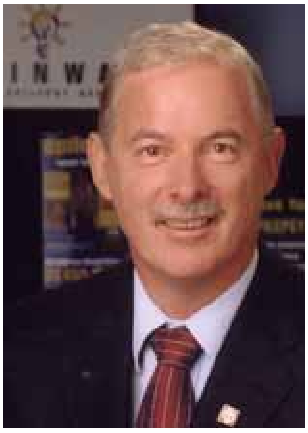
International
Epilepsy News
Newsletter of the International Bureau for Epilepsy Issue 4 - 2009

Looking forward to a new decade

The President's Message



Dear IBE Members and Supporters

As I write this message I am conscious that we are coming to the end not only of another busy year but of the close of the first decade of the 21st century. It seems almost like yesterday that the world was buzzing with excitement at the thought of the start of a brand new century and the promise it held.

Looking back, it is clear that the world is quite a different place than it was in 1999. Most world economies have, since then, seen some extraordinary boom times and are now struggling to survive the worst recession in living memory. In emerging nations economic hardship is not tied to recession, of course, but is a permanent state of affairs.

Around the world epilepsy associations are struggling to find the funds necessary to continue their services. Some traditional sources of income have dried up, as governments cut back on grants and there is less money in the public's pocket to donate to charity. New and more innovative campaigns are now required in order to generate income.

I realise that at this time of year, or in the next few weeks, many members will be planning activities for the coming year. IBE is always happy to provide support to its members in their campaigns. We can provide permission for the use of the IBE logo, send messages and letters of support, promote the event in the IE News, on our website www.ibe-epilepsy.org and, if possible, accept invitations to attend the event in question. But we do ask that we are involved from the first stages of preparation, so that we can ensure that the initiative is framed in a way that allows IBE to support it without acting unfairly to other members.

Here in IBE we are also busy planning for 2010, and beyond. In the next 12 months we will be involved in four regional congresses - 2nd East Mediterranean Congress, Dubai; 12th European Conference on Epilepsy & Society, Porto; 6th Latin American Epilepsy Congress, Cartagena; and 8th Asian & Oceanian Epilepsy Congress, Melbourne. I look forward to meeting many of you at these meetings.

But, for the moment, may I wish you a Very Happy New Year.

All the best,

Mike Glynn
President

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The International Bureau for Epilepsy, with membership of 120 epilepsy associations based in 92 countries worldwide, works to improve the quality of life for all people affected by epilepsy.

International Epilepsy News No. 4 - 2009

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The Editor's Letter

Dear friends,

There are several items that I would like to emphasize in this issue of IE News.

In late November, there was an important meeting in Rome of the IBE International Executive Committee, dedicated to the task of considering and elaborating on IBE's Long Term Strategy for the next 4 years. Included in discussion were the new Task Forces that are to be created by the President to address issues of importance.

For 2010 eleven Promising Strategy projects were pre-selected for further consideration. This is the fourth round of this very worthwhile program and each year several new and creative proposals are submitted by member associations.

We are including a report on results of the first Journalism Awards, a very successful joint initiative between IBE and UCB Pharma.

I know that all IBE members and supporters will be interested to read Philip Lee's very original recounting of the birth of the candle as the IBE symbol.

We are busy getting ready for 2010, when we will have our regional congresses and we include a short update on the programme for Porto. We hope to report on preparations for the regional congresses in the next issue. But you should take note of the venue and date details of all four meetings, which are on the back cover of the magazine.

Besides all this, there are reports from the Philippines, Georgia and Paraguay as well as news from The Global Campaign Against Epilepsy and EPICURE. Our President Mike Glynn has also prepared a review of a book that is very accessible to anyone with an interest in epilepsy.

I think that you will find lots of interesting items to read in this issue.

Best wishes for everybody,

Dr Carlos Acevedo Sch.
IE News Editor

International Epilepsy News on the Web

IE News is also 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.

Contents

6

4

9

8

10

16

Visit to Paraguay

Carlos Acevedo and Tomás Mesa report on an initiative of the Latin American Regional Executive Committee to encourage new IBE members in the region

Durante los días 13 a 15 de Noviembre, se realizó en Asunción, Paraguay, una reunión en el marco de la puesta en marcha del Plan Estratégico de Creación de Nuevos Capítulos del IBE en Latinoamérica. Previamente esta idea había sido planificada, con la invitación del Dr Carlos Oliveira, al V Congreso Latinoamericano de Epilepsia en Paraguay, con el acuerdo del Capítulo de ILAE de Paraguay.

Asistieron a dicho evento:

- Dra Alicia Aldana, neuropediatra.
- Dr Carlos Arbo, neurólogo
- Dra Ada Cabrera, odontóloga
- Dra Marta Cabrera, neuróloga infantil
- Sra Mariana Gagliardone, psicóloga
- Dra Marta Lezcano, neuropediatra
- Dr Carlos Oliveira y Silva, neurólogo
- Dra Laura Rojas de Recalde, neuropediatra
- Dr Luis Taboada Renna, psiquiatra
- Sra Norma Villafañe, Laboratorio Recalcine
- Mr Martin
- Dr Carlos Acevedo, neuropediatra
- Dr Tomás Mesa, neuropediatra.

Los temas tratados fueron:

- ¿Qué es el IBE?: Objetivos y organización. *Dr Tomás Mesa*
- Calidad de vida en Epilepsia. *Dr Carlos Acevedo*
- Epilepsia, educación y trabajo. *Dr Tomás Mesa*
- ¿Cómo formar el Capítulo del IBE en Paraguay?. Experiencia en Chile. *Dr Tomás Mesa*
- Banco de medicamentos. ¿Qué es?. ¿Cómo se formar uno?. Experiencia en Chile. *Dr Carlos Acevedo.*

El encuentro se realizó en las dependencias facilitadas por laboratorio Recalcine, laboratorio farmacéutico que está presente en varios países del Latinoamérica. Estaba presente la Dra. Marta Cabrera, representante del Capítulo del ILAE paraguayo.

Se hablaron de los temas, haciendo énfasis en:

- La importancia del IBE Internacional y Latinoamericano, destacando lo obtenido en su misión.
- Trabajar en forma coordinada con el capítulo de ILAE, pero con una organización independiente.
- Como generar ingresos haciendo incapié en las distintas posibilidades de autofinanciamiento, considerando las características de cada país. Entre estas están: banco de medicamentos, actividades sociales de recolección de fondos, colectas nacionales, etc.
- Se remarcó la importancia de establecer vínculos con la industria farmacéutica local, la cual estaba presente y participando.
- La importancia de ir estableciendo metas realistas a corto y largo plazo.

Se concluyó:

- En que en un plazo de 30 días, se van a dar los primeros pasos, para crear la organización, estudiando los estatutos del Bureau y adecuarlos a su realidad local. Esto, ya que a través del Dr Carlos Oliveira, tienen los estatutos del IBE internacional, la experiencia reciente enviada por el Dr Franklin Montero de R Dominicana, y los estatutos de la Liga Chilena contra la Epilepsia.
- Esto será comunicado, en dicho plazo a la secretaría del Comité LA de Epilepsia.
- Asistencia al VI Congreso LA de Epilepsia en Colombia, para integrarse al menos, como miembro provisorio.

Hay que hacer notar, que este es la primera visita en un proyecto de iniciativas similares para incorporar a nuevos países el IBE.

Pictured from left to right: Dr Luis Tabeada, Dr Carlos Acevedo, Dr Tomás Mesa, Dra Marta Lezcano, Dra Alicia Aldana, Sra Mariana Gagliardone, Dra Marta Cabrera, Dra Ada Cabrera, Dra Laura Rojas, Dr Carlos Oliveira and Dr Carlos Arbo

The meeting in Asunción, Paraguay from November 13th to 15th, was in line with the Strategic Plan to help in the creation of a new IBE Member in Latin America. It had been planned, through the invitation of Dr Carlos Oliveira to the 5th Latin American Epilepsy Congress and with the agreement of the ILAE Paraguay chapter and Dr Carlos Arbo.

The participants were:

- Dr Alicia Aldana, pediatric neurologist
- Dr Carlos Arbo, neurologist
- Dr Ada Cabrera, dentist
- Dr Marta Cabrera, pediatric neurologist.
- Mrs Mariana Gagliardone, psychologist
- Dr Marta Lezcano, pediatric neurologist
- Dr Carlos Oliveira y Silva, neurologist
- Dr Laura Rojas de Recalde, pediatric neurologist
- Dr Luis Taboada Renna, psychiatrist
- Mrs Norma Villafañe, staff of Recalcine laboratory
- Mr Martin
- Dr Carlos Acevedo, pediatric neurologist
- Dr Tomás Mesa, pediatric neurologist

The topics discussed were:

- What is the IBE? Objectives, organization and plans. (Dr Tomás Mesa)
- Quality of Life in Epilepsy. (Dr Carlos Acevedo)
- Epilepsy, education and work. (Dr Tomás Mesa)
- How to set up the IBE Member in Paraguay? Experience of Chile. (Dr Tomás Mesa)
- Drug Banks. What is it? How was established? Experience of Chile. (Dr Carlos Acevedo)

The meeting was held in the offices of Recalcine's Pharmaceutical Laboratory, which has headquarters in many Latin American countries. Dr Marta Cabrera attended as the representative of the ILAE Chapter of Paraguay. Focus on the following:

- The significance of the International Bureau for Epilepsy and its Latin American Regional Committee in enhancing its mission.
- To work in a coordinated way with the ILAE Chapter, but with an independent organization.
- How to generate income and identify sources for self-finance, such as drug banks; social events and national collections in order to collect funds.
- The importance of establishing links with the local pharmaceutical industry, who attended and took part of the meeting.
- The significance of establishing realistic goals in the short and in the long term.

It was concluded that:

- During the following month, the Bureau's statutes would be studied in relation to the local situation and the first steps would be taken to create the organization. Thanks to Dr Carlos Oliveira the statutes of IBE were available for review, as well as the recent experiences provided by Dr Franklyn Montero of the Dominican Republic and the statutes of the Chilean League against Epilepsy. Once the IBE statutes had been studied, contact would be made with the Secretariat of the IBE Latin American Committee.
- Efforts would be made to attend the 6th Latin American Epilepsy Congress in Colombia, at which point it was hoped that at least Provisional Membership status would have been achieved.

It is important to note that this is the first visit in a planned project of similar initiatives to attract new countries to the IBE.

Journalism Award Winners Announced

The winners of the Excellence in Journalism Award 2009, an initiative of the IBE and UCB Pharma, were announced on 20th October. The award aims to increase awareness, improve understanding, and to encourage accurate reporting of epilepsy, by inviting journalists to submit stimulating, informed and compelling stories about knowledge, data and real life experiences of people with epilepsy around the world.

Susanne Lund, IBE Immediate Past President and a member of the judging panel, commented, "We received 37 terrific entries from 17 countries around the world covering a wide range of topics relating to the social issues facing people with epilepsy.

"These entries truly demonstrate how journalists can help to combat the fear and ignorance about epilepsy and improve the lives for those living with the condition."

The seven member judging panel, consisting of media experts as well as people with experience of epilepsy, was tasked with identifying responsible, informed, original and stimulating stories on epilepsy. The judges selected winners as well as a highly commended entrant in two categories — print/online and broadcast.

> These entries demonstrate how journalists can help combat fear and ignorance about epilepsy

Aliyah Baruchin (pictured above left) was announced winner of the print/online category for her article *Epilepsy in the African-American Community*: *Access Education and Advocacy*, published in EpilepsyUSA, Issue 4, 2008.

"A well-written, easy to read article highlighting the challenges that are often faced by the African-American community when trying to gain access to appropriate epilepsy care - a topic that rarely gets the coverage it deserves," said award judge Dr Mark Porter, GP, Broadcaster and Medical Correspondent for The Times, UK.

In a letter of thanks which Aliyah sent, she wrote: "I am writing to thank you so much for having selected my article on African-Americans with epilepsy for the Excellence in Epilepsy Journalism Award. It was very gratifying to see this topic given more recognition and a much broader audience than it now has. And I'm so glad that this award competition exists.

"I hope that it will encourage more, clearer, and increasingly impactful coverage of epilepsy—coverage that can help break the silence and stigma that hamper funding, research, and the progress of individual lives.

"I hope to use the award monies to report on epilepsy in Sierra Leone, where my husband is from, and where the health care infrastructure is in dire disrepair and specialty care is essentially non-existent. An article on Sierra Leone would also give me a chance to offer some background reporting on the state of epilepsy care in sub-Saharan Africa overall."

> If programs like this were broadcast around the world, it would make a meaningful impact

Television journalist and producer **Miguel Ángel Tobías** (pictured right on previous page) was judged winner in the broadcast category for his program, *Hora de Salud: Epilepsia (Health Hour: Epilepsy)*, broadcast on Spain's Canal 9 TV.

A member of the judging panel, Joachim Mueller-Jung, writer and journalist for Frankfurter Allgemeine Zeitung in Germany said, "The judges felt this program had everything. It takes epilepsy to a broader audience in a clear and comprehensive way with educational insights into epilepsy. If programs like this were broadcast around the world, it would make a meaningful impact."

Australian journalist **Julia Medew** received a highly commended award for her article *Art Helps Lift the Veil on Epilepsy*, published in The Age newspaper. Her article, which reached more than one million readers, told the story of a young woman's participation in a study examining the influence of epilepsy on artistic expression.

In the broadcast category, the judges highly commended **Floriane Closuit** for her thought-provoking film - *Par Surprise(s) (By Surprise)* and its powerful ability to humanise epilepsy.

A special mention was awarded to **Majlinda Aliu** for her compelling broadcast entry *The Treatment of Epilepsy in Kosovo*.

According to award judge Roger Sergel, Managing Editor, Health Coverage, ABC News, USA, the film "is a gritty piece of journalism that gives us a window into a world we seldom see while providing a stark illustration of the challenges facing people with epilepsy in Kosovo."

The independent judging panel considered 37 high quality entries from 17 countries. The international judging panel comprised the following judges:

- **Mr Robert Cole** (Australia) Epilepsy Association of South Australia and the Northern Territory, Australia; and Chair, IBE Editors Network
- **Dr Carlos Acevedo** (Chile) IBE Vice-President Latin American Region and Editor, International Epilepsy News
- **Mr Joachim Mueller-Jung** (Germany) Writer and Journalist, Frankfurter Allgemeine Zeitung
- **Mrs Susanne Lund** (Sweden) Immediate Past President, International Bureau for Epilepsy
- **Mr David Josephs** (UK) Epilepsy Advocate
- **Dr Mark Porter GP** (UK) Broadcaster and Medical Correspondent for The Times
- **Mr Roger Sergel** (USA) Managing Editor, Health Coverage, ABC News

Julia Medew, from Australia, whose entry received a highly commended award

The two main award winners each received travel vouchers and are encouraged to use their prize to defray travel costs related to further journalistic research and publications about epilepsy, which Aliyah Baruchin has already indicated she intends to do.

Entries were assessed on the following criteria:

- Helps to increase the awareness and understanding of epilepsy
- Gives a voice to people with epilepsy
- Is conceptually or visually innovative and creative
- Is well structured, well researched and compelling
- Uses language responsibly when reporting or writing on epilepsy

Announcing the Excellence in Journalism Award 2010

Following the very successful launch of the first journalism awards, IBE and UCB Pharma are pleased to announce the Excellence in Journalism Awards 2010.

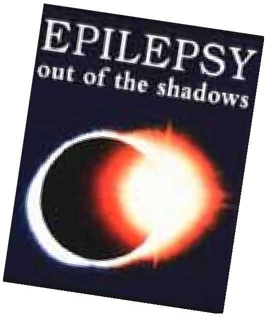
The final details are now being put in place and it is expected that the Application Forms and full information on the categories, prizes and closing dates will be available early in the New Year. All details will be available on the Activities/Journalism Award page of IBE's website.

Member associations right around the world are encouraged to promote the initiative at local level. By highlighting the award, associations are also helping to raise awareness and encourage correct reporting on epilepsy.

Global Campaign Against Epilepsy

Public Awareness Campaign in Georgia

Report by Natela Okujava and Sofia Kasradze



In 2008 the important initiative "Epilepsy Management at Primary Health Care Level" was launched as a Demonstration Project of the ILAE/IBE/WHO Global Campaign Against Epilepsy in Georgia. The Global Campaign Secretariat is responsible for the project, which is supported by the Ministry of Labour, Health and Social Affairs and the Parliament of Georgia. Its execution was delegated to the Centre for Epilepsy Management, Research and Education (CEMRE) and the Centre of Epilepsy Control and Prevention (CPCE) in Georgia.

The local management team comprises Prof Otar Toidze (Principal Investigator), Prof Natela Okujava (Principal Investigator) and Dr Sofia Kasradze (Senior Researcher). At international level the project is managed by Ms Hanneke de Boer (Global Campaign Against Epilepsy, SEIN), Dr Tarun Dua (WHO), Prof Ley Sander (Scientific Leader). The project is based in Georgia's capital, Tbilisi and will run for four years, to 2011.

The principal aim is to promote public awareness about epilepsy by means of an educational programme aimed at the community and at specific target groups in order to reduce stigma. A public awareness campaign in Georgia was planned during the first technical meeting of the project committee in Tbilisi in June 2008 and its execution is discussed regularly.

So-called 'Inclusive Schools' were chosen as the target group for a special educational program. These schools are open to both healthy children and those with special needs, including children with epilepsy, and all are educated together. There are 10 such schools in Tbilisi. Preliminary meetings with the representatives of the Ministry of Education and the Management of the Inclusive Schools revealed high interest for such an educational campaign and a readiness for cooperation. Teaching booklets for inclusive schools and leaflets for community intervention were developed. An educational program for teachers, psychologists and parents was introduced in the inclusive schools. Meetings with local authorities, the national WHO office, non-governmental organizations and representatives of local media were arranged, in order to develop and promote public awareness activities.

The most important activities of the campaign are described briefly:

- The Demonstration Project was presented at the Mental Health and Psychological Support Subcluster Coordination Meeting in the WHO Country Office, were the problem of raising public awareness on epilepsy was stressed once more. The event was organized with the support of the National WHO Office.
- Within the framework of the Disability Forum, supported by USAID, the play "Snow Queen" was performed by a cast comprising both healthy and special needs children, including children with epilepsy. The event was organized in collaboration with the Neuropsychological Department of the Epilepsy Prevention and Control Centre (CPCE).
- June 2009 - Printed materials (teaching booklets for inclusive schools and information pamphlets for community intervention) were made available at the Exhibition of Informational Materials on Disability. This was organised by the "Coalition for Independent Living" with financial support from USAID.
- The Demonstration Project was presented at the "8th International Medical Summer Conference" in Kobuleti, Georgia and the printed materials were exhibited in the exhibition hall of the conference.
- July 2009 – the Experts Group for the Development of Inclusive Education in Georgia was formed at the Ministry of Education. Experts from the Demonstration Project were invited to participate, in order to optimize inclusive education for children with epilepsy and to discuss psycho-social and legal problems of epilepsy in Georgia. The first result of the work of this group is the development and implementation of the "Protocol for Inclusion of People with Epilepsy in National Examination's for Higher Schools". Measures for the creation of optimal conditions for people with epilepsy during national educational examinations were undertaken (including permission to take medication during an exam; choosing the optimal time for an exam; taking into account chronobiology of seizures etc.). Training of national examination staff in the delivery of first aid in the event of a seizure was conducted.
- Printed materials were widely disseminated in the community of Tbilisi. Medical and non-medical institutions were chosen as target groups, as these are places where people often wait and may have time to read the pamphlets. As a result, the pamphlets have been disseminated in poli-clinics, in obstetric poli-clinics and in hairdressing salons. This initiative has been very successful.

The major achievement of our campaign is a really fruitful cooperation with a number of governmental and nongovernmental organizations and groups of professionals. Therefore we hope that the Public Awareness Campaign in Georgia will successfully develop further.

View of Porto from the narrow streets of Vila Nova da Gaia, across the river Douro from the city.

Epilepsy: So what?

EREC prepares for 2010

Report by Dr Athanasios Covanis
Chair, European Regional Executive Committee

The European Regional Executive Committee (EREC) met in Dublin on the 25th September 2009 when discussions focused, in particular, on preparations for the 12th European Conference on Epilepsy & Society, which will take place in Porto, Portugal from 25th to 27th August 2010. Much of the programme is now in place but some conference details still need to be finalised. The theme chosen for the conference is “Epilepsy: So what?” and we hope that delegates will find the programme both attractive and interesting.

The programme will cover a wide range of topics including ethics, genetics, AEDs and lifestyle issues. Topics of a more scientific nature, including photosensitivity and new advances in epilepsy treatments will also feature.

In addition, we are introducing an exciting new structure that will provide delegates with a greater opportunity to interact and to discuss their own viewpoints. A series of Discussion Groups will address issues such as epilepsy and disability; driving and insurance problems; epilepsy emergency cards and warning devices; best practice in twinning of IBE members; training and personal development opportunities; and advocacy work. The Youth Session was very successful at our last conference in Marseille and, as a result, we plan to repeat this session in Porto! I must also mention that IBE members will have the opportunity to discuss their activities through poster presentations.

Following the meeting in Dublin, as Chair of the 12th ECES Organising Committee, I visited the city of Porto on 19th November 2009. Several venues with the potential to host the conference were inspected and it is expected that the final decision regarding the venue will be made shortly.

During my short stay in Porto I met with the local members of the Organising Committee, José Lopes Lima and Nelson Ruão, when the programme and the involvement of Epi-Apfape, as the IBE Full Member in Portugal, was discussed.

Acknowledgments: We express our sincere gratitude to the following organizations: Ministry of Education of Georgia, WHO Country Office, USAID, and Coalition for Independent Living. We express our special gratitude to the Neuropsychological Department of the Epilepsy Prevention and Control Centre and its leader Prof Tamara Gagoshidze.

Photo previous page, from left: Sofia Kasradze, Natela Okujava, Hanneke de Boer, Ley Sander and Tarun Dua.

GCAE Task Force

A new joint IBE/ILAE Global Campaign Task Force has been created by Mike Glynn and Nico Moshé, co-chairs of the campaign. The WHO is represented on the task force by Tarun Dua and the group met for the first time in Boston in early December (pictured right)

In the next issue of IE News we hope to bring you a full report on the aims and objectives of the Task Force as well as information on its membership.

Back row from left: Carlos Acevedo, Sam Wiebe, Nico Moshé, Raidah Al-Baradie, Emilio Perucca, Charles Begley and Anthony Zimba.

Front row: Shichuo Li, Hanneke de Boer, Helen Cross, Tarun Dua and Mike Glynn

The Spark that lit the Flame

Haro Hodson emerged from Victoria underground station in London. He pulled his trilby hat down and turned his collar up against the cold. It was February 1952. Big Ben sounded the quarter hour in the background. He didn't want to be late for his meeting and he was trying to keep warm. He still wasn't used to the cold British winters since returning from active service with the army in India during the Second World War.

As he walked, he played out in his mind how the meeting might go. Which one would they like? Maybe none of them. He didn't really know any of the members of the committee he was heading to meet. Except of course for Sheridan. It was Sheridan who had got him into all this in the first place.

Hodson was an artist and a writer. Like many others of his generation, his education and career had been interrupted by the war and only now was he beginning to find his feet. Barely two years earlier he'd joined the staff of the London *Observer* newspaper as an illustrator.

Not long afterwards in 1951 an acquaintance, Sheridan Russell, had approached him with an unusual request. Russell worked as an almoner – a sort of medical social worker - at the National Hospital in Queens Square in London but his interest in contemporary art brought him into contact with the Haro Hodson's of this world. Russell was also involved with a new charity. Russell had told him, "we need someone like you, Haro, who can write and draw a bit, someone with a bit of creative flair. We're setting up a publications committee; you'd be perfect for it. There's no money in it of course but it's a good cause."

How could a twenty eight year old idealistic artist just beginning to break through resist such flattery? Hodson accepted the challenge.

He reached his destination and made his way down to the basement where the charity had its office. Just off to the side was a larger room used for meetings. Nervous and uncomfortable Hodson edged his way into the room already crowded with people. Irene Gairdner, the charity's honorary secretary recognised him and smiling she took his hat and coat. Sheridan Russell saw him from across the room and broke off from another conversation. His face lit up in welcome, "Ah, the man of the moment. Hodson old man, how are you? Got the drawings I hope? Let me introduce you to everyone."

Russell first introduced him to Lady Cynthia Colville, the Chairman of the committee, followed by the six others. He finished by saying, "Irene Gairdner you know already of course."

"Yes, it's very nice to meet you all", said Hodson unconvincingly.

The business of the meeting proceeded slowly. Hodson sat at the far end of the table waiting for his moment to come.

"And now we come to the medallion. Mr Hodson, you have something to show us I believe?" Lady Colville's words woke him up and Hodson scrambled for his briefcase. He extracted three cards and placed them face down on the table. He looked up to see everyone staring back at him expectantly.

He began his presentation by repeating back to the committee the brief they had given him. "We need an emblem we can use in all aspects of our work. We especially need a pin badge and something we can put on the front of our publications. We need something distinctive. Something immediately recognisable as our own. Something that tells people who we are and what we're all about. In short, we need something that symbolises the whole cause."

He turned over each card in turn explaining what he had done and how the design attempted to fulfil its function. Each card had a different drawing on it; his attempts to capture the essence of the new charity and of epilepsy in a simple and precise form. He turned over the last card but this time he didn't speak. Nobody spoke. They all just looked at the card. Sheridan Russell broke the silence. "A brightly burning candle", he said, "of course. It's perfect. A symbol of hope, of enlightenment." He looked up and smiled at Hodson, "that's the one."

(continued on page 12)

The candle is a popular logo for lay epilepsy associations around the world. This is the story of how it all began.

With thanks to Philip Lee, Chief Executive of the British Epilepsy Association, who provided this true story and to the IBE members who submitted their logos to accompany this report.

The Spark that lit the Flame

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(continued from page 10)

There was unanimous agreement; this was what they were looking for. This was the symbol for their new charity – the British Epilepsy Association. British Epilepsy Association was not the world's first lay organisation for epilepsy ever created. However, its emergence in 1950 came at a time of heightened interest in what lay organisations could do. Its early achievements and strength of purpose soon aroused the interest of like-minded people in other countries and it soon became a source of inspiration for others. Its literature, sent all over the world, carried the brightly burning candle and the symbol quickly became synonymous with the Association and, by extension, increasingly linked with epilepsy.

In the 1950's as other national epilepsy associations began to form they looked for a suitable emblem of their own and they rarely looked further than the brightly burning candle. Its symbolic significance of hope and enlightenment resonated everywhere.

In 1961, at the 9th meeting of the International League Against Epilepsy held in Rome, and at the League's request, British Epilepsy Association organised a meeting of representatives from 15 countries titled, 'The Role of the Lay Organisation in the Treatment of Epilepsy'. At the conclusion of the meeting Dr Abraham Mosovitch from Argentina proposed what is now called the 'Mosovitch motion', calling on those present to form an International Bureau for Epilepsy.

The final part of the motion proposed:

"To use the emblem of the candle for this activity because this was already being used by associations in Britain, Australia, Canada, Sweden and New Zealand."

With the birth of the International Bureau for Epilepsy and its adoption of the candle image, it was assured that national epilepsy associations to be developed in the years to come would also consider using the candle as their symbol.

Back in London on that cold evening in February 1952 the meeting was over. Haro Hodson stood in the doorway of the offices of British Epilepsy Association. He was happy that his ideas had been so warmly received but he had no idea then what he had just set in motion or how far his candle concept would travel. Although he continued to help and support British Epilepsy Association for many years to come, nothing else he ever did for it was to have such a momentous and far reaching impact as his candle design. Once again, he turned his collar up and pulled his hat down against the cold. With the newly adopted candle design back in his briefcase, Haro Hodson stepped out of the shadows of the doorway and walked back up Victoria Street.

Fifty seven years later it is September 2009. An 86 year old man lives quietly in Oxfordshire in England. He opens the morning post starting with an unfamiliar looking large envelope. Inside is a letter from the British Epilepsy Association. The man reads the letter and then empties the remaining contents of the envelope face down on to the table in front of him. He turns the papers over in turn to see numerous pictures of different candle based logos from around the world. A smile of recognition spreads across the face of Haro Hodson.

Note from the author:

All of the people in this story are real and all of the events portrayed actually happened. Only the words attributed to the characters have been interpreted.

Annual Dues 2010

The annual call for membership dues has been sent out in recent weeks.

Please remember to pay by the deadline of 1st April 2010 to safeguard your association's membership.

It is also important to make sure that the Dues Form is completed giving up to date address and contact details for your association. The form must be signed by an authorised signatory of the association.

EPICURE Update:

As 2009 draws to a close, EPICURE partners prepare their end of year reports

Funded by the EU 6th Framework Programme - Project EC LSH-037315

Fourth Annual Meeting

Following meetings in Venice (2006), Malta (2007), and Berlin (2008), the 4th annual reporting meeting of the EPICURE partners will take place in Marseille in late January.

Over 100 participants, representing 30 EPICURE partners in 13 European countries are expected to travel to Marseille to report to EU representatives, during special plenary sessions, on progress made at participating centres since the last meeting, in January 2008. Reports will be presented on the following sub-projects:

- Epilepsy and development
- Acquired channelopathy and neuronal network reorganisation underlining temporal lobe epilepsy
- Genetics of human epilepsies
- Functional consequences of mutations in ion channel genes associated with idiopathic epilepsy and genetically determined pharmacoresistance
- Pharmacogenetics of refractory epilepsy, mechanisms of drug resistance and new therapeutic strategies.

In the last two years, special teaching courses have been arranged in tandem with the annual meeting. These have proven to be so popular that they are usually over subscribed.

EPICURE is one of the most exciting research projects on epilepsy currently underway in Europe. It is expected that, when the project ends, a little under two years from now, EPICURE will have been responsible for major ground-breaking research. The main focus of EPICURE is to identify disease causing genes and their functional role for both inherited acquired epilepsies and epilepsies due to developmental cortical abnormalities.

News from Italy

Epicure has made the headlines in Italy. It was reported by the Italian national news agency ANSA who described how neurotrophic factors have been found which could prevent spontaneous seizures in an epilepsy model. The research was carried out by EPICURE's Michele Simonato's team at the University of Ferrara and published in PNAS in April 2009.

The novel aspect of this research is that a genetically modified virus is used to administer the proteins to the brain. A study in rats suggests that localized hippocampal delivery of FGF-2 and BDNF may be useful for decreasing seizure frequency. In a rat model of epilepsy, hippocampal delivery of a vector containing BDNF and FGF-2 decreased the incidence of spontaneous recurrent seizures, the number of seizures per day and seizure severity compared with what was seen using a control vector. The vector also increased hippocampal volume and neurogenesis compared with that seen using the control vector.

Next steps include evaluating the approach in other epilepsy models and developing better delivery methods.

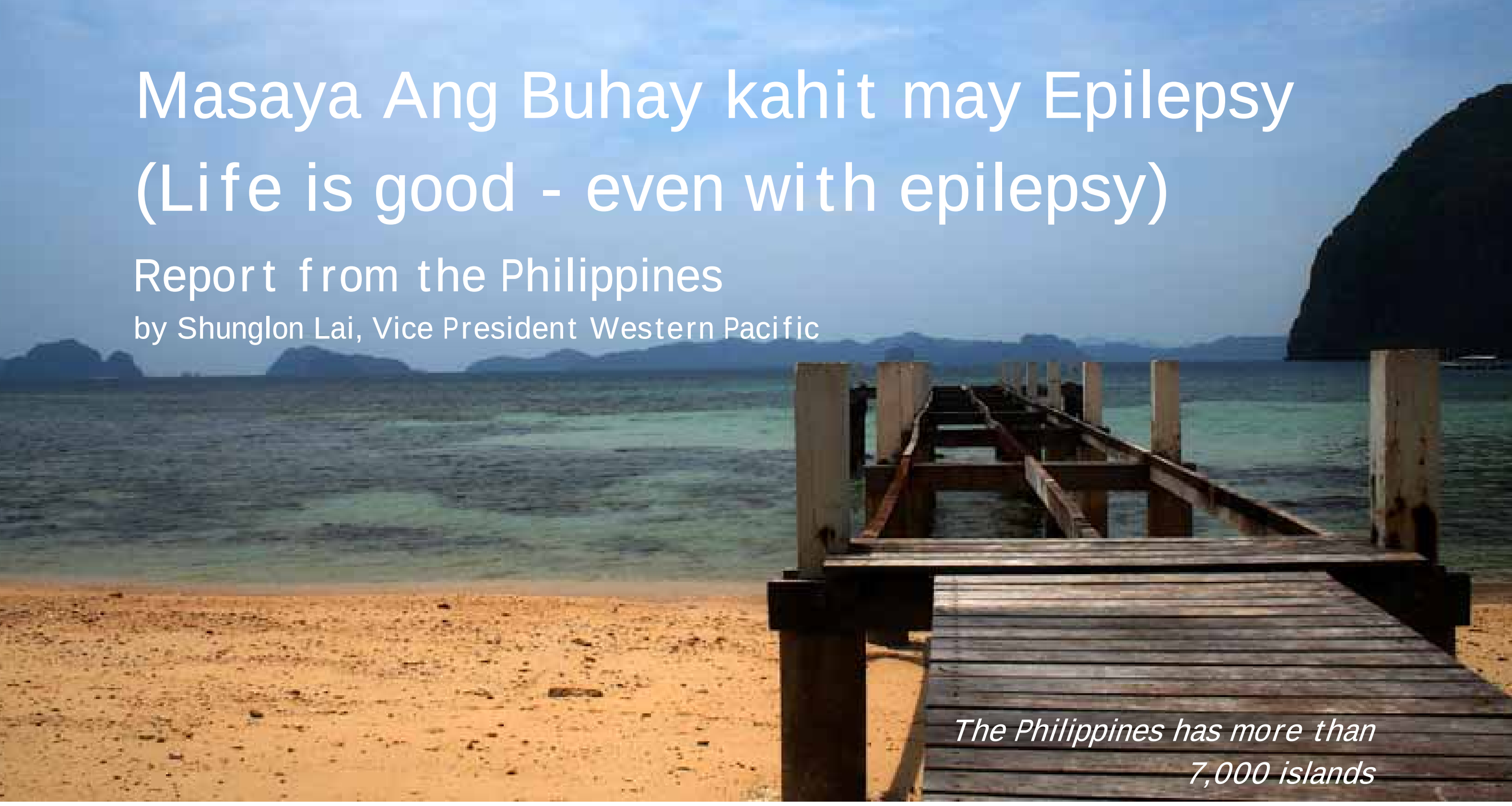
This research was also reported in ***il resto del carlino*** and ***Libero*** newspapers, which explained how the research opens new perspectives in clinical applications. The newsletter of *the Fondation Pour La Recherche Medicale* quoted Professor Ben-Ari from the Mediterranean Neurobiology Institute, describing how these research results are extremely interesting. The results were also quoted in SciBX Science and Business eXchange.

We hope to bring you a report on the meeting in Marseille in the next issue of IE News.

Masaya Ang Buhay kahit may Epilepsy (Life is good - even with epilepsy)

Report from the Philippines

by Shunglon Lai, Vice President Western Pacific



The Philippines has more than 7,000 islands

Epilepsy Awareness & Advocacy Inc (EAAI) in the Philippines is currently funded under the IBE Promising Strategies Program in the production of a multimedia pack to educate people about epilepsy. With a DVD and accompanying materials in comic book style, the association will use its nationwide network of volunteer groups to disseminate the program throughout the Philippines.

I serve as the foreign adviser for this program so, when EAAI invited me to their National Epilepsy Symposium for Lay People 2009, I was delighted to accept. By travelling to the Philippines I was able to see how the program was functioning. I also had the opportunity to talk about the International Bureau for Epilepsy and it's relationship with the local association, in order to enhance the strong tie between IBE and the EAAI.

The EAAI in cooperation with the Philippine League Against Epilepsy (PLAE) had organized a series of activities to promote "Quality of Life in Persons with Epilepsy" during the 5th Filipino National Epilepsy Congress from September 2 to 5, 2009.

The National Epilepsy Symposium for Lay People was held on September 5, 2009 in Tacloban City, with the main theme: "Masaya Ang Buhay Kahit May Epilepsy" which translates as "Life is good - even with epilepsy". This excellent symposium allowed us to learn from the speakers about their effort to combat the disease.

The first part of the symposium focused on the effort of both EAAI and PLAE including *The National Epilepsy Campaign* reported by Dr Leonor Cabral-Lim and *Epilepsy School Caravan* reported by Dr Lourdes L Ledesma.

From the report we can understand that the situation for the Philippines is indeed unique, compared to some "developing" countries; despite their limited financial resources they have "relatively more" trained and highly qualified health professionals in the field of epilepsy. However, despite the availability of highly qualified health professionals, the following scenarios are evident:

- Many people with epilepsy do not seek treatment either because they don't know that "epilepsy can be treated" or that care is available.
- Some of those who seek treatment are not properly treated because of inadequate education and training of health care providers.
- Some of those who get adequate treatment and are "seizure free" are afraid to come out and speak openly about their epilepsy due to fear of stigma and discrimination, not only by peers, but discrimination in school and at work, or even the fear of losing their jobs.

The Philippines has pursued the same strategy as the Global Campaign. This strategy includes two parallel and simultaneous tracks:

- To raise general awareness and understanding of epilepsy.
- To support the Department of Health in identifying the needs and promoting education, training, treatment, services, research and prevention nationally.

In respect of the Epilepsy School Caravan, "We focused on introducing this campaign in schools because many school-aged children with epilepsy suffer from discrimination as most people around them are not well informed about their condition," said Dr Lourdes Ledesma. "It cannot be denied that a great number of people diagnosed with epilepsy have experienced some kind of discrimination, either at school or in the workplace."

The school caravan features a reading by volunteers of PLAE's book *Life is Good-Even with Epilepsy*, written by Dr Lourdes Ledesma and Dr Marilyn Ortiz. As a treat to the students, there was also a special dance number to the tune of "Happilepsy," a catchy song composed especially for the school caravan.

Through the caravan, it is hoped to attract more advocates willing to help in sharing the right information about this often-misunderstood condition and, in the process, provide support for people with epilepsy.

With the right treatment and care, epilepsy patients can enjoy safe and lasting control of their seizures which will allow them to lead normal lives.

Promising Strategy Program in the Philippines

Supported by the IBE Promising Strategies Program 2009, the EAAI is producing a multimedia pack to educate people about epilepsy. With a DVD and accompanying materials in comic book style, the association will use its nationwide volunteer groups to disseminate the program throughout the Philippines. The pack will be produced in English and in at least five of the most commonly used dialects in the Philippines: Tagalog, Ilocano, Cebuano, Ilonggo and Bicolano. The materials will include:

- a human interest story, narrated by a person with epilepsy
- facts and fallacies about epilepsy
- first aid for seizures
- what to do next.

The production of the DVD and associated materials will take about four months to prepare and the local campaigns will take a further 14 months to complete. A pilot BHW-epilepsy support group has been established in Iloilo City in the Visayas (Central Philippines) demonstrating the concept of this Promising Strategies project.

Being diagnosed with epilepsy should not stand in the way of achieving one’s dreams.

The second part of the symposium addressed medical issues including the following topics:

- **“Epilepsy Module”**
  Dr Bernadette Terencio
- **“Epilepsy: Facts and Fallacies”**
  Dr Maria Victoria Bael
- **“May Bukas Pa”** (What happens next after diagnosis –There is still tomorrow, There is future)
  Dr Rosario Latorre
- **“Super Twins”** (co-morbidity of epilepsy)
  Dr Hazel Paragua.

Persons with epilepsy and their caregivers can learn a great deal about epilepsy from these lectures.

The last part included my own presentation “The International Bureau for Epilepsy (IBE): what it does offer persons with epilepsy”, as well as an update on the activities of the EAAI (Ngayon at Kailanman – Now and Forever) reported by EAAI President Ms Jeannie Khonghun.

A very special guest Dr Ronald Magbitang, who is 2008 Epilepsy Exemplar Awardee, talked about “Maalaala Mo Kaya” (Remember me). Launched by the PLAE and EAAI in 2003, the Epilepsy Exemplar Awards identify role models and spokespersons for persons with epilepsy. The awards are open to all Filipinos aged from eight to 65 years old who have been diagnosed with epilepsy. Dr Ronald Magbitang, who is a medical doctor, talked about his experience of being an epilepsy patients He used his own words to encourage everybody who suffers from the condition and he also serves as a very good role model in fighting the disease.

After the lay symposium, I observed the get-together meeting of people from all parts of the Philippines. The Philippine is a country made up of over 7,000 islands, making it difficult for people to travel. There are also language problems, with local dialects on many islands.

EAAI was founded in 2002 and has been developing workshops since 2003. The organization registered as a national association in 2004 and joined IBE in 2005. There are currently 18 chapters throughout the country. Each chapter presented a short report on the activities it had undertaken during the previous year. It was quite impressive to learn how active many of the chapters are in helping their members through a range of interesting activities.

The EAAI had just received the first portion of the funds allocated by IBE for their Promising Strategies project. I learned that they will use different languages to make the teaching DVD to educate people in the Philippines to better understand epilepsy.

Shunglon Lai, seated front row second from left, with speakers and participants. Seated third from left is Jeannie Khonghun, EAAI President

Benvenuto a Roma!

International Executive Committee meets in the Eternal City

Members of the International Executive Committee take time out during their deliberations in Rome for a photocall!

Back row: Mike Glynn, President

Centre, from left: Shunglon Lai, VP Western Pacific; Vinod Saxena, VP South East Asia; Anthony Zimba, VP Africa; and Carlos Acevedo, VP Latin America.

Front: Mary Secco, VP North America; Grace Tan, Treasurer; and Janet Mifsud, VP Europe.

Photos: Ann Little

A two-day meeting of the International Executive Committee took place in Rome in November.

This was a special extended meeting and was the first time the committee had come together since the start of the new term of office during the International Epilepsy Congress in Budapest at the beginning of July.

While a lot of progress has been made through email communication in the intervening months, holding a face-to-face meeting, thanks to the support of Eisai Europe Ltd, allowed for more in depth discussion on a round table basis.

With a meeting running over a two day period, this also provided the opportunity for the new committee to discuss at length current activities of IBE, the creation of new Task Forces and Working Groups and future plans for joint initiatives of IBE and ILAE. Of particular focus was a review of IBE's Long Term Strategy, which was first documented in 2001 and which has been reviewed biennially since then.

President's Discussion Paper

In advance of the meeting, President Mike Glynn had circulated a Discussion Paper inviting comments and suggestions from other members of the committee, on a range of topics, and this provided an excellent launching platform for discussion.

IBE's communication strategy was one of the topics included on the President's Discussion Paper and this prompted consideration of issues such as the future direction of the International Epilepsy News, and the potential for the use of Podcasts on the IBE website.

In relation to the newsletter, it was agreed that although the current format had worked very well since it was introduced almost eight years ago, it was timely to consider a new layout and design. Carlos Acevedo,

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assisted by Ann Little, will begin considering a fresh look for the newsletter and it is hoped that the new design will be in place soon.

The current website went live just over two years ago and has continued to develop since then. It now carries a substantial amount of content. One suggestion made was to make the News section more visible and over the coming months ideas on how to achieve this will be discussed with the web designer.

In the meantime, the Regional Executive Committees have been invited to consider suitable topics for Podcasts and this issue will be revisited at the next meeting of the International Executive Committee in March 2010.

It was also noted that the Regional Committees play an important role in providing new and fresh information for the website and it is hoped that even further, and more regular, data can be provided in the future.

It is also hoped to use the website to celebrate IBE's Golden Jubilee celebrations in 2011.

The 'E' word

The inappropriate use of the word 'epileptic' when describing a person with epilepsy continues to arise, particularly in media reporting. This is an issue that IBE President Mike Glynn has campaigned on in the past and, although some improvement has been seen, the problem still remains.

The Journalism Awards, which are reported on page 7 of this issue of IE News, is an initiative of IBE and UCB Pharma, to attempt to stamp out the inappropriate use of this word as a noun. However, all IBE Members and supporters can also play a vital role in erasing the word wherever it appears and in being vigilant in encouraging others to do likewise.

Review of Terms of Office

Role descriptions and terms of office of elected officers have not been revisited since early 2005, when IBE's regional structures were first constitutionally recognised. Following five years experience in working with the current documents, it was agreed that it was timely to carry out a review.

The Regional Committees play an important role both in identifying issues of concern at local level and in working with members in their region. It was agreed that the tasks delegated to the regional groups required clarification and in the review of procedural documents particular focus is being put on the Terms of Office of the Regional Committees and the Role Descriptions of the Vice Presidents. This work is due to be completed in early 2010.

Rome 2011

We are just 18 months away from the 29th International Epilepsy Congress in Rome, which will be the high point of the celebrations of IBE's Golden Jubilee. It was for this reason that Rome was selected as the venue for the committee meeting and why the topic was high on the meeting agenda when the committee met in November. Many suggestions were proposed to mark IBE's 50th anniversary and these will be considered by a Golden Jubilee Task Force that has been established to oversee the event. The task force is being chaired by Immediate Past President Susanne Lund.

Task Forces

The start of a new term of office also brings with it the creation of new commissions and task forces. The President shared his thoughts on the areas he considered worthy of focus and, with the agreement of the committee, the following groups will be set up, or continue their work:

- Driving Regulations Task Force
- Constitution Task Force: which will carry out a review of the Constitution and make recommendations for proposals to amend both the Constitution and the Byelaws
- Research Task Force: this group will include Janet Mifsud, Vice President Europe

In addition, a Global Campaign Against Epilepsy Task Force has been created as a joint IBE/ILAE group.

It is hoped to carry full details of the membership of all Task Forces in the next issue of IE News.

The final agenda item was IBE's Long Term Strategy and the updated document will be circulated to all Full Members for approval shortly.

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Views of Rome (from left):

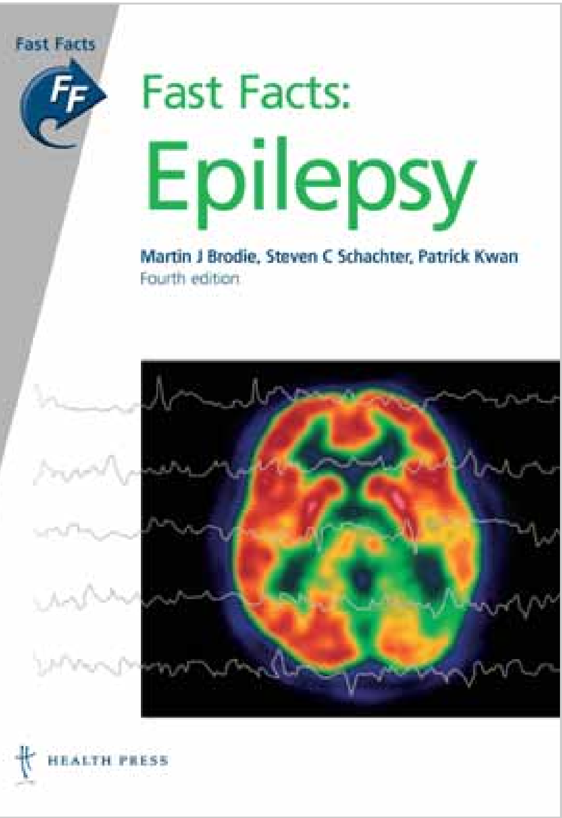
1. The famous Trevi Fountain
2. A view of the Roman Forum from Capitolina Hill
3. A display of pumpkins at a market stall on Campo Dei Fiori
4. St Peter's Basilica seen from across the Tiber River
5. There's always room to squeeze in one more church!

Visit to China

President Mike Glynn recently attended the 3rd biennial epilepsy congress organised by the China Association against Epilepsy in Beijing. As a guest speaker, Mike made a presentation on the work of IBE, with focus on activities in the Western Pacific and South East Asian regions.

The conference gave the opportunity to meet with many people who are working on behalf of people with epilepsy in China. One such person is Dr Ding Ding, pictured right with Mike, who has worked with great dedication in Shanghai to foster the talents of young people through the Seahorse Clubs, which were highlighted in the last issue of IE News.

A major celebration was the launch of the WHO report on epilepsy in the region. The Global Campaign Against Epilepsy has played a major role in the improvement of services for people with epilepsy in China.



Book Review

by Mike Glynn, IBE President

The fourth edition of this excellent book has just been published.

Written by three world renowned experts in epileptology: Prof Martin Brodie from Glasgow (who is also Chair of the IBE/ILAE EUCARE initiative); Prof Steven Schachter from Boston; and Prof Patrick Kwan from Hong Kong (who is also involved in EUCARE), the book was first published in 1999.

It is aimed, primarily, at those working in primary care such as GPs, practice nurses and public health and epilepsy specialist nurses. However it is the type of publication that anyone, willing to take the time to study the condition of epilepsy, will gain great benefit from. *Fast Facts: Epilepsy* manages to pack a huge amount of information into just 138 pages and is, at this point in time, easily the most up to date book on current anti-epileptic drugs (AEDs) - including every new drug on the market right up to this year.

Non-medical readers should be warned, however, that although all details given on AEDs are in respect of their generic names i.e. if you are looking for details about, say, Keppra you must look under it's generic Levetiracetam; no brand names are included here.

Obviously, in the limited space available, detailed explanations on specific epilepsy subjects cannot be included. However, references to what the authors consider the best available literature on each subject are included at the end of each chapter, to enable further reading if this is required.

The book is laid out in an excellent, easy to follow, format using colour coding to separate different topics. There are clear tables, charts and pictures used throughout the book to illustrate different aspects of each chapter. The book is divided into ten chapters with key headings such as Diagnosis, Quality of Life etc. In addition, there is an excellent Index, a Glossary and a list of key epilepsy organizations.

I can recommend highly *Fast Facts: Epilepsy*, which is available from all good bookshops at the recommended retail price of €15, £10, AUS$25 or US$20. It is published in paperback (soft cover) by Health Press Ltd.

ISBN: 978-1-905832-59-3
Published: August 2009

Special Offer!

Reduced purchase price for readers of IE News!

Readers of IE News can avail of an offer to buy this book at a greatly reduced price. To get the book at the low price of US$12, €9, £6 or AUS$15 please order via www.fastfacts.com and enter **Coupon Code SP6** at Checkout.

Promising Strategies 2010

The International Executive Committee has short-listed eleven applications to the Solidarity Fund for further consideration. The associations whose applications have made it through to the next round are based in Argentina, Bangladesh, Chile, China, Colombia, Czech Republic, Lebanon, Namibia, South Africa, Uganda and Zambia. These applicants have now been invited to submit full detailed proposals which will be reviewed early next year. Those selected for funding in 2010 will be announced in early April. A total of just under 30 Letters of Intent were received before the closing date for submissions was reached.

IBE Office Address Change

Although the IBE office has not moved, the Post Office has recently introduced a change to our mailing address, due to the location of the office through while our mail is sorted.

To avoid any delays in delivery, please use the following address, with immediate effect:

International Bureau for Epilepsy
11 Priory Hall
Stillorgan
Blackrock
Co Dublin
Ireland

New IBE Member in Macedonia, FYR

IBE welcomes a new Full Member in Europe. The application of Epilepsija Aura, based in Macedonia, FYR, was recently ratified by the General Assembly in an electronic vote.

IBE now has 34 Full Members and
17 Associate Members in the European Region.

Getting ready for 2010

IBE will be involved in the organisation of the following regional congress, which will take place in 2010.

2nd East Mediterranean Epilepsy Congress

Dubai, UAE

3rd - 6th March 2010

12th European Conference on Epilepsy & Society

Porto, Portugal

25th - 27th August 2010

6th Latin American Epilepsy Congress

Cartagena, Colombia

Dates in August 2010

8th Asian & Oceanian Epilepsy Congress

Melbourne, Australia

21st - 24th October 2010