

International

Epilepsy News

Newsletter of the

International Bureau for Epilepsy Issue 4 - 2008



Translational Research
New Australian Initiative
IBE Election Results

The President's Message



Dear Friends

Isn't time flying? It seems that I have just written a President's Message but, when I look into the diary, I see that several weeks have passed since then. I imagine that, when you have a lot of things happening around you, time passes quickly; at least that's how it feels. IBE is in the middle of a very busy period with preparations for meetings and congresses and I am looking forward to many exciting activities during the year.

Many member organisations are struggling with communication issues, trying to influence the media and politicians: sometimes both at the same time. Journalists are a very important target for our attention. Their knowledge, personal experience and attitude towards people with epilepsy are often reflected in their writing, no matter what angle they take. We always have to be attentive, prepared to assist and to have our eyes open and alert to ensure that the correct language is used when speaking and writing about epilepsy. Two events will highlight this during 2009: The Excellence in Journalism Award, a collaboration of IBE and UCB, and the ILAE Film Award of which I am a member of the judging panel. Both awards will be presented during the congress in Budapest at the end of June.

IBE is a growing organisation and I am happy to inform that we have 3 new members, approved and ratified by the General Assembly. We will continue our efforts to increase our network and to empower people with epilepsy to achieve a good quality of life. Friends and members in national epilepsy organisations are vital in increasing our global presence and strength and I would like to encourage IBE Members to help us in identifying new members.

As always the International Epilepsy News reports on a wide range of ongoing activities in IBE and in the field of epilepsy. I am very proud and happy that IBE has such an attractive magazine, thanks to our Editor Carlos Acevedo and Ann Little, Executive Director. The newsletter reflects very well the tremendous diversity and colour that is the IBE family.

Until next - best wishes to all!
Susanne Lund
President

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The International Bureau for Epilepsy, with membership of 126 epilepsy associations based in 92 countries worldwide, works to improve the quality of life for all people affected by epilepsy.

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The Editor reserves the right to edit content for reasons of space or clarity.

The Editor's Letter



Dear friends:

We are finishing the year 2008 with IE News 4—2008.

With this opportunity I would like to say 'Thank You' to our subeditors and all our Members for their regular contributions for each issue. We try to include all of them, but this is not always possible and, when a report is very long, we sometimes need to reduce down its length, in order

to be able to include it.

In this issue we include a report on employment training from Italy, an extensive report on the EUCARE session in Marseille and an article about an important initiative in Australia, the Parliamentary Friends for Epilepsy.

With the election of the International Executive Committee now completed, we can introduce you to the new incoming committee and we also provide information on the ongoing Regional Elections, including an updated list of IBE Members by region. I am also happy to include a report from the Latin American Regional Executive Committee.

We are delighted to receive, as one of our expert column contributors, an article presented by Prof Nico Moshé, giving us some clues about the importance of basic research in the field of epilepsy. We feel extremely honored to having Prof Moshé contribute to the magazine, as he is the recently elected incoming President of ILAE for 2009-2013.

We also include early details of planned IBE activities at the International Epilepsy Congress in Budapest in June; this will be a special congress with ILAE celebrating its centenary.

Finally, as usual, Susanne Lund has provided us with her nice IBE President's letter.

Kind regards

Carlos Acevedo
Editor

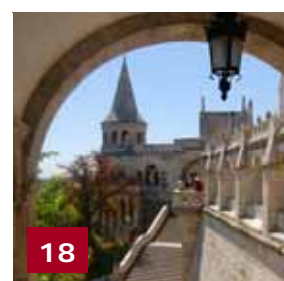
International Epilepsy News on the Web

IE News is now available on the IBE website
www.ibe-epilepsy.org

Previous issues can be found under the tab **IE News**, while the current issue is available to IBE Members on the **Members** section.

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International Executive Committee meets in Marseille

Special meeting at the European Conference on Epilepsy & Society



The Old Port of Marseille

For the first time in many years, thanks to support provided by Eisai pharmaceutical company, a special one-day meeting of the International Executive Committee was held at the time of the Epilepsy & Society Conference in Marseille last October.

This provided a great opportunity for members of the committee, who are based in countries around the world, to meet with delegates to the conference and to share news and information on a range of issues relevant to IBE and to its members.

The committee met for a full day of discussion in advance of the start of the conference and addressed a number of issues, including:

Membership Enlargement

The Membership Drive 2008 had been very successful in identifying associations that met the criteria for membership and in encouraging them to consider IBE membership. By mid-October, six new membership applications had been ratified by the General Assembly, using electronic balloting. These new Members are in the following countries:

- USA
- Australia (2)
- Bulgaria
- Czech Republic
- Russia

This gave a total membership figure of 123 Members, with 91 Full Members and 32 Associate Members. Of

course, since then, we have welcomed more new Members to the Bureau (see next page)/

Action Zone! Awards

IBE President Susanne Lund reported on the important Communiqué Awards that had been awarded to IBE for the Action Zone! game that had been developed as a collaboration between IBE and UCB Pharma. IBE won two major awards:

- Best International Public Relations Campaign
- Communiqué Campaign of the Year 2008 Award

Journalism Awards

The committee discussed the new Excellence in Journalism awards, which would be presented in Budapest at the time of the 27th International Epilepsy Congress.

The awards could play an important role in encouraging journalists to report widely and accurately on epilepsy both in the printed media as well as on radio, TV and the internet.

It was also vital to see that journalists used the correct terminology and language when focussing on epilepsy. All too often there were cases where inappropriate language was used—either due to lack of accurate information or, more worryingly, in order to sensationalise a story for the sole purpose of increasing readership. The committee was agreed that, if

successful, the journalism awards could become a biennial initiative.

Future Congresses

Looking forward, attention was paid to the next two International Epilepsy Congresses: Budapest 2009 and Rome 2011. Both of these meetings would mark important anniversaries with ILAE celebrating its centenary in Budapest and IBE celebrating its Gold Jubilee in Rome.

Budapest will see many special activities marking one hundred years of ILAE, but IBE is also planning for the congress. The committee spent some time in considering interesting activities for IBE Members and for all delegates to the conference. Elsewhere in this magazine you can read more about IBE plans for Budapest.

Two years from now, IBE will reach its 50th Birthday and already the committee is beginning to make exciting plans to mark the event. The 28th International Epilepsy Congress will take place in Rome, the city where the Bureau was founded, and the Eternal City will be a fantastic location for the congress.

Regional Membership

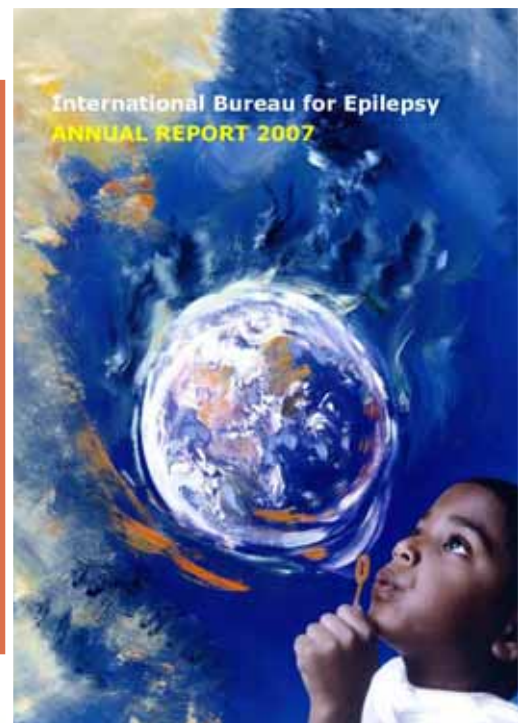
A final issue for discussion was the planned new Regional Membership category, which is being considered. It is hoped that a proposal will be ready in good time for discussion at the Assembly in Budapest.

Annual Report 2007

The IBE Annual Report 2007 was now available on the IBE website for reading online or for personal download. Thanks are again extended to Members who provided information and photos on activities in their association, for inclusion in the report.

If you would like to receive a hardcopy version of the report, you may do so by contacting the IBE office at ibedublin@eircom.net. Copies, which are limited in number, will be distributed on a first come, first served basis.

We are beginning to prepare the next Annual Report and Members will once again be invited to contribute.



Journalism Awards

Initial response to the new Excellence in Journalism Awards has been terrific, with a very high number of requests received for Entry Forms and Award Rules. The awards will be presented in Budapest in July, with prizes in three categories:

- Medical print/online
- Consumer print/online
- Broadcast

The winner of each category will receive €4,000 in travel vouchers. Full details of the award, including forms and rules, can be found on the IBE website

www.ibe-epilepsy.org/activities

Or may be requested directly from ibedublin@eircom.net



Welcome to New Members

The IBE General Assembly recently ratified the following membership applications using electronic voting:

Full Members

- All Russian Charity Foundation (Russian Federation)
- Sociedad Dominicana Unidos Por la Epilepsia - SODOUE (Dominican Republic)

Associate Members

- EpiStop (Czech Republic)
- Epilepsy Queensland (Australia)

IBE now has 126 Full and Associate Members in 93 countries worldwide.



TRANSLATIONAL RESEARCH



Prof Nico Moshé, Secretary General and President-elect of the International League Against Epilepsy (ILAE), writes about the importance of translational research in the field of epilepsy.

The beginning of the League's second century offers us unprecedented opportunities to improve epilepsy care worldwide through a coordinated program of education, research and the development of centers of excellence in countries where they do not now exist. One area of great potential

for improving treatments for patients with epilepsy is translational research.

Translational research is the many steps that are involved in moving discoveries in the laboratory to new treatments for patients. Successful translational research involves researchers who recognize the potential clinical value of a new laboratory discovery and who can take that discovery to a new treatment.

To accomplish this critical goal we need researchers who are trained in the clinical sciences but who also have a strong background in laboratory research. It is this group that will close the very real gap that now exists between the clinic and the lab. As we consider moving this part of medical research forward we have to make sure that we have trained enough translational researchers who can perform this important work.

One very important development that has helped epilepsy research move ahead so quickly in recent years has been the introduction of a number of

animal models that have many features in common with human types of epilepsy. We are now able to study the effect of seizures on the brain as well as how seizures and their consequences can be influenced by age and gender. The availability of these models will also allow us to develop new epilepsy treatments. Epilepsy is fortunate that it has such realistic animal models, because, unlike many diseases such as Alzheimer's disease for which there are no good models, the results in our models are more likely to predict what will happen in patients.

Translational research is a major focus of the ILAE's Neurobiology

Translational research is the many steps involved in moving discoveries in the laboratory to new treatments for patients

Commission which wants to raise the visibility and demonstrate the importance of epilepsy research to the

clinical community as well as to the basic scientists. Until now the focus of translational research has been on epilepsy in the developed world, but we are very aware of the immense need for new treatments for types of epilepsy that predominate in areas where there are currently very limited re-

sources. The Neurobiology Commission of the ILAE is actively involved in developing plans to address this critically important but long understudied problem. Key to the success of strengthening translational epilepsy research that will move epilepsy treatments forward in all parts of the world is the education of clinicians in basic science and the basic scientists in clinical epilepsy.

ILAE is planning programs to develop appropriate clinical and research skills in developing countries

To achieve these goals both groups must actively interact. The ILAE can foster this interaction by designing symposia that include a focused and relevant basic science component in predominantly clinical programs or a

clinical component in a basic science program. One current League program to bring these groups together is the Workshop on the Neurobiology of Epilepsy (WONOEP), which is held every two years in conjunction

with the International ILAE Congress.

Translational research in developing countries will

require an effective infrastructure that includes improved education as well as an augmentation of local resources. In this setting, it is important to emphasize research aiming at solving the problems of specific causes of epilepsy endemic to their areas (for example, infections, perinatal injuries and head trauma).

The League is planning programs to develop appropriate clinical and research skills in these countries by training researchers and providing them with opportunities to carry out research in their countries.

As another part of efforts to achieve these goals, the ILAE is establishing collaborative efforts with other associations, such as the International Brain Research Organization (IBRO), the Academy of Sciences for the Developing World (TWAS), The Federation of European Neurosciences, the American Epilepsy Society, as well as foundations and state ministries to promote research and training in many resource poor countries. These goals will form the centerpiece of the League's activities as it enters its second century.

Supporting Members in Developing Countries



IBE would like to acknowledge donations to the Solidarity Fund, submitted between 1st July 2008 and 28th February 2009, which are gratefully received. All donations are acknowledged in the IE News, the Annual Report and on the IBE Website.

These funds are used to support IBE Members in developing coun-

tries to play an active role in IBE activities. In particular, the fund is used to support the Promising Strategies Program, which is now entering its third year of funding, and to meet the dues payments of Members in countries deemed to be Low Income according to World Bank figures.

IBE would like to encourage

Members to include a donation when paying annual dues; the Dues Form has been designed to facilitate this. However, remember all donations, no matter how small, are welcome at any time from both Members and supporters.

Contact ibedublin@eircom.net to find out how you can help.

Donations received since 1st July 2008

All previous donations have already been acknowledged

US\$500 and over

2008

- Epilepsy Hospital Bethel, Japan

US\$150 to US\$300

2008

- Swiss Epilepsy Centre, Switzerland
- ANLICHE, Chile
- Indian Epilepsy Association, India

2009

- Swiss Epilepsy Centre, Switzerland

Up to US\$100

2008

- Epilepsy and Environment, Georgia
- Caritas, Malta
- Par-Epi, Switzerland

2009

- Epi-Suisse, Switzerland
- Epilepsy Connections, Scotland
- JECA, Australia
- Par-Epi, Switzerland
- Epilepsy Queensland, Australia
- Stichting Kempenhaeghe, Netherlands
- Slovenian League Against Epilepsy, Slovenia
- Epilepsie Vereniging Nederland, Netherlands
- Taiwan Epilepsy Association, Taiwan

Solidarity Fund

International Executive Committee 2009 - 2013

The newly elected committee will begin its term of office at the time of the General Assembly in Budapest on Wednesday 1st July 2009



Mike Glynn
President



Eric Hargis
Secretary General



Grace Tan
Treasurer



Susanne Lund
Past President



Anthony Zimba
VP Africa



Abdulaziz Alsemari
VP Eastern Mediterranean



Janet Mifsud
VP Europe



Carlos Acevedo
VP Latin America



Mary Secco
VP North America



Vinod Saxena
VP South East Asia



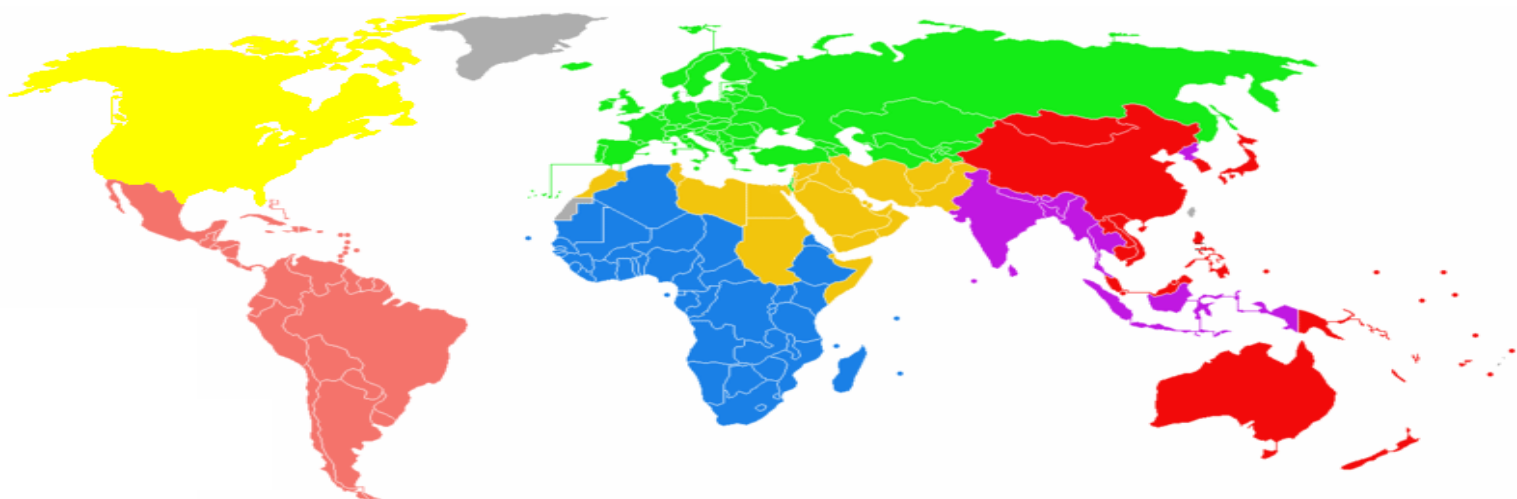
Shunglon Lai
VP Western Pacific



The President, Secretary General and Treasurer of the ILAE Executive Committee are also ex-officio voting members of the International Executive Committee. Nico Moshé (pictured left) was recently elected ILAE President 2009-2013, while elections to fill remaining positions on the ILAE Executive Committee were still ongoing as IE News went to print.

Ballot Paper
Regional Executive
Committees 2009-2013

Election of Regional Executive Committees 2009-2013



Following closely the WHO regional definitions, IBE has seven Regional Committees:

- **Africa**
- **Eastern Mediterranean**
- **Europe**
- **Latin America**
- **North America**
- **South East Asia**
- **Western Pacific**

Every IBE Member is a member of a Regional Committee. These committees are charged with co-ordinating IBE activities in their region, as outlined by a set of Terms of Reference approved by the International Executive Committee. To oversee this work, each Regional Committee elects a Regional Executive Committee, which is decided by a ballot of all Full Members from within the region.

Each Regional Executive Committee comprises a Chair, a Vice Chair and a Secretary. In the case of Europe, the

committee also includes two elected Members.

The Vice President elected by each region to sit on the International Executive Committee, is also an ex-officio voting member of his or her Regional Executive Committee.

The Regional Executive Committee reports to the International Executive Committee as well as to the Members within its Regional Committee. The role of the Vice President is to act as the liaison point between the Regional Committee and the International Executive Committee.

Following completion of elections for the International Executive Committee 2009-2013, the election process for the Regional Executive Committee began at the beginning of February. The elections are overseen by the Election Task Force whose members are Mike Hills (Chair), Marshal Mo-Song Hsih and Philip Lee.

Already all of the relevant papers have been circulated to Full Members

and are also available on the Members Section of the IBE website.

All Full Members in good standing are encouraged to play an active role in the elections. Until early March, eligible members are invited to nominate candidates to stand for election in their region and to assist in seconding other nominations.

Once the nomination period closes, ballot papers, including the election statements of candidates, will be made available. The ballot period will run until early June and the results will be announced as soon as possible after the close of balloting. The new committees will begin their terms of office at the time of the General Assembly, which will take place in Budapest on Wednesday 1st July.

Timelines:

March 6th: nominations close

April 1st: ballot period begins

June 5th: balloting ends

Early June: results announced.



Where do you belong?

A guide to IBE regional divisions

Countries, states and regions where IBE is represented are highlighted in blue.

If you are aware of an epilepsy organisation in a region where IBE is not yet represented, we would love to hear from you.

<p>Africa</p> <ul style="list-style-type: none"> • Algeria • Angola • Benin • Botswana • Burkina Faso • Burundi • Cameroon • Cape Verde • Central African Rep • Chad • Comoros • Rep of Congo • Côte d'Ivoire • Dem Rep of the Congo 	<ul style="list-style-type: none"> • Equatorial Guinea • Eritrea • Ethiopia • Gabon • Gambia • Ghana • Guinea • Guinea-Bissau • Kenya • Lesotho • Liberia • Madagascar • Malawi • Mali • Mauritania • Mauritius 	<ul style="list-style-type: none"> • Mozambique • Namibia • Niger • Nigeria • Rwanda • Sao Tome & Principe • Senegal • Seychelles • Sierra Leone • South Africa • Swaziland • Togo • Uganda • Utd Rep of Tanzania • Zambia • Zimbabwe 	<p>Latin America</p> <ul style="list-style-type: none"> • Argentina • Belize • Bolivia • Brazil • Chile • Colombia • Costa Rica • Cuba • Dominica • Dominican Rep • Ecuador • El Salvador 	<ul style="list-style-type: none"> • Guatemala • Guyana • Haiti • Honduras • Mexico • Nicaragua • Panama • Paraguay • Peru • Suriname • Uruguay • Bolivarian Rep of Venezuela
<p>Eastern Mediterranean</p> <ul style="list-style-type: none"> • Afghanistan • Bahrain • Djibouti • Egypt • Iran, Islamic Rep of • Iraq 	<ul style="list-style-type: none"> • Jordan • Kuwait • Lebanon • Libyan Arab Jamahiriya • Morocco • Oman • Pakistan 	<ul style="list-style-type: none"> • Qatar • Saudi Arabia • Somalia • Sudan • Syrian Arab Rep • Tunisia • Utd Arab Emirates • Yemen 	<p>North America</p> <ul style="list-style-type: none"> • Antigua and Barbuda • Bahamas • Canada • Jamaica • Grenada 	<ul style="list-style-type: none"> • St Kitts and Nevis • Saint Lucia • St Vincent and the Grenadines • Trinidad and Tobago • USA
<p>Europe</p> <ul style="list-style-type: none"> • Albania • Andorra • Armenia • Austria • Azerbaijan • Belarus • Belgium • Bosnia and Herzegovina • Bulgaria • Croatia • Cyprus • Czech Republic • Denmark • Estonia • Finland • France • Georgia 	<ul style="list-style-type: none"> • Germany • Greece • Hungary • Iceland • Ireland • Israel • Italy • Kazakhstan • Kyrgyzstan • Latvia • Lithuania • Luxembourg • Malta • Monaco • Montenegro • Netherlands • Norway • Poland • Portugal 	<ul style="list-style-type: none"> • Rep of Moldova • Romania • Russian Federation • San Marino • Scotland • Serbia • Slovakia • Slovenia • Spain • Sweden • Switzerland • Tajikistan • FYR Macedonia • Turkey • Turkmenistan • Ukraine • United Kingdom • Uzbekistan 	<p>South East Asia</p> <ul style="list-style-type: none"> • Bangladesh • Bhutan • DPR Korea • India 	<ul style="list-style-type: none"> • Indonesia • Maldives • Myanmar • Nepal • Sri Lanka • Thailand • Hong Kong
			<p>Western Pacific</p> <ul style="list-style-type: none"> • Australia • Brunei Darussalam • Cambodia • China • Cook Islands • Fiji • Japan • Kiribati • Korea, Rep of • PDR Lao • Malaysia • Marshall Islands • Micronesia, FS 	<ul style="list-style-type: none"> • Mongolia • Nauru • New Zealand • Niue • Palau • Papua New Guinea • Philippines • Samoa • Singapore • Solomon Is • Taiwan • Tonga • Tuvalu • Vanuatu • Viet Nam

REUNIÓN CONJUNTA

Comité Latinoamericano del IBE – Comisión Latinoamericana de la ILAE

Durante el V Congreso Latinoamericano de Epilepsia realizado entre el 5 y 9 de Noviembre 2008, en Montevideo, Uruguay, se llevó a cabo, una reunión conjunta del Comité Latinoamericano del IBE y de la Comisión Latinoamericana de la ILAE, con el propósito de coordinar las actividades de ambas instituciones en la región. Damos a conocer el reporte de lo tratado en dicha reunión:

Asisten: IBE

Carlos Acevedo (Chile), Alicia Bocagz (Uruguay), Mike Glynn (Irlanda), Beatriz González del Castillo (Venezuela), Tomás Mesa (Chile), Lilia Nuñez Orozco (México), Carlos Oliveira (Paraguay)

Asisten ILAE

Patricia Campos (Perú), Marcelo Devilat (Chile), Marco Tulio Medina (Honduras), Nico Moshé (USA), Alejandro Scaramelli (Uruguay)

Asisten IBE-ILAE:

Salvador González Pal (Cuba), Henry Stokes (Guatemala)

Agenda Tratada:

Dra Lilia Nuñez, Presidenta del Comité Latinoamericano del IBE, hace una introducción y presenta la tabla a tratar.

1. Informe IBE
2. Informe ILAE
3. Situación ALADE. Comisión Educación
4. Congresos Latinoamericanos de Epilepsia
5. Varios

Dr Marco Tulio Median, presidente de la Comisión Latinoamericana del ILAE, presenta las actividades realizadas por la Comisión, destacando: Alade, Lasse, Revista Epilepsia en Español, Subcomité de Cirugía de la Epilepsia, Intercambio de profesionales entre Latinoamericano y Norteamérica (USA-Canadá), contactos con la OPS y apoyo a la organización del V Congreso Latinoamericano en Montevideo.

Dra Lilia Nuñez, da cuenta de las actividades realizadas por el Comité Latinoamericano del IBE. Entre estas destacan: Participación en reuniones plenarias en el Congreso, apoyo y presencia en la presentación en el Congreso de la Ley Colombiana para la gente con epilepsia., participación activa en la revista Internacional Epilepsy News, con una sección en castellano y carta enviada a Dra Elza Yacubian, Presidenta de la Comisión de Educación ILAE y al Dr M Tulio Medina, Presidente de ALADE, para cooperar activamente, desde la perspectiva de IBE, en la realización de los cursos.

Dr Carlos Acevedo, vicepresidente regional del Comité Ejecutivo del IBE, hace notar lo que se está haciendo respecto a leyes para personas con epilepsia, destacando lo sucedido en Colombia y luego las conversaciones en Marsella, Francia, recientemente.

Se acuerda utilizar en la campaña global contra la Epilepsia, el término

en español: Epilepsia fuera de las sombras.

Se analizan los nuevos posibles miembros IBE-ILAE: en este congreso, hay significativos contactos con Paraguay, Bolivia y Costa Rica. El Dr H Stoke, se encargará de hablar con gente de Belice y de Trinidad y Tobago.

La Dra Nuñez cuenta que en el congreso de Budapest, habrá una instancia para discutir sobre Epilepsia y Familia, la cuál ella estará a cargo.

La directiva del Comité del IBE Latinoamericano se reunió en Santiago de Chile, en Mayo 2008, con ocasión de la celebración de los 55 años de la Liga Chilena contra la Epilepsia.

La Dra A Bogacz, da cuenta las actividades del IBE en este congreso, haciendo especial mención al Día del Bureau realizado el 5/11/08.

Se discute sobre los futuros congresos Latinoamericanos de Epilepsia, concluyendo que: deben seguir cada 2 años, tanto el Comité IBE como la Comisión ILAE, deben participar activamente en el diseño de los congresos y tratar de disminuir costos. Se hace proposición a los comités ejecutivos IBE-ILAE de tres posibles países para organizar el VI Congreso LA de Epilepsia: Argentina, Colombia y Ecuador.

Tomas Mesa

Secretario, Comité LA del IBE



Concerted Action for Change

Mike Glynn, Member EUCARE Political Action Group reports on the EUCARE session in Marseille.



Background

EUCARE is a joint initiative of the International League Against Epilepsy and the International Bureau for Epilepsy, whose goal is to raise the profile of epilepsy across Europe through research and political activity. The latter is achieved through the Political Action Group, whose objectives are:

- To identify issues which may be addressed by EUCARE within the political arena
- To formulate a plan of action and develop a proposal concerning political activities.

Pictured right: Dr Graham Harding, Mrs Hanneke de Boer and Dr Tarun Dua. Photo: Eoghan Megannety



Action for Change

In her opening remarks, Mrs Hanneke de Boer, Chair of the EUCARE Political Action Group, who organised this session, said:

‘We are today calling for Concerted Action for Change. This title came from EUCARE’s name which is an acronym for European Concerted Action and Research in Epilepsy.’

The Political Action Group (PAG) is seeking changes and one of the ways in which it will achieve them is through making MEPs aware of the problems facing the 6 million people with epilepsy in Europe.

‘Already’, Ms de Boer said, ‘there have been meetings with key MEPS in Brussels. Recently, a survey was conducted amongst MEPs to establish what their level of knowledge about epilepsy is.

‘Thankfully, 80% of MEPs had some overall level of knowledge of the condition but many had very little understanding of the scale of the problem and, on specific aspects of epilepsy care, such as medication, insurance, employment and epilepsy deaths, the knowledge gap was considerable’.

According to Hanneke de Boer, the message going out to MEPs from today’s meeting must be that six

million people living with epilepsy call on the European Parliament to provide legislation to:

- **SECURE** availability, accessibility and affordability of appropriate treatment;
- **PROTECT** people with epilepsy from discrimination and stigma;
- **ENSURE** equal job opportunities for people with epilepsy;
- **REDUCE** the socio-economic burden of epilepsy

Other objectives which the PAG had identified within the social arena include:

- Promoting development of appropriate European guidelines
- Developing booklet on examples of good practice
- Promoting increased amount of time devoted to epilepsy curricula in medical schools
- Organising a workshop on the development and implementation of European guidelines for broadcast materials and video games

‘The four speakers in this session will provide very good examples in their presentations of how the EUCARE

PAG could proceed with these objectives,’ Hanneke de Boer concluded.

Professor Martin Brodie, chair of the EUCARE management group then

spoke about the FONDE project. EUCARE was set up with two arms, the PAG, which Hanneke de Boer had addressed, and the research arm which oper-

ates as FONDE (Following Outcomes in Newly Diagnosed Epilepsy). Both of these elements of EUCARE link together and seek jointly to improve the lot of all people with epilepsy in Europe through research and political advocacy.

Introducing FONDE

FONDE aims to bring together data from epilepsy specialists all across Europe, which will provide vital information that will lead to better treatments for all. Prof Brodie outlined some of findings from the work that he and his team in Glasgow have been carrying out over the last 24 years (between 1982 and 2005) on almost 1,100 patients with newly diagnosed epilepsy. These findings had been instrumental in the development of new approaches to treatment,

80% of MEPs had some knowledge of the condition but many had very little understanding of the scale of the problem

with the findings published in many leading international journals around the world over the years. In particular, these findings illustrated that the number of people fully controlled on AEDs continues to stay below 70%, even when receiving treatment at a tertiary centre such as the Glasgow one.

Prof Brodie's data also highlighted the fact that only a small percentage (less than 7%) of people achieve seizure-freedom on a combination of more than one AED and the vast majority of these do not take more than two AEDs. All of this data confirmed that efficacy and tolerability are the two key components which determine the effectiveness of a drug for an individual.

'These findings from just one centre give an indication of just what can be achieved by FONDE, which is a multi-centred, multi national project,' Professor Brodie concluded.

Alzheimer Europe strategy

Mr Jean Georges, Executive Director of Alzheimer Europe then spoke about how his organisation is seeking to make Dementia a European priority and of their progress to date. Alzheimer Europe (AE) is a European umbrella body for all Alzheimer organisations throughout Europe, very similar to the IBE structure, except that it only operates in Europe. The Strategic Objectives of AE are as follows:-

- representing the interests of people with dementia and their carers,
- involving and supporting national Alzheimer associations,
- improving the information exchange between Alzheimer Europe, its members and European structures,
- promoting best practice through the development of comparative surveys,
- developing policy statements
- developing strategic partnerships

For AE, achieving agreement on the part of all its national members was a key stepping stone in their strategy. In 2006 this was accomplished when all AE members signed up to its 'Paris Declaration'. Since then, AE

has campaigned strongly at EU level to get the support of MEPs for its objectives. So far, 82 MEPs have

pledged their support, which is a considerable achievement.

'The challenges facing AE are remarkably similar to those of IBE, as outlined by Hanneke de Boer earlier,' Jean George said. 'The key challengers for AE are:

- 6.1 million people with dementia in European Union
- Socio-economic impact of the disease
- Late diagnosis
- Impact on carers
- Lack of services
- Differences across Europe with regard to access to treatment and services.

'These are very difficult challenges,' continued Jean Georges, 'but AE has been encouraged by some excellent developments, such as a French national €1.6 billion plan for dementia, a German dementia research initiative and the UK's dementia strategy; all of which provide real encouragement to continue.'

Photosensitivity

Professor Graham Harding, from the Neurosciences Institute at Aston University in the UK, then spoke about Guidelines for Flashing Lights and Images. Prof Harding is the acknowledged world opinion leader in this area and, uniquely, was involved in the creation of guidelines for photosensitivity in epilepsy for television in both the UK and Japan - the two countries most associated with difficulties in flashing light and image problems for children and adults with photosensitive epilepsy.

Television (TV) is the most provocative visual stimulus and evokes seizures in susceptible children, adolescents and adults. Very many of these children experience their first seizure whilst watching some type of screen. This happens especially when flickering and patterned images are shown.

Television is the most provocative visual stimulus and evokes seizures in susceptible children, adolescents and adults

In 1997 in Japan 685 children were admitted to hospital with suspected seizures. This became known as the 'Pokemon' incident because all of the children were watching the broadcast of this comic game on TV at the time. The incident led to the establishment of guidelines for TV in Japan. Earlier, guidelines had been set up in the UK arising from a number of incidents of provoked seizures there. In fact, software has been developed in the UK by a company called Cambridge Research Systems which can monitor, in real time, the output from a TV station to ensure no dangerous flickering occurs. This software is known as the 'Harding FPA Flash and Pattern Analyser'.

The development of new types of TV screens will not remove the need for control of broadcast material. It could be argued that rather than protect the whole viewing audience by the application of broadcasting guidelines, only those who are photosensitive should be protected. But maybe we should do both, because most known sensitive patients will benefit from greater safety and will not be dependent on fashionable ideas from commercial broadcast companies that are not (yet) familiar with the guidelines. The BBC, although it had signed up to the UK guidelines and has the Harding FPA software, still managed to create a major fuss recently when it did not check out its own new flashing logo for the 2012 Olympics. The logo had to be withdrawn after several complaints to epilepsy charities from members of the public.

Even in those countries where Guidelines for TV exist, no such guidelines exist for video material, electronic screen games, and the Internet. It would

seems wise to adopt the Guidelines for all video material and electronic screen games and all relevant materials.

WHO's View on Epilepsy

Dr Tarun Dua, who is the Medical Officer for the World Health Organization's (WHO) Programme for Neurological Diseases and Neuroscience spoke next on the WHO's 'Views on and Commitment to Epilepsy'. Dr Dua is also the key link person at the WHO for the Global Campaign

against Epilepsy (GCAE). She outlined how the GCAE had been set up. In 1995 the partnership between Professional (ILAE), Public/Patients (IBE) and Political (WHO) organisations was created. Dr Dua outlined the many GCAE activities since then and their positive outcomes. The Demonstration Project in China illustrated this particularly well as follows:-

Prior to demonstration project:

- Prevalence: 5 million
- Treatment Gap: 30%

After demonstration project:

- Prevalence: 9 - 12 million
- Treatment Gap: 65%

The Demonstration Project in China has led to approval by Ministry of Health for an expansion from 6 to 16 provinces of China, with an expanded coverage from 2.5 million to 40 million inhabitants. In addition, epilepsy care is to be included in primary care in rural China with funding plus administrative and financial support through local governments.

The outcome assessment of the Dem-

onstration Project in Brazil has led to a model of epilepsy treatment at primary health level, based on the existing health system which is effective in providing important reductions in

Ninety percent of those surveyed said they would continue to be active in the Global Campaign in the future

seizure frequency and general well being. Epilepsy has been officially adopted as a theme to be considered in elementary education by the Ministry

of Education, and a National Epilepsy Programme is under review at the Ministry of Health. The ultimate goal of the Demonstration Projects is the development of a variety of successful models of epilepsy control that can be integrated into the health care systems of participating countries and regions and, finally, applied on a global level.

Scaling up Epilepsy Care

Dr Dua illustrated that the cost of scaling up activities to help people with epilepsy in the developing regions was relatively cheap when undertaken on a major scale and this before any account is taken of the benefits to societies when people with epilepsy play a full economic

and social role in their communities.

A study estimated the avertable burden of epilepsy and the population-level costs of treatment with first-line AEDs in developing countries

- Extension of coverage of treatment to 50% would avert 13-40% of burden
- The annual cost per person would be 0.20-1.33 International Dollars
- At a coverage rate of 80%, the treatment would avert 21-62% of the burden
- The cost to secure one extra healthy year of life is less than average income per person

GCAE is a very a successful partnership with 135 IBE/ILAE organisations in 103 different countries actively engaged in Global Campaign related activities, covering 86% of the world population. In a recent survey arranged by Philip Lee, co-Chair of the Global Campaign Against Epilepsy, two thirds of Campaign activities reported by the organisations were seen to be either very successful or moderately successful. Ninety percent of those surveyed said they would continue to be active in the Global Campaign in the future



Obituary

Maurice Parsonage,
BSc; MB, CH B; Dip CH; FRCP

Maurice Parsonage, who gave great commitment and service to both IBE and ILAE between from the 70's to the 90's died in Harrogate, UK, on December 5th 2008, aged 93. Born in Nantwich, Cheshire, he graduated in Medicine in Manchester in 1939 and then obtained the Diploma in Child Health. The Second World War interrupted his paediatric plans and he served in the Royal Army Medical Corp between 1940 and 1946 as a Lieutenant Colonel. His postings in-

cluded the Military Hospital for Head Injuries, Oxford, which influenced his neurological career, and later India.

Between 1946 and 1951 he trained in neurology at Manchester, Guy's Hospital and the National Hospital in London, and at the Columbia New York Neurological Institute. From 1951 to 1980 he was Consultant Neurologist to the Leeds Regional Hospital Board, and Physician-in-Charge of the Neuropsychiatric Unit at Bootham Park Hospital, York, where he established a Centre for Epilepsy.

Through contact with George Burden and later Alec Aspinell, General Secretaries of the British Epilepsy Association (BEA), he provided a unique professional and educational service for people with epilepsy throughout the UK. With the establishment of IBE, he participated with George Burden, Harry Meinardi and others in educational lecture tours in Africa (1972), India (1974) and Kenya/South (1976), and was awarded an IBE/ILAE Ambassador for Epilepsy. His clinical and research interests embraced classification, neurophysiol-

ogy, pharmacology, as well as psychological and social dimensions. He was Chairman of the ILAE Commission on Anti-epileptic Drugs (1974-1978) and Chairman of the ILAE/IBE Commission on Driving Licences (1981-1993). He served on the Board of Directors of IBE from 1977 to 1981. His patients and colleagues can confirm his charming communication skills and unfailing courtesy and diplomacy in the face of difficulty or provocation. He was a wise man who held firmly to his opinions while respecting those of others.

During neurological training in Guy's Hospital (1948) Maurice Parsonage and JW Aldren Turner, Neurologist to St. Bartholomew's Hospital, wrote the definitive article in *The Lancet* on Neuralgic Amyotrophy, based on war experiences in the UK and India. The syndrome is now widely known as Parsonage-Turner syndrome.

His wife, Marion, pre-deceased him in 2002 and they are survived by two sons, John and Michael, and their daughter, Fiona.

E.H. Reynolds, January 2009.



Employment Training for People with Epilepsy

Results of a 10 year initiative in Milan, Italy

Report by Piazzini Ada, Somenzi Paola, and Canger Raffaele, Regional Epilepsy Center, S. Paolo Hospital, Milan

People with epilepsy often face considerable problems in getting and keeping a job. Most of the time, these difficulties are not related to objective professional obstacles but to social prejudices that still exist in epilepsy. For those reasons, we decided to arrange specific projects on work integration for people with epilepsy and with mild cognitive disabilities, which offered professional/vocational training and some work opportunities to those people with epilepsy who have never been able to get a job, or were not satisfied with their professional positions.

The first project took place in Milan, in October 1998 and the final one in June 2008; the last two projects were led by “Piano Emerso” and “Fondazione Adecco”. The “Piano Emerso” project, also called “Orienta e Informa” took place between February and December 2007, with the support of Ce.Fos (Centro di Formazione Orientamento e Sviluppo), Fondazione Don Gnocchi, and the Regional Epilepsy Center, S. Paolo Hospital in Milan.

The final project, called “Percorsi di educazione al lavoro e formazione professionale” ran from September 2007 to June 2008, with the support of Fondazione Adecco per le Pari opportunità” and the Regional Epilepsy Center, S. Paolo Hospital. Both projects were focussed on people with epilepsy and a disability.

Homogeneous groups for clinical and psychosocial variables for each project were recruited, in order to offer an educational programme targeted to the candidates’ capacities. The global evaluation included a clinical, a

neuropsychological, a psychological, and a social investigation.

On the basis of the complete clinical evaluation, the participants were divided into five categories of increasing risk in occupational suitability which, together with the frequency of their seizures, gave us a better quantification of the possible difficulties that each candidate might meet in job placement. The neuropsychological assessment aimed to have a complete profile of the candidates’ main cognitive abilities. The psychological evaluation verified the candidates’ personality traits and studied their possible behaviour reactions on work organizations. Finally, a social examination was performed, in order to find out previous employment (if any) of participants, their studies, living situation, financial status, mobility and family.

Clinical, neuropsychological, psychological and social information were investigated in order to obtain an overall assessment of the participants, which focused on their real/assumed abilities or limitations, which could allow us to recruit those who might present higher potential capabilities into the labour market.

Some studies speculated that people with epilepsy often show a lack of interpersonal competences, probably due to limited exposure during adolescence to social organizational activities, through which communicative capacities are developed. These poor social competences can be also exacerbated by frequent seizure activity and AED side effects. An awareness of personal limitations in social communication, as well as

consecutive training in different personal and social approaches represent important psychological tools to reach a more mature psycho-social adjustment in the labour context.

Seventy percent of patients who participated to our courses found a job within one year time, even though the majority of these were temporary positions. Patients who had already a professional experience before entering our courses had the chance to better understand the demands of work, so that they could seek alternative employment opportunities.

The possibility to participate in an educational programme offering better technical and social training can be particularly useful for people who, as some investigations pointed out, are over-represented in unskilled or semiskilled positions.

Training courses for people with epilepsy deserve more attention, considering that, at least in Italy, similar experiences are still rare. It is recommended that these projects should continue to be made available, especially involving young people, in order to acquaint them at an early stage with the skills required in the job market.

We believe that training courses should offer multi-faceted programmes, such as education on job skills, on specific task abilities, on work adaptive competences, and on social and interpersonal capacities. These courses should also be part of a larger network of labour mediation agencies, which can provide outplacement and facilitate a quicker integration into the labour force.

Parliamentary Friends of Epilepsy Group

The Joint Epilepsy Council of Australia, IBE's Full Member in Australia, announces the formation of this important group with the support of Ms Jill Hall and Senator Gary Humphries



Jill Hall, Member for Shortland (left) and Senator Gary Humphries, co-convenor of the Parliamentary Friends of Epilepsy Group

On the 17th March 2008, Jill Hall, Member for Shortland (an elected public representative), on behalf of the Joint Epilepsy Council of Australia, called upon the Australian Parliament to accept the challenge to take steps to make lasting changes to the lives of people with epilepsy and their carers.

Ms Hall reminded the House that while recent mental health initiatives were a good example of what governments could achieve, there had been a failure to address many of the issues facing people with epilepsy.

Referring to the ILAE/IBE/WHO Global Campaign Against Epilepsy "Out of the shadows", which identified epilepsy as arguably the most misunderstood, most stigmatised and most under-resourced health condition in the world today with an estimated 60 million plus people with epilepsy in the world, Ms Hall went on to say that:

"While Australia has a great deal to

be proud about in its medical treatment of people with epilepsy, there are many for whom current medical treatments are woefully inadequate. At any one time, around 200,000 Australian citizens have epilepsy. As many as 10% of those have poor control of their seizures and for a smaller percentage there is so little control that life is almost unbearable for them and for those who love and care for them. I have experienced this at a personal level.

"My sister-in-law has suffered from uncontrollable epilepsy since she was 10 years of age, and I know the impact that it has had on her and her family's lives."

Drawing from the submission "A National Strategy for Epilepsy", prepared by JECA for government, Ms Hall further informed the House:

"The JECA has asked that a national epilepsy working group be established and resourced to oversee a national public education program, in

tandem with an applied social research program to ensure that the right messages are being targeted to the right people, and to develop strategies to address many of the issues faced by people with epilepsy based upon credible, rigorous applied social research.

"The Joint Epilepsy Council has asked the parliament to form a Parliamentary Friends of Epilepsy Group. I am pleased to advise that this will take place. In conjunction with Senator Humphries, I will convene this group.

"We will work to ensure that people living with epilepsy are able to be included in the mainstream life of Australia and, as the Global Campaign Against Epilepsy puts it, come out of the shadows."

In lobbying for the submission "A National Strategy for Epilepsy" JECA Board Members met with, corresponded with, and lobbied federal and state parliamentarians. In particular, former JECA Chairman Jacinta Cummins, and former Secretary Russell Pollard, met with many politicians in Canberra and with their senior advisors – including the senior policy advisors to the Prime Minister and the Health Minister in the Prime Minister's Office.

Through this work JECA gained the very supportive attention of a great many Members of Parliament and was able to discern a good deal more than was previously known about who had particular interests in epilepsy, and why.

The purpose of the Parliamentary Friends Group is to meet with JECA

on a regular basis in order to advance the epilepsy cause based around an earlier agreed Pre-budget Submission to Parliament. JECA provided its agreed outline of what it required, which followed several years of discussion and negotiation, asking for

- A public awareness campaign run in parallel with a national survey conducted with credible research methodology.
- A number of major research projects each looking at practical outcomes around vexed issues facing Australians living with epilepsy.
- The removal of generic substation practices in the prescription and distribution of anticonvulsant medications.

To achieve these objectives, JECA asked that a national working party be established with JECA as a key advisory body.

For JECA, the 17th March 2008 will be remembered as a watershed for the Australian Epilepsy movement. The

submission was the first agreed submission to the Federal Government from the epilepsy movement in the last 20 years.

Following this, the Parliamentary Friends of Epilepsy held its first official meeting at Parliament House, Canberra in September 2008. Welcoming the Friends with congratulatory messages of support from Susanne Lund (IBE) and The Earl Howe (Chairman of the All-Party Parliamentary Group, Houses of Parliament, London), Jacinta Cummins, Chair of JECA, then spoke of the need for Australia to do better to support the needs of people with epilepsy.

In presenting a 6-point vision and action plan that outlined the need for improved understanding of the economic and social impact of living with epilepsy, she invited the Friends to share the vision and, with their active support, effect lasting change.

Informing the meeting that around 300 Australians die every years from epilepsy-related causes, many preventable, and around 150 of these

deaths due to SUDEP, the urgency for better community understanding and awareness was highlighted when guest speaker Margaret Callaghan related her family's experience with epilepsy and the untimely death of her son Matthew, aged 26.

In response to the vision and the issues that it raised, co-convenor Jill Hall MP, proposed that an inquiry into epilepsy be conducted by the Friends in 2009.

In early 2009 Jill Hall confirmed that the inquiry would take place and terms of reference have been submitted to the Group. It is anticipated that hearings will be held in the capital, as well as mini-hearings across the country throughout the course of 2009. This will be the first time that Australians living with epilepsy will have the opportunity to personally inform Federal politicians of the impact epilepsy has on their lives.

This article borrows from a report featured in The Epilepsy Report, May 2008, with kind permission. Updates were provided by Denise Chapman.

Annual Dues 2009

The deadline for payment of annual dues for 2009 has now passed. Most Members have already arranged payment, and many also have donated generously to the Solidarity Fund; however a small number of payments remain outstanding.

To avoid jeopardising membership privileges, you should settle any outstanding payments as soon as possible. Remember that Full Members must have their dues payments up to date in order to cast ballots in the Regional elections. Full Members will also need to be in good standing to vote at the General Assembly that will take place during the 28th International Epilepsy Congress in Budapest on 1st July.

How to help children with epilepsy

A manual for mothers, families and teachers

'How to help children with epilepsy' is a recent publication by the WHO Regional Office for the Eastern Mediterranean on epilepsy. The manual has been produced in Arabic for field testing in several countries of the Region. This manual provides basic information and knowledge for caretakers, mainly mothers, families and teachers dealing with children with epilepsy as well as for the children themselves.

In doing so it is hoped that misconceptions regarding epilepsy can be dispelled and the stigma and discrimination associated with the condition combated.

The manual also attempts to provide simplified guidance on addressing different issues related to the disease in the day-to-day life of children with epilepsy and their families in order to enable them to become active contributing members of their community.

The manual is currently being field-tested. If you are interested in field-testing it please contact mnh@emro.who.int.





Only 4 months to go!

Budapest 2009

www.epilepsybudapest2009.org



General Assembly

Wednesday 1st July 2009

Welcome Reception: 12.00

Meeting begins: 13.00

Venue: meeting room to be confirmed

Highlights:

- Looking back on 4 years
- Celebrating Members activities
- Welcoming new Members
- Announcement of the Volunteer Award Winner 2009
- Ratification of New Members and presentation of certificates
- Introduction of the International Executive Committee 2009-2013
- Reports and Discussion



Visit the IBE Stand

IBE's Stand promises will be as busy as ever, showcasing the many activities of IBE and its Members. It is the traditional **meeting point** for IBE members to drop in for a chat.

We hope to see you there!



Members Posters

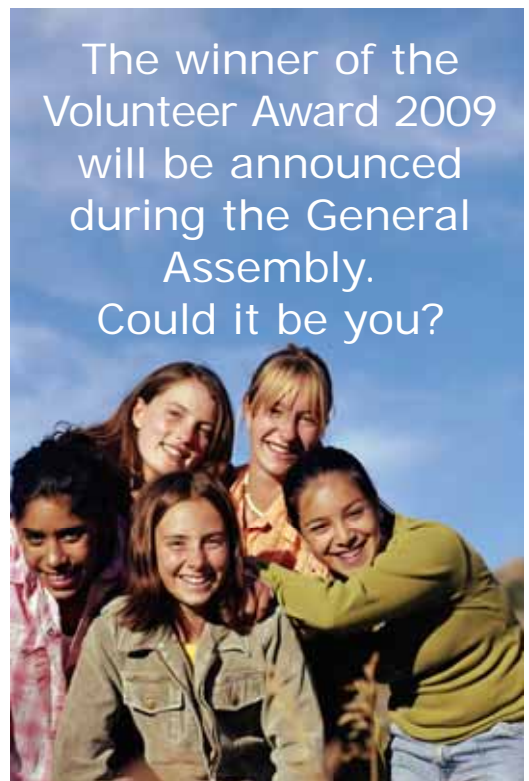
Following the successful displays in Paris and Singapore, we are organising a another display of posters to highlight the activities and achievements of our Members. We hope that as many Members as possible will take part—in Singapore we had almost 50 posters!

At the end of the congress participating Members will be able to take home their association's poster to use again to promote their association's work.

Business Meetings

Regional Committees, Commissions, Task Forces, and Networks will all be arranging business meetings during the congress. As details are confirmed, information will be circulated by email and will also be uploaded to the IBE website.

As the current 4-year terms of office come to an end, these will be particularly important meetings as the new committees begin their work.



The winner of the Volunteer Award 2009 will be announced during the General Assembly. Could it be you?

Derogation for MRI in Europe

Alliance for MRI sent IBE an important update from Brussels



The Alliance for MRI welcomes the European Parliament Environment and Public Health Committee support for a derogation for MRI from EMF Directive

During yesterday's (17th February 2009) vote by the European Parliament Committee on Frederique Ries' Draft Report on Health concerns associated with electromagnetic fields, the amendment calling for the European Commission to introduce a derogation for MRI from the scope of the EMF Directive (Amendment 35) received cross-party support. In addition, the following two recitals were carried:

'Whereas the use of Magnetic Resonance Imaging (MRI) must not be threatened by Directive 2004/40/EC as MRI technology is at the cutting edge of research, diagnosis and treatment of life-threatening diseases for patients in Europe,'

'Whereas the MR safety standard IEC/EN 60601-2-33 establishes limit values for electromagnetic fields which have been set so that any danger to patients and workers is excluded.'

Many thanks to all who supported our position and we look forward to cross party support in the plenary vote on 26th March.

Report by SCENIHR on the "Health Effects of Exposure to EMF"

The Alliance for MRI welcomes the publication of the Opinion on "Health Effects of Exposure to EMF" by the Scientific Committee on Emerging and Newly Identified Health Risks (SCENIHR).

The Alliance for MRI would like to underline that the medical application of magnetic resonance imaging

which solely uses magnetic fields needs to be clearly distinguished from electromagnetic fields related to power lines and mobile phones. The frequency range of the fields applied in MRI is also different. The Alliance for MRI would like to reiterate that there is no known harmful effect associated with the MRI if it is used in accordance with existing international standards and safety guidelines.

The Alliance is however concerned about the clear lack of awareness regarding the threat posed to MRI by the implementation of Directive 2004/40/EC. This Directive has been postponed until April 2012 to ensure that the future of Magnetic Resonance Imaging (MRI) is safeguarded. The Alliance regrets the inclusion of the statement that 'exposure of therapists or other medical personnel needs to be controlled to avoid that their exposure exceeds the exposure limit values foreseen by Directive 2004/40/EC for occupational exposure' which is clearly inappropriate.

Magnetic Resonance Imaging has been safely used in diagnosis and treatment for over 25 years, with over 500 million patients exposed to up to 100 times the occupational exposure limit set in Directive 2004/40/EC, without evidence of harm to workers or patients.

The use of MRI has provided immeasurable benefits to patients. It is an essential tool in diagnosing and

treating illness and in medical research. MRI scans produce detailed pictures of the inner structure and function of patients' bodies using magnetic fields and radio waves. It is central to important treatments and research programmes for many illnesses, in particular, cancer, heart disease and neurological problems. If implemented, the Directive would prevent healthcare staff from assisting or caring for patients during imaging. It would mean that some patients who cannot be imaged without this care – if they are young, elderly, frail or confused – would either be denied imaging or have to undergo alternative procedures such as x-rays.

The established MR safety standard IEC/EN 60601-2-33 (as amended and harmonised under the Medical Devices Directive) establishes limit values for time-varying electromagnetic fields which have been set so that any danger to patients and workers is excluded.

The MRI Alliance would also like to draw attention to a report prepared on behalf of the Institute of Physics by Dr. Stephen Keevil, Guy's and St Thomas' NHS Foundation Trust and King's College London. The report deals with important aspects regarding the implications of the EMF Directive for MRI, outlines the actions of the MRI community and prospects for the future.

IE News needs YOUR help!

Do you have news we might include in a future issue of IE News?

It could be a report on a special achievement - for people with epilepsy or by people with epilepsy. It might be the announcement of new legislation that could help other countries to lobby for change. Or is it an image that records an important moment in your association?

We would love to help you share the good, or even bad, news with our readers, so write to us at ibedublin@eircom.net.

28th International Epilepsy Congress Budapest, Hungary June 28th—July 2nd 2009



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