities to advance the cause of epilepsy.

***Presented to:* Juhn Atsushi Wada, Canada**

Prof Juhn Wada was born in Japan in 1924 and has, over an illustrious career, carved a reputation for research in epilepsy, including his description of the Wada test for cerebral hemispheric dominance of language function.

He worked at University of Minnesota and Montreal Neurological Institute, then settled at University of British Columbia in 1956, where he was Professor of Neurology. He created the first surgical epilepsy program and seizure monitoring unit in British Columbia. His main interest has been in researching Human Brain Asymmetry and Neurobiology of Epilepsy, for which work he has received many internationally renowned awards.

He was an associate of the Medical Research Council of Canada 1966-1994; founding president Canadian League Against Epilepsy 1977-1979, and president American Epilepsy Society 1988. He received the Wilder Penfield Gold Medal in 1988, appointed Officer of the Order of Canada in 1992 and awarded the Queen Elizabeth II Diamond Jubilee Medal in 2012.

Social Accomplishment Award

Every two years, one person who has carried out outstanding activities aimed at improving the social circumstances of people with epilepsy, over a long period of time, is recognised.

***Presented to:* Jane Hanna, UK**

When Jane Hanna was bereaved in 1990, through her then partner's unexplained death from epilepsy, she had the vision to use her experience to highlight the largely unrecognised issue of epilepsy mortality.

At the time she had a prestigious academic career as a lecturer at Oxford University. This was eventually sacrificed to dedicate her future to a unique problem: that SUDEP and other epilepsy deaths were not recognised or understood and, therefore, people with epilepsy were at risk of dying unnecessarily.

She pioneered advocacy on SUDEP and co-founded Epilepsy Bereaved, established to support families, influence clinicians and politicians, and promote research on the causes of epilepsy-related deaths.

Twenty-two years of conviction, enthusiasm and refusal to be deflected resulted in a seismic shift in thinking and practice on SUDEP and epilepsy mortality internationally. Her personal contribution to the field was marked in the UK by Queen Elizabeth IIawarding Jane an OBE for distinguished services to families in 2010.

Ambassador for Epilepsy Award

The Ambassador for Epilepsy Award is the oldest IBE/ILAE award, having been introduced in 1968. To date, a total of 300 worthy recipients have received an Ambassador pin to reflect international peer recognition and which is given for the lifetime of the recipient. Twelve Ambassadors will be presented with their awards in Montreal.

Gretchen Birbeck, USA

Dr Birbeck spends time annually in sub Saharan Africa providing epilepsy care services and conducting research. She is founding Director of Chikankata Epilepsy Care Team in rural Mazabuka, Zambia and lectures at University of Zambia. She developed training materials for non-physician healthcare workers which served as a model for the WHO mhGAP programme in epilepsy care.

Alla Guekht, Russian Federation

Prof Guekht served for 12 years on the Commission of European Affairs and was Chair of the European Advisory Council. She has been a Member of Committees for European Congresses on Epileptology and invited speaker at many International and European Congresses on Epileptology. She implemented the Migrating Course of Epilepsy and is currently its Director.

Dale Hesdorffer, USA

Dr Hesdorffer is a recognized international expert in the epidemiology of epilepsy and is co-chair of the ILAE Commission on Epidemiology. The Commission's work has focused on ameliorating the burden of epilepsy through the work in four topical task forces: mortality, comorbidity, definition of status epilepticus, and reliability of the ICD-11 epilepsy codes.

Sunao Kaneko, Japan

Prof Emeritus Sunao Kaneko is a graduate of Hirosaki University School of Medicine, Japan. He is President of Japan Epilepsy Society and the Japanese Society of Clinical Neuropsychopharmacology. He introduced the measurement of blood AED drug concentrations in clinical settings; elucidated the teratogenecity of AEDs drugs during pregnancy and proposed prevention measures.

Byung-In Lee, Koren

Dr Lee is a key opinion leader in epilepsy in Asia; pioneer of clinical epileptology in Korea and instrumental in the promotion of Asian epilepsy communities. In 1986 he applied SPECT, combining both interictal and ictal studies to the protocol of pre-surgical evaluation of refractory epilepsy, which pioneered work for image based localisation of epileptogenic region.

Li, Li Min, Brazil

Dr Li is Professor of Neurology at State University of Campinas. His research areas include epilepsy, stroke and neuroscience. He coordinated a demonstration project of the Global Campaign in Brazil and helped coordinate courses on Health Science Journalism and Ethics, and Values and Health for teachers. He is involved in epilepsy stigma related projects working closely with IBE.

Presentation of Ambassador for Epilepsy Awards

The Ambassador for Epilepsy Awards, together with the Social Accomplishment and Lifetime Achievement Awards will be presented during the Opening Ceremony of the congress in Montreal on Sunday 23rd June 2013.

Daniel Lowenstein, USA

Dr Lowenstein is an internationally recognized expert on the management and treatment of patients with status epilepticus and was an early advocate of the concept of an operational versus mechanistic definition of status epilepticus, which has been adopted widely since first proposed in an article published in Epilepsia in 1999. He has been a program organizer for the Colloquia on Status Epilepticus in recent years.

Gary Mathern, USA

Dr Mathern's contribution has been to better clinical care for children undergoing surgery for medically refractory epilepsy. His group at UCLA is at the forefront of research, performing translational tissue on the tissue removed at surgery in children. This led to breakthrough discoveries on mechanisms of epileptogenesis, and Dysmature Cerebral Developmental hypothesis to explain how seizures develop in areas of severe cortical dysplasia.

Gay Mitchell MEP, Ireland

Mr Mitchell has been a supporter of IBE for many years and a strong voice for people with epilepsy in Europe during his three terms as a Member of the European Parliament. He hosted the launch of the 1st European Epilepsy Day in 2011; created the European Advocates for Epilepsy special interest group of MEPs; and submitted the EU Written Declaration on Epilepsy in 2011, which was approved by 459 MEPs .

Jorge Rodríguez, USA

Since 2006, Dr Rodriguez has been Senior Advisor on Mental Health of PAHO/WHO in Washington, DC. He coordinates technical cooperation in the field of mental health, neurological disorders and substance abuse in Latin America and the Caribbean. As PAHO Senior Advisor he coordinated the working group (PAHO/ ILAE/IBE) which prepared the Strategy on Epilepsy for the Americas which was adopted by the PAHO Directing Council in September 2011.

Ingrid Scheffer, Australia

Dr Scheffer is Chief Investigator of NHMRC funded research grants totalling AU$17.5 million over 4 years. This work laid foundations for clinical research in the genetics of common epilepsy syndromes, with emphasis on demonstrating that careful clinical observation can identify kindreds for linkage studies leading to identification of genes and gene products as causes of epilepsy. Her work with Dr Berkovic has defined membrane ion channels as one of the causes of genetic generalised epilepsies.

Matthew Walker, UK

Prof Walker has organised international workshops in epilepsy and neuroscience and was involved in the production of the European Consensus Statement on Status Epilepticus. He contributed to the SIGN epilepsy guidelines; co-produced the BBC website's guide on epilepsy and has written the British Medical Association educational module on status epilepticus. On the scientific advisory board of Epilepsy Action, he is also Chair of the Joint Epilepsy Council of UK and Ireland.

2013 MONTREAL
23rd - 27th JUNE, 2013
30th INTERNATIONAL EPILEPSY CONGRESS

GETTING READY FOR MONTREAL!

IBE General Assembly

Date and time: Wednesday 27th June 2013
Time: 13:00 to 17:00 including lunch reception
Venue: Hall 7, Palais des Congrès de Montréal

Act Local Think Global!

DATE FOR YOUR CONGRESS DIARY!

Date: Sunday 23rd June 2013
Time: 17:00 - 18:30
Venue: Palais des Congrès de Montréal

EXCITING WORKSHOP SHOWCASING SUCCESSFUL RESEARCH PROJECTS

IBE's Research Task Force is planning an interactive workshop that will be of interest to all those who have ever considered undertaking research. The event will act as a catalyst for improving the social condition and quality of life for people with epilepsy.

Showcasing research carried out by IBE members, and others working to support people with epilepsy and their families, this will be the ideal opportunity to discover new methods that could be adopted for use at local level. There will also be ample Question and Answer time for you to pose your questions to the session speakers.

MARK THIS DATE IN YOUR DIARY!

Members of the IBE Research Task Force: *Ley Sander (Chair) - UK, Rosey Panelli (Acting Chair) - Australia, Malachy Bishop - USA, Pascalina Chanda - Zambia, Ding Ding - China, Patrick Kwan - Australia, Li Min Li - Brazil, Tomás Mesa - Chile, Janet Mifsud - Malta.*

EPILEPSY RESEARCH FORUM

DUBLIN 2013

The leading voices in the epilepsy community around one table

There is much excitement about the future of epilepsy research in Europe following the recent signing of the European Written Declaration on Epilepsy.

To build on this new atmosphere, the **European Forum on Epilepsy Research 2013** will take place in Dublin, Ireland from 25th to 27th May 2013. The forum is a collaborative research conference co-funded by the 7th Framework Programme of the European Commission in conjunction with the Irish Presidency of the European Union in 2013 and the European Month of the Brain - May, 2013.

As the 8th Framework Programme ***Horizon2020*** will be launched in 2014, this conference aims to bring together European epilepsy researchers, care providers and policy makers to discuss a strategy for increasing funding for epilepsy research.

The forum is a ground breaking initiative and has come into being to facilitate discussion, debate and strategy in the field of epilepsy research ahead of ***Horizon2020***, due to launch on 1st January 2014.

> "To achieve the goal of improved research support in Europe, the epilepsy community must speak with one voice when the European Union formulates the future strategies to improve healtcare and health research across the EU"

The aims of the forum are to achieve more focused research to improve diagnosis and treatment; to raise public awareness and reduce stigma associated with epilepsy; and to improve access to optimal standards of care across Europe for people with epilepsy.

To achieve the goal of improved research support, the epilepsy community must speak with one voice when the European Union formulates the future strategies to improve healthcare and health research across the EU.

For this reason it is important that as many IBE and ILAE associations in Europe as

possible are represented at the forum.

A number of IBE and ILAE member associations are already fully engaged with the forum's goals and are informing and encouraging European Union National Contact Points (NCPs), Ministries of Health Officials and Members of the European Parliament (MEP) to attend.

Epilepsy Advocacy Europe - the joint task force of IBE and ILAE, which is organising the event, is also asking members in European Union member states to make contact with their National Government representatives and NCPs to encourage them to attend the forum.

To assist in the development of research proposals there will be a pre-conference workshop dealing with the new features of the ***Horizon2020*** applications, time schedules and the decision-making process, which will be of interest to many delegates. There will also be a reception with EU Health Research National Contact Points from European Union Member States.

The two-and-a-half day meeting has six Main Sessions:

- Epilepsy Stigma Across Europe
- Standards of Care
- Epilepsy in the Developing Brain
- New Targets for Innovative Diagnostics and Treatment
- What is Required for Prevention and Cure of Epilepsy?
- Epilepsy and Co-Morbidities - Special Focus on Ageing and Mental Health

To present on these topics an Advisory Committee has identified internationally recognised speakers, including Christian Elger, Germany; Ley Sander, UK; Renzo Guerrini, Italy; Torbjörn Tomson, Sweden; and Bert Aldenkamp, The Netherlands.

An excerpt from a letter of greeting sent by the European Advocates for Epilepsy Group, a special interest group of MEPs in the European Parliament, reads as follows:

"We are pleased to support this major Epilepsy Research Forum, which will provide a platform for leading epilepsy researchers and policy makers in Europe to discuss coordinated strategy for epilepsy research into the future and we are confident that their deliberations will have a major impact on establishing the future direction for epilepsy research in Europe.

This will result in an improved quality of life for all people with epilepsy and we applaud this impressive initiative."

The European Forum on Epilepsy Research 2013 will be held at the new Convention Centre Dublin, a world class international conference and event venue situated in the centre of the city and within walking distance of several hotels. IBE and ILAE member associations are being encouraged to send at least one delegate to the meeting. In addition, ILAE chapters are being asked to sponsor a member from a less affluent member state, where funds permit. There will also be a limited amount of bursary support for IBE members where association finances would prevent attendance.

With Dr Tonio Borg, EU Commissioner for Health and Consumer Policy and Mrs Máire Geoghegan-Quinn, EU Commissioner for Research, Innovation and Science invited to address the forum, and with a number of MEPs and NCPs due to attend, this is an excellent opportunity for associations across Europe to highlight the urgent need for more focused research in epilepsy in order to improve diagnosis and treatment. It is also the chance to focus on the need for greater public awareness in order to reduce stigma associated with epilepsy and to call for improved access to optimal standards of care across Europe for people with epilepsy.

We hope to welcome many of you to Dublin in May, for what promises to be a great occasion!

SEVENTH FRAMEWORK PROGRAMME
No.: HEALTH-F1-2012-306020
The Seventh Framework Programme of the European Union for funding of research and innovation in Europe

ADVOCATES FOR EPILEPSY WORKSHOP

Introducing a new concept for Ljubljana 2013

13TH EUROPEAN CONFERENCE ON
Epilepsy & Society
LJUBLJANA, SLOVENIA
28TH - 30TH AUGUST 2013
IBE

Plans are now well advanced for the 13th European Epilepsy & Society Conference, taking place in Ljubljana, Slovenia in late August this year.

With the theme ***Stand Up for Epilepsy to Break Down Barriers***, a very interesting programme has been developed by the European Regional Executive Committee with an emphasis on interactive participation between delegates and speakers.

The conference registration system has now opened and information on bursaries and posters will soon be available.

Those of you who are considering attending the conference will be interested to hear of a new initiative being introduced as part of the conference activities.

Advocates for Epilepsy is an exciting new workshop concept, designed to raise awareness and improve patient care through collaborative practice. The workshop will take place on the 28th of August, prior the 13th European Conference on Epilepsy & Society, which runs from Wednesday 28th to Friday 30th August. The workshop is planned to be highly interactive and will be an excellent learning experience for all participants.

WHO SHOULD ATTEND

This workshop will appeal to nurses, people with epilepsy, allied health professionals, carers, psychologists, neuropsychologists, physiotherapists, social workers and teachers.

WHY ATTEND

Participants will learn how to develop strategies to help them better understand and support the individual living with epilepsy, using a person-centered approach. Topics will be presented by a range of experts in the field, and participants will be actively involved through Question and Answer sessions and group discussions.

LEARNING OBJECTIVES

This workshop will address several important areas of epilepsy research, highlighting problems and concerns, and proposing methods to overcome them, with a view to raising awareness and promoting epilepsy research. Participants will gain a practical knowledge of how to become better advocates for people with epilepsy.

The main workshop topics will be:

- Epilepsy networks
- Epilepsy: seizures and syndromes
- Seizure observation
- Case reports
- Acute management of seizures
- Risk of seizures and safety measures
- Comprehensive epilepsy care
- Epilepsy everyday activities (sports, driving, work place and travel)
- Risk factor of pre-disposing to seizures
- Raising awareness and contributing to better epilepsy research
- How can I be a better advocate?

MAIN PROGRAMME

The official Opening Ceremony will take place on the evening of Wednesday 28th, followed by a Welcome Reception. After that there will be two busy days of plenary sessions, debates and group sessions.

The Epilepsy & Society conference has a special emphasis on informing people with epilepsy, their families and healthcare providers on social issues that affect people with epilepsy and on new advances in care provision.

www.epilepsyandsocieity.org

A visit to Chalfont

IBE was very pleased to help assist in arranging a visit to the Epilepsy Society's Chalfont Centre in London for members of the Association of Parents of Children with Epilepsy (APCE), IBE's Full Member in Bulgaria. The visit was made possible by the support of Mr Graham Faulkner, Chief Executive of Epilepsy Society, who warmly welcomed the visitors to Chalfont.

At present, there is no epilepsy centre in Bulgaria for young people with epilepsy and Mrs Veska Sabeva, APCE President, and her colleagues were interested to find out more about how such centres are operated. The group was in London to attend the ILAE Congress on Epileptology, which was held last October. Mrs Sabeva was accompanied by two colleagues - Mrs Sashka Stoichkova, a board member of the association and a parent and Mrs Pepa Petkova, a parent of a child with epilepsy. Mrs Gergana Hristcheva, a reporter from the Bulgarian National Radio, who works on a programme called „Horizont“ also attended. Mrs Hristcheva was reporting on the congress and on the efforts of APCE.

More than 100 people over the age of 17 years live full time at the Chalfont Centre, in specially designed houses on a large site. The visitors were very impressed with the facilities offered to the residents, with furniture and equipment adapted to the needs of the residents and where a range of therapies including art, music and rehabilitation programmes are offered.

"Unfortunately, we in Bulgaria have no such centre," Veska explained. "There is little support for parents who must take care of all the needs of their child or other relative with serious epilepsy and at the same time care for the rest of the family. The residential centres that currently exist frequently refuse access to children and adults with epilepsy due to the specifics of the illness and the absence of a physician to care for them. Regardless of the fact that a centre will look after children and adults with disabilities, there is no resident physician to care for them," she continued.

"Things are very different at the Epilepsy Support Centre in London. We did not manage to ask all the questions we had hoped to during the short time we were there, but the time was sufficient to stir up a spectrum of feelings in us – humiliation that we cannot rely on any support in our country, anger because this makes us feel like second-rate persons, and helplessness to change things. In the end there were tears in our eyes because our families live and work in Bulgaria and our sick children and our healthy children should receive timely support from Bulgarian institutions.

We remain in hope that this meeting is the beginning of a new cooperation and with the hope to end our journey soon!"

From left: Pepa Perkova, Veska Sabeva, Graham Faulkner, Gergana Hristcheva and Sashka Stoichkova

WRITING ON THE WALL IN VALENCIENNES!

Popular French artist Tanguy Dohollau has painted this striking 3 metres high by 8 metres long fresco on a wall in full line of view of the city tramline, a short walk from the station, in the center of Valenciennes in France. The image shows two people, a young girl and an adult, standing together looking into the distance. The message of Epilepsie France inscribed on a clear sky is: "Together let us fight against prejudice."

Author and illustrator, Mr Tanguy Dohollau, who lives in Brittany, has exhibited throughout Europe, as well as in Pakistan and Japan.

FUTURE CONGRESSES

2013 MONTREAL

23rd - 27th JUNE, 2013

30th INTERNATIONAL EPILEPSY CONGRESS

IBE

INTERNATIONAL LEAGUE AGAINST EPILEPSY ILAE

Dublin 25th -27th May 2013

Irish EU Presidency

European Forum on Epilepsy Research

13TH EUROPEAN CONFERENCE ON

Epilepsy & Society

LJUBLJANA, SLOVENIA

28TH - 30TH AUGUST 2013

IBE

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