

International

Epilepsy News

Newsletter of the

International Bureau for Epilepsy Issue 3-2010

A young boy with short brown hair and a slight smile is holding a koala. The koala is dark grey with white fur on its chest and is eating a green eucalyptus leaf. The background is a soft-focus green forest.

**6th AOEC
Melbourne 2010**

*And a look back on
Cartagena and Porto*

The President's Message



Dear IBE Members and Supporters

While the last few months have been a busy time at IBE, it has also been a very rewarding period. In early August, I travelled to Cartagena for the 6th Latin American Epilepsy Congress. This was a successful meeting both in terms of the congress programme and delegate attendance. I was very pleased to visit the local IBE member association, FIRE, for the special programme that Jaime Fandiño-Franky, Mauricio Olave and their colleagues had organised for delegates and for people with epilepsy and their families living locally.

The work that has been carried out at the centre in the past almost 50 years ago is truly inspirational.

The European Congress on Epilepsy & Society, which took place in Porto in late August, was the venue for some important developments. The Global Campaign had long-awaited publication of the WHO European Report on Epilepsy: Fostering Epilepsy Care in Europe, and IBE was honoured to have Dr Matt Muijen, WHO Regional Advisor for Europe, in attendance for this important event. We also took the opportunity to announce the launch of the Global Campaign website, which will serve as a great source of information on campaign activities as well as a repository for a wealth of documents and reports published in connection with the campaign over the last 12 years.

We also promoted European Epilepsy Day in Porto and we are continuing with plans for the launch in February next year. In the coming weeks we will bring our members in Europe more information on how the event will be celebrated and, more importantly, how they can be involved.

As I write, I am preparing for a meeting of the Global Campaign Secretariat with Dr Ala Alwan, Assistant Director General at WHO. Activities within the campaign continue to move forward with recent meetings in Rhodes, Porto and Cartagena. Dr Muijen attended the meeting in Porto while Dr Jorge Rodriguez, Chief of PAHO Regional Mental Health, Substance Abuse and Rehabilitation Unit, attended the meeting in Cartagena.

In closing, I would like to pay tribute to IBE Secretary General Eric Hargis, who played a vital role on the Executive Committee for 11 years. As he steps down from the committee, we wish him well in his new career.

All the best,

Mike Glynn
President

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The International Bureau for Epilepsy, with membership of 122 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's Letter



Dear Friends

In this issue of IE News there is emphasis on the two congresses, in Cartagena and Porto, that have taken place since the last issue.

The meeting in Cartagena was a huge success with more than 600 delegates attending. During the congress a very important meeting took place between representatives of the Global

Campaign Against Epilepsy, including the co chairs Mike Glynn and Nico Moshé, and Dr Jorge Rodriguez, who is Chief of PAHO Regional Mental Health, Substance Abuse and Rehabilitation Unit. Dr Rodriguez had travelled from Washington DC to attend the congress. And I mustn't forget the wonderful one-day programme organised by FIRE, IBE's Full Member in Colombia.

The European Conference on Epilepsy & Society took place in Porto at the end of August and the magazine also reports on publication of the WHO European Report on Epilepsy, which was launched by Dr Matt Muijen, WHO Regional Advisor for Europe, during the conference. In addition, we were very pleased to have Gay Mitchell, Member of the European Parliament, as a guest speaker.

We also look to Melbourne and, if you are attending the 8th Asian & Oceanian Epilepsy Congress, you will have found this magazine in your delegate bag.

Apart from information on congresses, the magazine also includes a very important and interesting article provided by ILAE past President, and a founding member of the Global Campaign Against Epilepsy, Ted Reynolds, who writes about the origins of ILAE.

Ann Little writes about a visit to the IBE member in Ecuador; a new IE News award is introduced, and we learn a little about the Japanese translation of the newsletter.

And, if this was not enough, there is also a charming interview with Dr Ding from China who talks about her background, her interest in epilepsy and the support she provides for people with epilepsy through the Seahorse Club in Shanghai.

Best regards,

Dr Carlos Acevedo

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.

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THE ORIGINS OF THE



In the last issue Harry Meinardi described some of the origins of IBE which evolved from ILAE in the early 1960's. In this article Edward Reynolds reviews some of the origins of the much older ILAE.



The ILAE was founded during the 16th International Medical Congress in Budapest between August 29th and September 2nd 1909. Medical congresses had been held every 4 years since 1867 (Paris) and over 5,000 delegates came to Budapest during one of the last years of the Austrian-Hungarian Empire. Forty six of them, mainly neurologists and psychiatrists, held two side meetings in the Hotel Bristol to found the ILAE, which was immediately approved by the Congress.

The two prime motivators were

Louis JJ Muskens from Amsterdam and Gyula J Donath from Budapest, both neurologists. They were assisted by August Marie, a psychiatrist from Villejuif, near Paris, and J van Deventer, a psychiatrist from Amsterdam. Marie chaired the two meetings and in his report to the Congress he described the purposes of ILAE as follows:

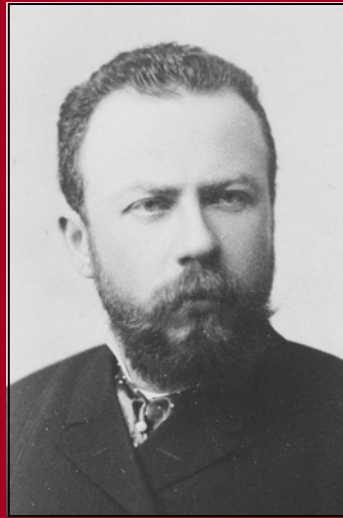
“The League will devote itself to special projects on behalf of epileptics, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation. Nor

will the League neglect experimental research and comparative physiopathology, or laboratory work, which is essential for elucidating a series of problems as complex as those raised by the origin, evolution and nature of seizure disorders, with their attendant range of somatic and psychic complications”.

Interestingly, the journal *Epilepsia*, which was immediately adopted as the official journal of ILAE, had been founded earlier in 1909 with the first publication in March of that year. The two key players were again Donath, Editor-in-Chief, and Muskens, Secretary of the Editorial Board. They had persuaded a distinguished group of patrons to support their initiative, including:

- W Bechterew (Russia)
- O Binswanger (Germany)
- J Hughlings Jackson (UK)
- L Luciani (Italy)
- H Obersteiner (Austria)
- F Raymond (France).

The purpose of *Epilepsia* was “*the study of the pathology, therapy and the social and legal aspects of epilepsy and nervous disorders of the same class*”.



Photographs:

Previous page:

A recreation of the facade of the original Hotel Bristol, The drawing was used in the design of a special booth to celebrate ILAE's centenary at the 28th International Epilepsy Congress in Budapest 2009.

This page:

Left: Louis Jacob Joseph Muskens (ca. 1909), far left, and Gyula Julius Donath (ca. 1909). Donath and Muskens were the two prime motivators of the foundation of ILAE.

Below, from left: Harry and Marianne Meinardi with Ted and Angela Reynolds at ILAE's celebratory dinner in Budapest

However it seems that a subsidiary objective was to promote the foundation of the ILAE and this was rapidly accomplished within 6 months of the first issue.

The ILAE got off to a flying start with subsequent meetings in Berlin (1910), Zurich (1912) and London (1913); the latter in the context of the 17th and last International Medical Congress attended by over 7,000 delegates. At this time the ILAE now had over 100 individual members from 19 countries. The First World War brought this encouraging momentum to a complete halt. As will be discussed in a subsequent article, the ILAE was not revived until 1935 and even then was nearly extinguished again due to the Second World War.

It took until the 1960's for as many as 19 countries to be represented again in the ILAE. This is one small example of the disastrous impact of the First World War on human creative endeavour. Nevertheless the ILAE did eventually revive and flourish and now has over 100 Chap-



ters world wide. As far as I am aware the ILAE and Epilepsia are the oldest sub-specialty organisation and journal in the field of neurology, even older than the World Federation of Neurology (1931).

References

Shorvon S, Weiss G, Avanzini G, Engel J, Meinardi H, Moshe S, Reynolds E, Wolf P. (2009). *International League against Epilepsy 1909-2009: A Centenary History*. Chichester, Wiley-Blackwell.

Edward Reynolds MD FRCP FRCPsych

Dr Reynolds qualified in medicine in 1959. He trained in neurology at the National Hospital for Neurology and Neurosurgery, Queen Square London from 1963 to 1969, and at Yale University, Dept of Neurology in 1970. He was elected a Fellow of the Royal College of Physicians of London in 1979 and a Fellow of the Royal College of Psychiatrists in 1985.

He was Consultant Neurologist to Maudsley and King's College Hospitals 1974-1999; Founder and Director of the Institute of Epileptology, King's College 1994-2001; Chair of the Fund for Epilepsy 1992-2004; and is currently Honorary Senior Lecturer in Neurology at Guy's, King's, St Thomas' School of Medicine, King's College University of London.

Dr Reynolds was Vice President of ILAE from 1989 to 1993 and served as President from 1993 to 1997. During his presidency he initiated the Global Campaign Against Epilepsy and was Chairman of the campaign from 1997 to 2001.

Epilepsy Centre at the Top of the World



Photo: Ann Little

I had set the alarm, not wanting to be late for a special appointment, but this was one morning when an alarm was not required. Instead it was the gentle rocking to and fro of my 16th floor hotel room with creaking curtain rails, rattling hangers and squeaking doors that created an entirely different wake up call. I was in Quito, the second highest capital city in the world. Quito sits on top of the world at 2,850 metres above sea level on the eastern slopes of the active volcano Pichincha in the Andes. And this was an earthquake registering 7.1 on the Richter Scale!

For the people of Quito such events happen about six times each year and life usually carries on as normal, just as it did on 12th August 2010.

My special appointment was to meet with Dr Galo Pesantez who was taking me to visit the public epilepsy clinic at the Centro Nacional de Epilepsia in the suburb of La Gasca, which he runs for people with epilepsy of limited financial means. He also has a private clinic in Quito city centre.

Galo was responsible for the formation of the Association of Parents of Children with Epilepsy in 1987, which joined IBE in 1991. The association was originally based in a hospital in the centre of Quito (the blue building in the photo above). Today the parents association and the Centro Nacional de Epilepsia work jointly as the IBE Full Member and there are 18,000 members with a countrywide network.

On arriving at the centre, it was amazing to see the IBE logo painted not only over the entrance gate but also on the main building itself. The centre, built in 1996 by Galo and his wife Monica (who is also a doctor), was designed to be a friendly, homely place with a lovely garden area complete with fountain—rather than a cold, austere clinic. And friendly it is! As soon as we get out of

Ann Little, IBE Executive Director, reports on a visit to Quito, Ecuador

the car, young patients bound forward, eager to greet their doctor with hugs and smiles. Everyone is met with a warm ‘buenos días’.

The centre has several epilepsy treatment areas, and also caters for patients with Attention Deficit Hyperactivity Disorder (ADHD) with a special activity room within the complex. Consultation fees are about \$1 per visit and the charge has a two-fold purpose—it safeguards the dignity of those attending and it also attaches value to the service. The centre also arranges tests, such as blood level tests, at much reduced fees, at other clinics.

Galo shows me a small pharmacy where newly diagnosed patients are provided with AEDs almost free of charge while they wait a few months before receiving their government medical card. Originally the pharmacy was funded by the government and when the support was withdrawn, pending the introduction of the new legislation covering free medicines for those on low income, the IBE Promising Strategies Program bridged the gap. Galo explained how crucial the funding had been for the centre at that critical time.

During my visit, Monica and Galo’s two charming daughters come to say ‘hola’. Gabriela and Jimena are following in their parents footsteps, with one finishing her first year at medical school and the other two years ahead. Their third child, a son called Galo after his Dad, is still at second level college and, so far, is more interested in studying music.

So how is the situation for people with epilepsy in Ecuador today? Well, there is good news and there is not so good news. The good news is that employment legislation is very favourable for people with a disability. In Ecuador, for every 25 people employed, one must be a person with a disability. This has been made possible because of pressure by the President, who has a personal interest in disabilities. Galo explains that many employers prefer to offer positions to people with epilepsy because they have been found to show more dedication and to be more conscientious in their work. Even as we chat, Galo takes a quick phone call from an employer with a vacancy; and such calls are frequent.

Not such good news is the situation on driving legislation. At the present time there is no legislation in place, although neurologists recommend that patients be 2 years seizure-free before driving. Ecuador is not alone in this situation with several other countries in Latin America also lacking in appropriate driving legislation for persons with epilepsy.

As we drive back to the city centre Galo points out the peaks of Pichincha and the higher Rucu peak (4,698metres) and tells me that these are favourite walking trails that the members in Quito climb each year on a special day out.

I wondered how Galo had first become interested in epilepsy and am surprised to hear that he might have had a completely different career—in music! For several years he trained as a singer and was a member of the Ecuador national orchestra as a singer and guitar player for five years. During this time he travelled extensively with the orchestra throughout Latin America while still studying medicine. Eventually travel fatigue set in and he opted to concentrate on medicine. However the music world has not lost him completely and neither has he lost his talent —playing on the car CD unit is a disk featuring Latin American classics which he and some talented colleagues have produced! A great way to end a memorable visit.

A view of the Virgin Mary monument on top of El Panecillo
Photo: Ann Little



The main entrance



Monica and Galo with daughters Gabriela and Jimena
Photo: Ann Little

VI Congreso Latinoamericano de Epilepsia, en Cartagena de Indias, Colombia

Tomás Mesa Latorre, Secretario Comité Latinoamericano del IBE



Photos:

Left:

- Meeting of the Latin American Regional Committee

Facing page, clockwise from top left:

- Tatiana Cárdenas (hostess) with Vania Silva and Ann Little at the IBE Exhibition Booth
- Franklyn Monteiro (Dominican Republic), foreground listens intently during the Promising Strategies meeting
- Jaime Fandiño-Franky and Mauricio Olave (Colombia) at the Promising Strategies meeting
- Carlos Acevedo, Jorge Rodriguez (PAHO) and Mike Glynn

En la hermosa ciudad de Cartagena de Indias, patrimonio histórico de la humanidad (UNESCO), se realizó el VI Congreso Latinoamericano de Epilepsia, durante los días 1 y 4 de Agosto 2010. Estuvo bajo los auspicios del Buró Internacional para la Epilepsia (IBE) y la Liga Internacional contra la Epilepsia (ILAE), con una gran asistencia (más de 700 personas), en el cual hubo numerosas actividades científicas (básicas, clínicas y sociales) y de fraternidad, entre las cuales destacan:

- Grupos de discusión de *Desafíos en calidad de vida en personas con epilepsia*, donde hubo exposiciones de las experiencias en Brasil, Chile, El Salvador y Uruguay, seguido de una amplia discusión del tema por los asistentes y se propuso realizar un estudio colaborativo Latinoamericano, para evaluar la situación de la región.
- La Jornada del Buró, se efectuaron durante todo un día, la cual estuvo abierta a la participación

del público en general y particularmente a personas con epilepsia y sus familiares, con preguntas y respuestas. Las jornadas estuvieron especialmente dedicadas a docentes y educadores de las áreas primarias y secundarias, como importantes agentes difusores a la sociedad. Hubo información de algunos aspectos de especial relevancia relacionados con la Ley de Epilepsia en Colombia y cambios realizados en el sistema de salud, de vital importancia para el conocimiento de personas con epilepsia y sus familiares.

- En el programa científico se trató Epilepsia y Legislación, destacando lo realizado en Colombia y Argentina, con la visión mundial de la Campaña Global.
- Hubo una reunión desayuno sobre los proyectos de Estrategias Promisorias, donde se mostraron algunos de las actividades ya realizados en nuestra región, con el objetivo de estimular a otros países a concursar a nuevos pro-

yectos y desafíos. Los países que expusieron fueron: Argentina con la “Guías Nacionales para Conducir Vehículos en personas con Epilepsia”, Chile, “Entrenando en Epilepsias a Escolares de I y II año del Ciclo básico: Video de Juanito” y Guatemala sobre Lecciones y Enseñanzas sobre Epilepsia en Audio, en diferentes dialectos, realizados en distintas partes de Guatemala.

- Se llevó a efecto la Asamblea General del Comité Latinoamericano del IBE, con la presencia del Presidente del IBE, Sr Mike Glynn, recordando lo sesionado en el Congreso Mundial de Epilepsia en Budapest, planificando el próximo congreso Latinoamericano y la presentación de cada capítulo Latinoamericano asistente.
- Por tercera vez, se llevó a efecto la reunión de las directivas del Comité Latinoamericano del IBE y de la Comisión Latinoamericana de la ILAE, con el objetivo de seguir trabajando en proyectos

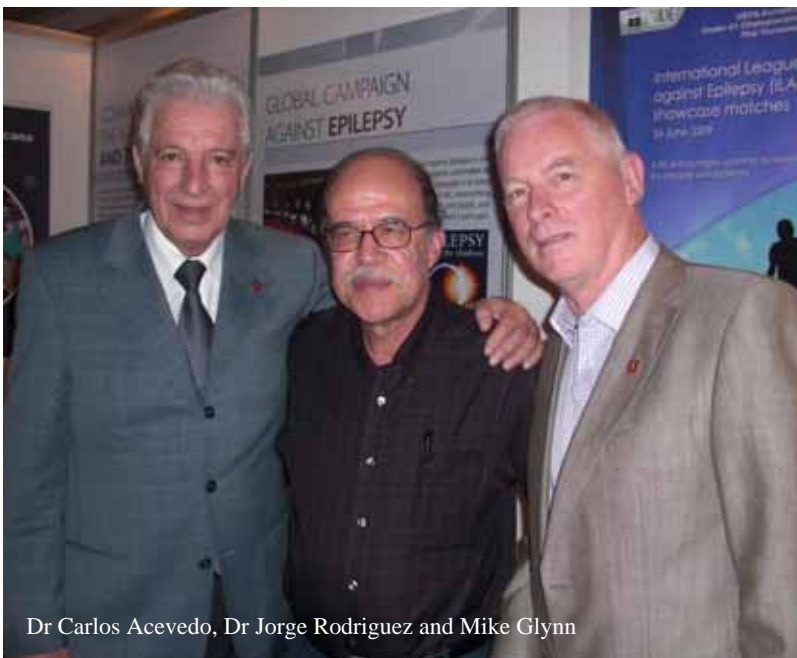


Latinoamericanos en conjunto, destacando la participación conjunta en ALADE (Asociación Latinoamericana de Educación).

- Una de las actividades más importantes fue la centrada en el lanzamiento de la tercera etapa de la Campaña Global contra la Epilepsia, con una sesión y además la formación de un comité para planificación y desarrollo en este nuevo periodo.
- Se expusieron los Afiches (Posters), relativos a la conformación y actividades que desarrolla cada Capítulo Latinoamericano del IBE. Esta idea es promocionada por el Comité Ejecutivo Internacional del IBE y estos mismos afiches, serán expuestos en el Congreso Mundial de Epilepsia en Roma, el 2012.
- Hubo durante el congreso, varios trabajos relativos a los social o educacional, ya sea en Afiches o Conferencias que fueron enviados por autores de diferentes países de nuestra región.
- La Estación o ‘Stand’ del IBE, estuvo muy activo, con abundantes documentos, afiches, revistas, material educativo...etc, que cada país realiza en sus actividades diarias.
- Las Conferencias inaugurales sobre “A 10 años de la declaración de Santiago: presente y futuro”, se recordaron los diferentes hitos, desde el I Congreso Latinoamericano de Epilepsia y se proyectaron los desafíos en los años venideros, tanto por el Vicepresidente regional del IBE, Dr Carlos Acevedo y de la ILAE, Dr Marco Tulio Medina. El Dr Daniel Nariño, como dueño de casa, nos invitó oficialmente a participar en cada una de las actividades.
- El exitoso Curso de ALADE, incluyó desde los aspectos neurobiológicos, genéticos a los clínicos de las epilepsias. Pendiente en su distribución, quedó un libro realizado por las Dras EM Yacubian y S Kochen, a quienes se les felicitó por esta gran iniciativa.

Meeting with Dr Jorge Rodriguez

Chief of PAHO Regional Mental Health, Substance Abuse and Rehabilitation Unit



Dr Carlos Acevedo, Dr Jorge Rodriguez and Mike Glynn

A very significant meeting took place in Cartagena between Dr Jorge Rodriguez, and representatives of the Global Campaign Against Epilepsy. An ambitious plan to have epilepsy on the agenda of health ministers at regional level within PAHO countries was discussed; epilepsy has not been on the PAHO agenda in 50 years. It is estimated that this could be achieved within the next three years.

Groundwork will be undertaken in 2010 and 2011 with a goal of having epilepsy on the agenda for discussion in Washington in 2012. Dr Carlos Acevedo, IBE Vice President Latin America, will liaise closely with Dr Rodriguez to bring this plan to a successful conclusion.

This was the first meeting of the Global Campaign to be attended by a representative of PAHO and it is hoped that this will be the model for other regions.



Photos: Ann Little

Memories of



A busy year

It has been a very busy year for IBE with no less than four regional congresses taking place over the course of 2010. Since the last issue of IE News alone, we have celebrated two meetings—the 6th Latin American Epilepsy Congress in Cartagena, Colombia at the beginning of August and the 12th European Conference on Epilepsy & Society at the end of that same month. And as this newsletter goes to print we are preparing for the 8th Asian & Oceanian Congress, which will take place in Melbourne in late October.

12th ECES Porto

The Porto conference was a special event for IBE members, being the only stand alone meeting of IBE. Organised by the European Regional Committee, the Porto venue proved a bit hit with the 300 delegates who had travelled to attend. In addition to European delegates, there were some participants from as far afield as the USA, Australia, Sierra Leone and South Africa.

Important guests

The conference was also very pleased to welcome two important VIPs—Dr Matt Muijen, WHO Regional Advisor for Europe and Mr Gay Mitchell, MEP (Member of the European Parliament).

Dr Muijen had accepted the invitation to launch the Global Campaign report *Epilepsy in the WHO European Region: Fostering Epilepsy Care in Europe*, a report that had been several years in the making. The published document is being circulated to all IBE members and is also available for download on the new Global Campaign website.

For Mr Mitchell, Porto represented the second time to speak at an Epilepsy & Society conference, having previously spoken in Copenhagen in 2006. His presentation: *The Role of the EU in Providing Support for People with Epilepsy* was well received by delegates.

Download presentations

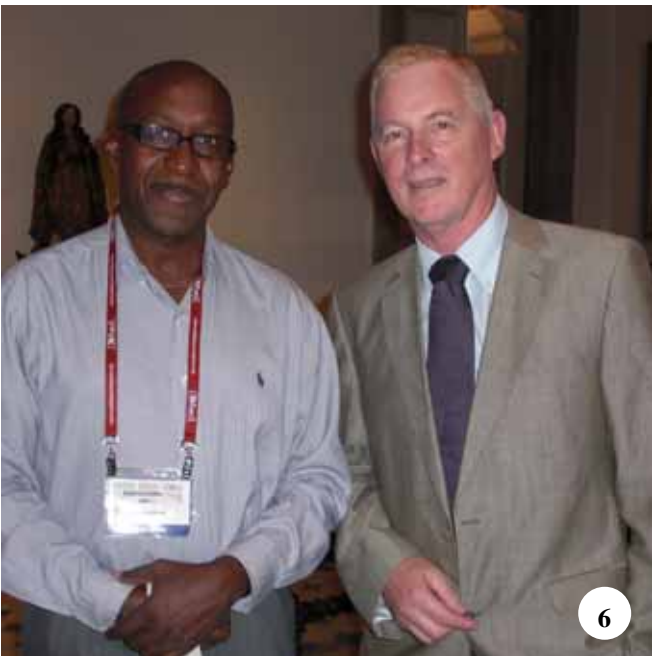
Both Dr Muijen's and Mr Mitchell's presentations are available to view on the IBE website site under Congresses/Previous Congresses/Porto.

In addition, you will find the presentations of almost another 20 speakers available to view on the site. Topics include:

- Epilepsy & Cognition
- Ethics in Epilepsy
- Epilepsy & Driving
- Photosensitive Seizures and Epilepsies
- Influencing Policy

Photos

1. Nelson Rua, President of IBE's member in Portugal, EPI-APFAPE, and a member of the Organising Committee, addresses delegates during the Opening Ceremony.
2. Delegates who attended the Global Campaign meeting for Stakeholders in Europe.
3. Members of the European Regional Executive Committee, from left: Mike Glynn, Seppo Sarkkula, Aisling Farrell, Thanos Covanis, Janet Mifsud, Michael Alexa and Victoria Dimech.
4. Helen Cross, Reetta Kälviäinen and Matt Muijen at the Opening Ceremony.
5. Dr Lisk, Sierra Leone with Mike Glynn at the conference.
6. Márcia Vasques (left) and Cristina Silva, two members of the local association who volunteered their services during the conference, are presented with flowers by Mike Glynn.
7. Aerial view of delegates at the Opening Ceremony.
8. Delegates enjoy a lesson in traditional Portuguese dancing at the Gala dinner held in Taylor's Port cellars, which is one of Porto's most prestigious labels.



8TH ASIAN OCEANIAN
EPILEPSY
CONGRESS

21–24 October 2010
Melbourne, Australia



Outstanding Persons with Epilepsy

Congratulations to the nine recipients of the Outstanding Persons with Epilepsy Awards 2010, who will be presented with special certificates of achievement by IBE President Mike Glynn during the IBE Programme: Epilepsy & Society, on 21st October at the time of the 8th Asian & Oceanian Epilepsy Congress (AOEC):

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

The first AOEC was held in Korea in 1996. It was at the 4th AOEC in Nagano, Japan in

2002, under the guidance of Dr Park (Korea), Dr Hsi (Taiwan), Dr Kubota (Japan) and Dr Mehndiratta (India) that the idea for this award was developed. The main aim was to encourage people with epilepsy to gain confidence and to overcome the culturally defined stigma and discrimination that exists in the region.

Each IBE member in the South East Asia and Western Pacific Regions is entitled to nominate a recipient each time the award is presented and support to attend the congress is provided through the budgets of the Regional Committees South East Asia and Western Pacific.



Epilepsy & Society

IBE Programme in Melbourne

One-day symposium on living with epilepsy

The symposium for people with epilepsy, their carers, families and friends will take place on Thursday 21st October. The event is also designed for professionals working with people with epilepsy in the community, whether in the sector of disability, education, employment, nursing, or leisure. The organisers promise something for everyone!

The day will begin with a keynote address by Graham Scambler, a sociologist from University College of London, who will speak to the topic epilepsy and stigma. This will be followed by presentations by Australian TV sports presenter and past

Australian Ruby League captain, Wally Lewis. Wally, who is also a published author, will talk about his own experiences of epilepsy over the past 20 years.

Discussion groups, led by national and international experts in their field, will examine a variety of epilepsy related issues that can impact on quality of life, including sexuality, memory, sports and exercise, practical means of managing depression, employment and advocacy issues, sudden unexpected death in epilepsy (SUDEP), and epilepsy and creativity. International speakers will include Dr Elson So from the famous Mayo

Clinic in the US, who will provide up-to-date statistics and information on SUDEP: who is at risk and how best to impart this information.

Marion Clignet, champion Olympic cyclist, will talk about how being diagnosed with epilepsy was the catalyst to taking up the arduous sport of cycling.

After lunch, IBE President Mike Glynn will present the Outstanding Persons with Epilepsy Awards and this will be followed by a book launch. Delegates attending the programme are invited to attend the Congress Opening Ceremony and Welcome Reception that evening.

Business Meetings in Melbourne

Thursday 21st October

- **ILAE/IBE/WHO Global Campaign Against Epilepsy**

Open to: Representatives of IBE and ILAE member associations in the region

Time: 16:00—18:00

Room: 112

- **SUDEP Intro Meeting**

Short get together meeting open to those affected by, or with an interest in, SUDEP

Time: 15.00-15.30

Room: 108

Friday 22nd October

- **Western Pacific (WP) Regional Committee**

Open to: IBE members based in the region:

Time: 09:00—11:00

Room: 107

- **South East Asia (SEA) Regional Committee**

Open to: IBE members based in the region.

Time: 09:30—10.30

Room: 108

- **Chief Executive Officers**

Open to: Salaried executive staff working in IBE member associations

Time: 15:00—17:00

Room: 107

- **Joint meeting of the SEA and WP Regional Committees**

Open to: IBE members in both regions

Time: 19:00—20:00

Room: 107

- **SEA-WP Welcome Reception**

Time: 20:00—21:00

Room: 112

Saturday 23rd October

- **Editors Network**

Open to Editors of magazines produced by IBE member associations

Time: 10:00—11:30

Room: 107





NEWLY ARRIVED
but already in business!

www.GlobalCampaignAgainstEpilepsy.org

The website of the ILAE/IBE/WHO Global Campaign Against Epilepsy offers a wealth of news, reports and downloads related to campaign activities.

Why not pay us a visit!



New Website for the Global Campaign

It took a long time in its planning and several months of hard work in identifying and uploading content but, finally, the new website of the ILAE/IBE/WHO Global Campaign Against Epilepsy went live at the 12th Conference on Epilepsy & Society in Porto in August.

The website contains a comprehensive range of information, reports and articles, categorised within sections that include:

Demonstration Projects, Regional Activities, News and Initiatives. Of particular interest to visitors will be the Document Library. Here you will find many interesting articles and reports including:

- Reports on Demonstration Projects
- Regional Declarations
- Technical Documents
- The Epilepsy Atlas
- Reports on the Campaign, including Annual Reports
- Other GCAE or WHO associated documents

Pictured left is a special poster created to promote the website at the 8th Asian & Oceanian Epilepsy Congress in Melbourne.



Secretary General Resigns

Following his resignation as Chief Executive Officer at Epilepsy Foundation of America, Eric Hargis has announced his resignation as IBE Secretary General.

Eric first joined the Executive Committee of IBE in 1999, taking over in mid-term following the retirement of Paulette Maehara.

With the introduction of the new IBE Constitution, he was elected Vice President North America in the first IBE elections in 2001. In 2005 he stood for the position of Secretary General and was successfully elected. He was elected

to serve a second term as Secretary General in last year's elections.

It was with regret that IBE accepted Eric's resignation as his new career takes him outside of the field of epilepsy.

Elections to fill the Secretary General vacancy are already underway and Eric's successor will be known in early January 2011.

The International Executive Committee wishes to thank Eric for his valuable contributions over the last 11 years and wishes him every success in his new career



IE News is not Lost in Translation!

It may come as quite a surprise to some readers to learn that the IE News has been available in Japanese translation for more than a quarter of a century.

Dr Yoshi Inoue (National Epilepsy Center, Shizuoka Institute of Epilepsy and Neurological Disorders), who is the current translator of the newsletter, shares some details with us.

The late Dr Masakazu Seino started to translate the IE News into Japanese in 1984, in order to inform as many persons connected to epilepsy in Japan as possible of the activities of IBE.

The IE News Japanese version includes all pages of the original IE News (although only black and white) as well as a special corner "Epilepsy Japan Speaks" (covering two pages) where someone working in the field of epilepsy or providing care or help to persons with epilepsy, contributes an article for the magazine. We have a different contributor in each issue. I took over the work of Dr Seino in 2007.

Publication of Japanese translation of IE News has been made possible by the continuous generous support of the Dainippon Sumitomo Pharma Co., Ltd.

Each issue has a print run of 9,000 copies. The magazine is distributed to all members of the Japanese Epilepsy Association as a supplement to its monthly journal (7,000 copies) and to physicians or caregivers, and to relevant institutions (2,000 copies). This is almost three times the print run of the original English IE News.

I am not only learning a lot from this important undertaking, but also enjoying the work very much.

STOP PRESS!

The Editor is pleased to announce a special award as part of IBE's Jubilee celebrations next year. The award is to encourage all IBE Members to submit an article for IE News outlining the history of their association.

IBE is aware that its members undertake many successful initiatives that make life better for their members. We are also aware that associations can experience difficulties in the course of their work. The prize will be given to the article which, in the judges opinion, is the most interesting and best written.

The winning article will attract a financial award to support a new initiative within the association that submits the winning entry. The article will also be printed in IE News. Full details, including rules for submission, the judging panel, prize fund and other details, will be included in the next issue of IE News.



FIRE: a day of celebration

**“Entre más conozcamos de Epilepsia, más querremos ayudar”
“The more we know about epilepsy, the more we want to help”**

Report by Ann Little, IBE Executive Director

Background

A special IBE Day took place during the 6th Latin American Epilepsy Congress in Cartagena on Saturday 31st July. Organised by Dr Jaime Fandiño-Franky, assisted by his wife Margaret, Dr Mauricio Olave and the staff at Fundación Instituto de Rehabilitación para Personas con Epilepsia (FIRE), this was a day with a difference.

The FIRE clinic complex is located about half an hour's drive from the centre of Cartagena and sits within a hectare of tropical gardens. The plot was originally purchased by Jaime Fandiño-Franky almost 50 years ago and the original buildings date back to 1964 when the centre first opened. Since then, there has been continuous development and improvement and even this year work continues with the construction, in traditional Colombian style, of a new reception building and erection of a new name plaque at the entrance to the complex.

From the day the centre first opened its doors to provide care and treatment for people with epilepsy, Jaime Fandiño-Franky has been the driving force. Now, after 47 years of hard work and dedication, he is preparing the hand over the reins to Dr Mauricio Olave, who he has identified as his

successor to head up FIRE.

The day at FIRE was a celebration of Jaime Fandiño-Franky's career at the centre as well as the recent success in a campaign for the introduction of legislation in favour of people with epilepsy. The new legislation was finally ratified by the Colombian Parliament after much debate in July.

Several international delegates who were attending the 6th Latin American Epilepsy Congress in Cartagena accepted an invitation to attend the event at FIRE. These included IBE President Mike Glynn, Vice President Latin America; Carlos Acevedo; Chair Latin American Regional Committee Lilia Nuñez; Franklyn Montero, Dominican Republic; and Hanneke de Boer, GCAE Coordinator. I was also very pleased to have been invited to attend.

Two other international delegates with a special interest in FIRE were Christoph Pachlatko from the Swiss Epilepsy Centre in Zurich, Switzerland and his wife Claudia. The centre in Cartagena has been supported by the Swiss centre for many years and a very important relationship has developed between the two organisations. An added connection is the fact that Jaime's wife Margaret is from Swit-

zerland and so a close personal bond has also been established.

Musical beginning

As we arrived a very talented local youth orchestra welcomed us with a wonderful performance of traditional Colombian airs as well as the National Anthem and the Anthem of Cartagena. This was followed by a welcome song sung by a group of young people with epilepsy who attend the centre.

After the official opening words by Jaime, the following presentations were made by international delegates:

- Mike Glynn spoke about the Global Campaign Against Epilepsy and about the work of IBE in general;
- Carlos Acevedo presented on the problems faced by people with epilepsy in developing nations;
- Lilia Nuñez talked on the importance of empowering people with epilepsy.

After a break for lunch, we were taken on a tour of the centre, finishing at a special exhibition of the work of the young people. Here we saw a wide range of products which are produced and sold by the young people. The





items made range from jewellery, shoes and bags, artwork and silk flowers, to lampshades and household items. The profit generated from the sales provides both income and a sense of self confidence and self belief in the young people who produce the goods.

The work at FIRE

During the afternoon we heard very interesting presentations made by some of FIRE's staff members and supporters:

- Martín Torres presented on multidisciplinary treatments, with an emphasis on rehabilitation;
- Carlos Medina Malo talked on the importance of raising awareness in order to change public perception;
- Claudia Trujillo spoke on the prevention of disability in the child with epilepsy;
- To great applause, Christoph Pachlatko displayed his fluency in Spanish by speaking in Spanish on the social and economic aspects of epilepsy.

Standing room only

The fourth element of the day was devoted to patients of the centre and their families. It was only at this point that we realised just how many people were attending the event. In addition to the main session room, there was an overflow of interested people who were listening and watching by video from the room terrace!

During the question and answer session, which could have continued until nightfall, the video equipment allowed us see those on the roof terrace as they presented their questions.

The Fiesta

In true Colombian style, and demonstrating the hospitality of Jaime, Margaret and everyone at FIRE, we were invited to celebrate the close of the event in carnival atmosphere.

First off were a troupe of young dancers who delighted us with their technique. Next up was a salsa band, who soon encouraged those with rhythm to take to the floor! Food and drinks were served and then it was time to leave after a wonderful day!

Photos:

- Above from left: Franklyn Monteiro, Carlos Acevedo, Lilia Nuñez, Mike Glynn, Hannneke de Boer, Christoph Pachlatko, Ann Little, Margaret Fandiño-Mertz and Jaime Fandiño-Franky.

Below, from left:

- The local youth orchestra gives a musical welcome to delegates;
- Jaime Fandiño-Franky with Senator Manuel Virgúez, who was instrumental in the introduction of the new legislation in Colombia, and Roberto Cadavid, a lawyer with the same law firm;
- Gladys Carrascal, Special Education Director at the FIRE workshop with Gregorio Diaz, Special Educator;
- Young dancers who added a carnival atmosphere to the Fiesta event;
- María Eugenia Castellón, Occupational Therapist at FIRE, takes to the floor with Jaime as the salsa band entertains delegates.





Meet Dr Ding Ding

The inspiration behind the Seahorse Club in conversation with Carlos Acevedo

Tell us a little about your background? What part of China are you from and when did you become interested in a career in medicine?

I was born in Shanghai, a very big city on the east coast of China. I studied medicine and public health in Fudan University and was a lecturer of epidemiology at the university from 1994 to 2002. After that, I joined the Institute of Neurology at Fudan University, working as a neuro-epidemiologist. I've been involved in a lot of scientific research, especially on neurological diseases. In the past I have been a visiting scholar at health institutions in Korea, Vietnam, Thailand, Hong Kong and the USA.

The choice of medicine as my major, when I entered university about 20 years ago, was actually the idea of my parents. They wanted me to be a doctor who could help people practically in their daily lives. By the end of my five years at college I realized that this was the right choice for me as I really enjoyed studying medicine. Later, my interest moved to public health from general internal medicine because I felt that studying public health problems was more important than focusing on the illness of one individual.

So, when I went on to study for my masters degree, I chose to study epidemiology, which is an important methodology of public health research, to identify risk factors for disease and to determine optimal treatment approaches to clinical practice.

Why did you decide to take a special interest in epilepsy?

In the late 1990's, I re-visited 150 patients had suffered from Japanese encephalitis in their early life. About 20% of these had latent sequelae

with epilepsy. This was the first time I faced epilepsy patients and was deeply touched by the severity of their seizures. In 2002, I was involved in the demonstration project "Epilepsy Management at Primary Health Level in China", an activity of the ILAE/IBE/WHO Global Campaign Against Epilepsy. Based on the field survey data, I estimated the disease burden of epilepsy, analyzed the mortality rate and evaluated the cost and outcome of Phenobarbital treatment. These achievements brought me the Young Investigator Award at the 26th International Epilepsy Congress in Paris 2005 and the Bruce S. Schoenberg International Award in Neuroepidemiology of the American Academy of Neurology in 2006.

My career of epilepsy research had begun and I was really encouraged by these awards. Working closely with epilepsy patients, I realised that epilepsy can cause not only physical impairment, but also psychological and emotional distress, and this is very unique when compared to other diseases. Since then, following my own interest, I have been undertaking projects, such as cognitive function and quality of life evaluation of epilepsy patients, knowledge and attitude of epilepsy, psychosocial impact of epilepsy, etc.

How is the situation is for people with epilepsy in China? Have there been any positive developments in the last 10 years?

The situation for people with epilepsy in China was not so optimistic. There are around 9 million people with epilepsy in China, including 6 million people with active epilepsy, and nearly 65% of these patients do not receive appropriate medical treatment. Moreover, there is an addition of 0.4 million new cases each



year. A lot of patients and their relatives traditionally believe some advertisements or hearsay without any scientific basis, as a Chinese saying goes, "seeking medical treatment blindly in case of sickness". This will not only delay appropriate medical treatment, but also result in great economic burden. Furthermore, due to the lack of relevant knowledge and under the influence of traditional custom or superstitious idea, they receive unfair treatment or even discrimination with respect to employment, education and marriage. People with epilepsy and their relatives often suffer deep mental stress due to the stigma associated with the condition. Therefore, epilepsy is not only a physical disease, but also an issue of public health in China.

But of course, there have been some positive developments in the last five years. Since we established the China Association Against Epilepsy (CAAE) in 2005, the scientific and social treatment of people with epi-

lepsy (PWE) in China has been improving quickly and is receiving more and more attention from both the government and the general public. The CAAE organized a lot of activities to rectify the social discrimination and prejudice against PWE, to safeguard their lawful rights, and to educate PWE on the true facts about epilepsy. However, because epilepsy has been in a culturally-devalued condition throughout history in China, it still takes a long time to get rapid progress. Anyway, I am confident that this situation will improve through the efforts of CAAE and related activities.

What are the principal problems faced today by people with epilepsy in China? Does it differ from province to province?

We undertook surveys on the knowledge PWE had about their physical

people with epilepsy questioned had problems in employment, marriage, and social relationships. The principal problems did not differ from province to province, but did differ between those living in cities as compared to those living in rural areas. As for urban patients, seeking for efficient AEDs is their most important requirement, while for patients in rural areas, accurate diagnosis and cheap AEDs are their basis requirements.

If you had a magic wand, what would you wish for people with epilepsy?

In May this year, I visited Stichting Epilepsie Instellingen Nederland (SEIN). As a national epilepsy center, SEIN provides very good conditions and services, not only in the care of epilepsy patients, but also in their education and in helping them to find employment. I really wish

University, Huashan Hospital. The club belongs to the Patients Self-help Cluster of CAAE.

We organized several activities, including group meeting of patients, lectures on epilepsy knowledge and free medical consultations. In late 2007, we sent artworks created by PWE to Ireland to participate in the "Freedom in Mind" art competition organized by IBE. In May 2008, we organized a group of PWE and their family members to attend the 7th AOEC in Xiamen, China. Two patients were awarded "Outstanding Persons with Epilepsy" awards by IBE. This was the first time for Chinese PWE to attend the international epilepsy congress. In August 2009, a 4-week course on handcraft making was conducted for PWE and their carers with great success. In 2010, having been awarded funding through the IBE Promising Strategies Program, the Self-help Art Studio for PWE was established. PWE now have a central place where they can relax, create artworks and exchange experiences of their epilepsy.

When you are not working, what hobbies do you have?

I like listening to the music, watching films and practicing Yoga.

How would you like to close this interview?

I would like to close this interview by a quote "many hands make light work". I am just one of those who contribute to the career of epilepsy care. I do believe that with efforts from related organizations and warm-hearted people, PWE will have the happy life of which they dream.

Dr. Ding Ding is:

- Associate Professor of the Institute of Neurology, Fudan University, Shanghai, China
- Vice General Secretary of the China Association Against Epilepsy (CAAE)
- Member of the Epidemiology Commission, International League Against Epilepsy (ILAE)

Photos:

- Previous page: Dr Ding Ding
- This page: Ding with Dr Shunglon Lai, VP South East Asia and a member of the Seahorse Club (centre)

situation and their treatment requirements in 2006 and 2007. The result was significant. It indicated that PWE's knowledge of epilepsy was very poor. Some did not understand the importance of adherence to their medication or the need to monitor plasma concentration and as a result suffered adverse events regularly. Most PWE thought that it was not convenient to see doctors because of long waiting times, traffic problems, and high costs. Thus their urgent requirement was obtaining AEDs at low cost and efficiently and conveniently. Meanwhile, almost all the


that in China, in the future, we will have such a kind of center at national level, to help PWE and their carers, thereby decreasing the burden of their families and society.

Tell us a little bit about the Seahorse Club: What is their connection to the CAAE?, How did they start? Where are they based? What activities do they undertake?

In July 2007 we organized our own self-help group "Seahorse Club" in Shanghai, based in the epilepsy diagnosis and treatment center in Fudan

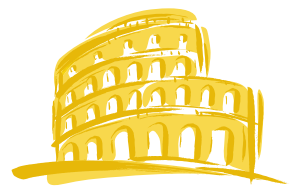





International Bureau
for Epilepsy
1961 - 2011
50 years focussed on epilepsy



29th International
Epilepsy Congress



ROME 2011



28th August - 1st September