

INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 50 years

1963-2013

In print for

50
years





Standing up for epilepsy together!

Sadly, this is my last President's message for IE News, but, I think there are quite a number of good things to look back on over the last four years and lots of initiatives in epilepsy to look forward to. As we look forward to the 30th International Epilepsy Congress (IEC) in Montreal, the opportunity to make advances in North America, based on the findings of the excellent Institute of Medicine report, beckons. The exciting news that the 2015 IEC will be held in Istanbul offers tremendous possibilities for IBE and ILAE. This fabulous city is, literally, where East meets West. Due to the unrest that there has been in the Middle East, we have been unable to schedule a 3rd East Mediterranean regional conference and

the Istanbul meeting may offer an opportunity to bring our colleagues from the region together. However, we will continue to look for new possibilities to have a much needed East Med regional meeting. One of the biggest recent successes was the 1st African Regional Congress in Nairobi and plans are now well advanced to have the 2nd African meeting in South Africa next year. In addition, work has now commenced on the ground on a number of new Global Campaign projects in both Africa and Asia. Along with the continuing success of IBE's Promising Strategies, all of these activities mean that IBE's mission to help people with epilepsy in the developing world is being advanced at a greater rate than ever before. In Latin America, the great work on the PAHO project, being carried out following Quito, continues at a great pace and we look forward to further good reports. Both our Western Pacific and South East Asian regional committees are very actively

involved in preparing for the next AOEC to be held in Singapore.

In Europe, the IBE/ILAE Joint Task Force continued to drive ahead the work based on the European Declaration on Epilepsy with major events on "Costs and Prevalence" and "Stigma" - as wonderfully described by a young Hungarian gymnast deprived of the right to participate in her sport due to her epilepsy - in Brussels for European Epilepsy Day. Later this summer, IBE will hold its European conference in Ljubljana, Slovenia the first time the conference has been in Central or Eastern Europe. Before that, the European Research Forum for Epilepsy will be held in Dublin, another unique, first, step for epilepsy.

All in all, I think we are "Standing up for Epilepsy".

With best wishes to all
Mike Glynn
President



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WHO

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

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After eight years it's time to say goodbye!

This IE News issue has a special meaning, because it will be inside the bag of 4,000 attendees of the 30th International Epilepsy Congress in Montreal, which will take place from June 23rd to 27th.

At the time of the General Assembly in Montreal, the elected officers for the term 2013-2017 of the International Executive Committee will take up their positions, as will the elected members of the Regional Executive Committees. In the last issue of IE News we introduced you to the new International Executive Committee. In this issue we focus on the newly elected members of the seven regional committees. I send all of them my best wishes and

every success in their management of IBE's affairs over the coming four years.

As usual, we have very interesting topics in this number, such as a new chapter of the IBE-ILAE history series, this time written by Ted Reynolds. This has been a very interesting column and I am sure that you will enjoy reading the latest segment.

We also highlight the Michael Prize, an award presented to a distinguished researcher on epilepsy around the world, and which, on this occasion in 2013, will be given to Dr Ding Ding, recently elected Vice-President Western Pacific of the IBE International Executive Committee.

There is a photo gallery of the 3rd European Epilepsy Day, an event celebrated by IBE and ILAE associations across Europe. Other news comes from China, Russia, Netherlands and Hong Kong.

This year is a very special one for IBE, because IE News reaches its 50 years of

existence. We look back on the history of the newsletter, on the Editors that have shepherded the magazine since its very first appearance in 1963, and on the development of the magazine from a two page typed letter to its current design. We also have a special celebration planned to mark the occasion in Montreal.

Finally, as all deadlines have been fulfilled, I am concluding eight years as IE News Editor, so it is time to say 'goodbye'. Thank you very much to all of you who made a contribution to the magazine over the past eight years and thank you, too, to those who took the time to read our newsletter.

I send you my best wishes.

Dr Carlos Acevedo
Editor

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CELEBRATING
50 YEARS!



In 1967 a new series of articles was introduced in the newsletter: Profiles of the Officers of the Bureau. The first profile appeared in issue no. 11, in which Irene Gairdner (IBE Treasurer) wrote about IBE President Ellen Grass, who was described as "...an energetic but not restless lady, of medium height, a charming smile and a capacity for making a rather weary traveller feel at home". The energetic Mrs Grass was to introduce the idea of the Ambassador for Epilepsy

When the late George Burden sat down to compose the first issue of the Bureau Newsletter, in the early days of January 1963, he did so on what was then "state of the art" equipment - a Remington manual typewriter. Corrections were made using a blue pen. The contents told of grants received and meetings planned and gave news on new initiatives in development. It also included a list of those who had agreed to be members of the Board of Directors - it would be 40 years later before IBE was to have its first elected Executive Committee.

From the beginning, the intention was to publish the newsletter quarterly, but this did not always happen. As co-founder of IBE and working as its Secretary General, George was already a busy man. Nevertheless, during the first five years 13 issues would appear, steadily growing in size and content.

In its infancy IBE focussed mainly on communication, so it is not surprising that the newsletter regularly reported on visitors to the London office from all over the world. The number of reports received from members also increased with good two way communication.

The first issues of the newsletter were dated by month of publication. This changed with issue no. 8 when publication was dated by season e.g. Spring 1966. However, as an international organisation, this was obviously not going to work! Recognising the problem, by issue no. 11 the magazine had reverted to being dated by month and settled into a pattern of three issues each year: March, July and October.

A replica of the first newsletter, produced by George Burden in 1963. The original is held by Hanneke de Boer



January 1963

Dear Friend,

May I wish you a very Happy New Year. This is the first formal Newsletter of our Bureau, we propose to issue one every quarter which we will send you for your personal use or for information to the Society you present as the case may be. If you would like more than one copy please let me know.

Our achievements so far are as follows:

We have received grants from the Swedish Epilepsy Association, the British Epilepsy Association, The Dutch Branch of ILAE promised a donation, ILAE will send a donation (GEP 600,-) and we are hoping to receive donations from the Canadian Neurological Society and the American Epilepsy Society. An emblem has been designed and a constitution is being developed.

The following have agreed to be members of the Board of Directors:
Mrs. Ellen Grass, Vice President, American Epilepsy Association
Dr. Francis McNaughton, President International League against Epilepsy
Prof. Henri Gastaut, Secretary of the International League against Epilepsy
Dr.A.M. Lorents de Haas, Medical Director of the Meer en Bosch Clinic, Heemstede, the Netherlands
Mr. H. Brulleman, also representing the Netherlands.
Mrs. Irene Gairdner, Hon. Secretary of the British Epilepsy Association
Dr. D. Pond, Chairman of the Medical Committee of the British Epilepsy Association
Dr. J. Romanes Davidson, Bridge of Weir.
Dr. K-A. Melin, Medical Director of the Stora Skondal, Farsta, Sweden.
Mr. Lew Simons has agreed to share the duties of Secretary with me and to represent the interests of the Bureau in the United States."

Our present plans are:

1. To participate in the Congress of the International Society for the Rehabilitation of the Disabled
2. To discuss with Prof. Gastaut the possibility of organising a seminar on Epilepsy and Society
3. To undertake the necessary arrangements for the organisation of the 3rd meeting on Juvenile Epilepsy
4. We are engaged in compiling a list of centres for the care of people with epilepsy throughout Europe
5. To make a collection and assessment of films about epilepsy in the United States
6. We propose that the Bureau be the channel of distribution of epiklesy.

In conclusion: may we hear from you? The Bureau can only be a success if you send us your enquiries, suggestions and information.

Yours sincerely,
George Burden

P.S. We have just received a letter from the Scottish Epilepsy Association telling us they propose joining the Bureau and promising to contribute 100 dollars.

INTERNATIONAL EPILEPSY NEWS 1963-2013

awards around this time, awards which would later become joint IBE/ILAE awards. There followed profiles of Vice-presidents Mogens Lund, Amparo Arcaya and Karl Axel Melin; Treasurer Irene Gairdner; ILAE President Jerome K Merlis and others. At the Council Meeting in Barcelona in 1973, it was decided that the newsletter should have a Honorary Editor. Harry Meinardi (Netherlands) was elected to this post and announced that, in the future, the newsletter would focus, not only on the Bureau, but also on news from the International League Against Epilepsy; making the publication a mouthpiece for both organisations. He planned to publish news on IBE, ILAE, and chapters. He also intended to publish on the general field of epilepsy – scientific news, upcoming events and editorial comment. In anticipation, issue no. 40 (March 1975) was re-named as "Epilepsy International" and carried the logos of both IBE and ILAE. It was described as the quarterly publication of Epilepsy International, the organisation for medical and social care of people with epilepsy all over the world. Harry Meinardi continued as Honorary Editor and, finally, Epilepsy International was described as the united activity of the International League Against Epilepsy and the International Bureau for Epilepsy.

In the March 1976 issue the colophon mentioned for the first time a number of correspondents – eight in total - although their roles were not clarified. In December of that year, an Editorial Administrator - Kurt Fleischmann (London) - was added. In the December 1977 newsletter, Harry Meinardi resigned from his position when he was elected IBE President in September 1977. He thanked his Assistant Editor Winifred Dawson (UK) and Kurt Fleischmann, who had been responsible for the lay-out of the newsletter.

Although his time as Editor of the newsletter ended in 1977, in the past few years Harry Meinardi has been newly involved in IE News, with his series of articles on the history of IBE - as reported in its newsletters - which are currently appearing in every second issue and are much enjoyed.

As IBE President, Harry Meinardi appointed Joop Loeber (Netherlands) as Honorary Managing Editor of the Epilepsy International newsletter. The Epilepsy International Executive Committee subsequently appointed Joop Loeber as Managing Editor and James Autry (US) as Chief Editorial Editor in 1978. In his professional career James Autry was involved in the publications industry in the United States and was later to become CEO of "Fortune 500" magazine.

During its meeting in September 1978, the Joint Executive Committee agreed that the newsletter should be more professional with respect to format, lettering, and the division of material into sections of interest

to readers. It was decided to attempt to publish the 1979 issues along these lines. With unanimous approval of the Joint Executive Committee, Mr James Autry, with colleagues from the publishing company, voluntarily worked on the development and design of Epilepsy International News. The first issue was published in 1979. The regular sections of each issue included:

- EI speaks: commentary from the Executive Committee
- Forum
- Research
- From all Nations
- News in Technology
- Public Education
- Special events and People

Roll Call of Editors



- 1963-1973** George Burden
1973-1977 Harry Meinardi: *Honorary Editor*
1977-1978 Joop Loeber: *Honorary Managing Editor*
James Autry: *Chief Editorial Editor*
1978-1985 Joop Loeber: *Honorary Managing Editor*
1985-1993 Hanneke de Boer: *Editor-in-Chief*
1989-1993 Richard Masland: *(ex-officio) Co-editor*
1993-1996 Jolyon Oxley: *Editor*
1997 Joop Loeber: *(ad interim) Editor*
1997-2000 Rajendra Kale: *Editor*
2000-2001 Ann Little: *(ad interim) Editor*
2001-2005 Susanne Lund: *Editor*
2005-2013 Carlos Acevedo: *Editor*



Dr Masakazu Seino

A Spanish edition of Epilepsy International News, which was available in Mexico, was first mentioned in December 1981 by IBE President Francesco Castellano. In 1988 the need for publication in other languages was to be raised again with the possibility of a Spanish edition once more considered. However, it is unclear whether the Mexican issue was still in existence at that time.

At the beginning of 1984, a Japanese edition was launched, thanks to the efforts of Dr Masakazu Seino. More than 13,500 copies were distributed throughout Japan. Almost 30 years later, this collaboration still continues, due to the support of Prof Yushi Inoue, Mr Yoshihiko Miyamoto and Dainippon Sumitomo Pharma Co., Ltd.

In 1985 the Epilepsy International News was returned to IBE and renamed International Epilepsy News (IE News). Hanneke de Boer (Netherlands) was appointed as Editor-in-Chief by Joop Loeber, who had stepped down from this position having served eight years in the post and following his election as IBE President. Dr Richard Masland (US) was appointed as (ex officio) Co-Editor. Joop Loeber would serve a further year, as interim Editor, in 1997.

Starting with issue no. 89 (September 1987), following a successful workshop on self-help and the establishment of the IBE Self-help Commission, a column dedicated to self-help developments in epilepsy was introduced.

In 1988, a special issue of the IE News was published to celebrate 25 years of IBE newsletters. The issue was to be special in two ways, according to the editor: on one hand it commemorated the 25th anni-

versary of the magazine and, on the other hand, it was the first issue to be dedicated to one main topic: Public Education.

Publication in other languages was a recurrent topic during Executive Committee meetings and guidelines for the production of such issues were finally prepared in 1987. Discussions with the industry to support the newsletter through sponsorship took place from time to time but, other than the Japanese edition, there was little progress.

During the Executive Committee spring meeting in 1987, distribution procedures of the newsletter was a point for discussion, as there was no clear system in place. Later that same year it was decided that the number of pages of the newsletter could be increased to 16, if the amount of copy in hand warranted this.

Feasibility of publication in colour was discussed, which was agreed upon on but only if finances would permit so to do. Concerning distribution, it was decided to send each chapter one copy for each US\$10 paid in annual dues.

During the 1990 spring meeting of the Executive Committee, ILAE's request to use the IE News to communicate with its chapters was discussed. It was agreed to add four pages to the magazine, for which ILAE would meet the cost, coupled to a resolution that ILAE would be responsible for editing these pages. This section was included in issues published between March 1991 and 1994, with the magazine expanding from 16 to 20 pages.

In 1991, revision of guidelines for foreign editions was discussed. Two different types of guidelines were mentioned.

1. The Japanese situation: where a Japanese sponsor takes over the contents of the magazine, takes care of printing and distribution, adds comments and an advertisement, and pays IBE a licence fee for use of content.
2. The Mexican situation: where articles are translated into another language, with no aim at profit and no intention other than a broader dissemination of the contents of IE News.

After years of discussions and attempts to make this happen, at last, in 1993, the Spanish edition was realised, although the interest of Spanish-speaking chapters was lower than had been anticipated. Despite this, the sponsor requested 1,500 copies for its use. It was also decided to re-visit the whole issue of distribution and a

survey, requesting information on national distribution, was sent to all chapters, with an aim to establish what happened to the magazines once they were sent to the national associations.

Jolyon Oxley (UK) was appointed Editor in 1993 by Hanneke de Boer, when she was selected as President for the term 1993-1997.

In 1996, uncertainty was reported in relation to continuity of sponsorship for the Spanish edition, after publication of the two issues to which the sponsor had committed itself. Later it became clear that two further issues would be sponsored by Ciba Geigy. In the meantime efforts were being made to publish the newsletter in Greek and also in Hindustani and Indian editions. The latter would be discussed with the editor of Epilepsia Digest. A version comprising photocopied graphics and typewritten in Romanian script had been produced by the Romanian chapter.

In 1997, following his appointment to the Executive Committee for the term 1997-2001, Rajendra Kale (India) was asked to become Editor of IE News. He made several improvements to the magazine: he enlarged the magazine's format from A5 to A4, changed the cover background from white to blue and chose a heavier matt paper instead of the light-weight gloss paper that had been used in earlier designs. The internal layout was also redesigned and modernised for easier reading and the scientific content of the magazine was increased.

Following his resignation from the IBE Executive Committee in spring 2000, Ann Little, IBE Executive Director, was asked to assume the role as temporary Editor to the end of the term. During this time, with permission received from the Executive Committee and the provision of a small budget allowance, purchased agency photos were used for the first time to accompany reports, although the inside pages of the newsletter were still printed in black and white.

When Susanne Lund (Sweden) was then appointed as the Editor for the term 2001-2005 by IBE President Philip Lee, Ann Little was invited to remain on in the newly introduced role of Co-ordinator, with responsibility for layout and design. Susanne Lund made more changes to the magazine's design and appearance, with a larger image on the cover, a new font face and an updated interior layout. Content was also to change slightly, using shorter more colourful reports and images, mixed with longer articles, to suit readers for

EDITORS 1963-2013

1. George Burden
2. Harry Meinardi
3. Joop Loeber
4. James Autry
5. Hanneke de Boer
6. Richard Masland
7. Jolyon Oxley
8. Rajendra Kalre
9. Ann Little
10. Susanne Lund
11. Carlos Acevedo



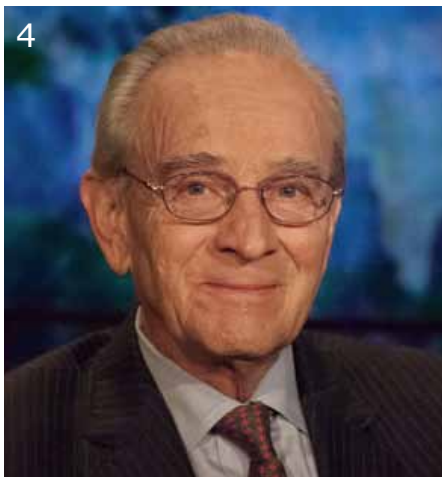
1963-1973



1973-1977



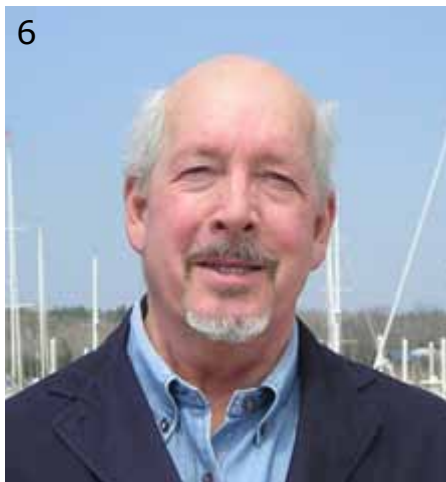
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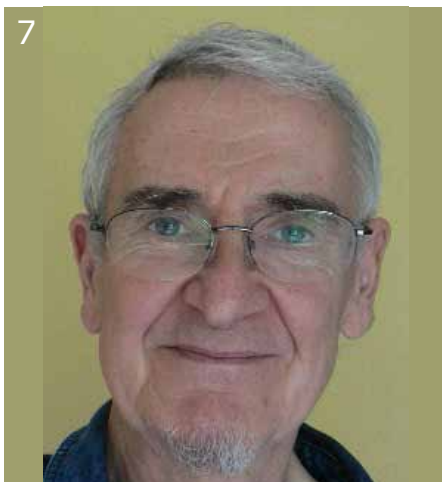
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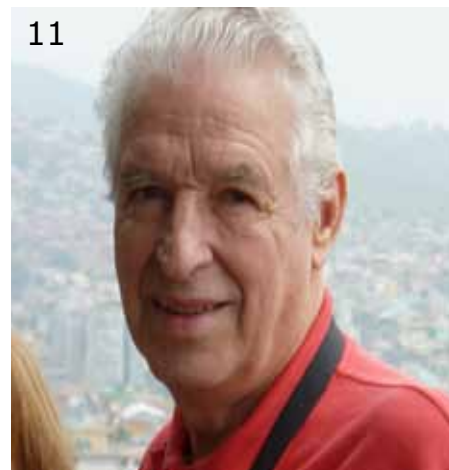
1997-2000



2000-2001



2001-2005



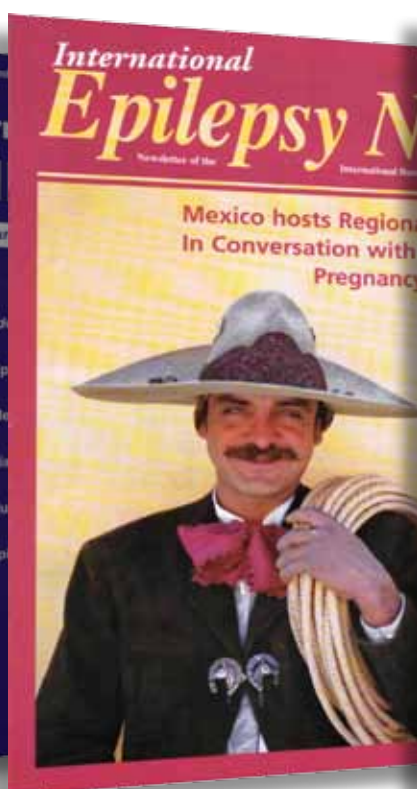
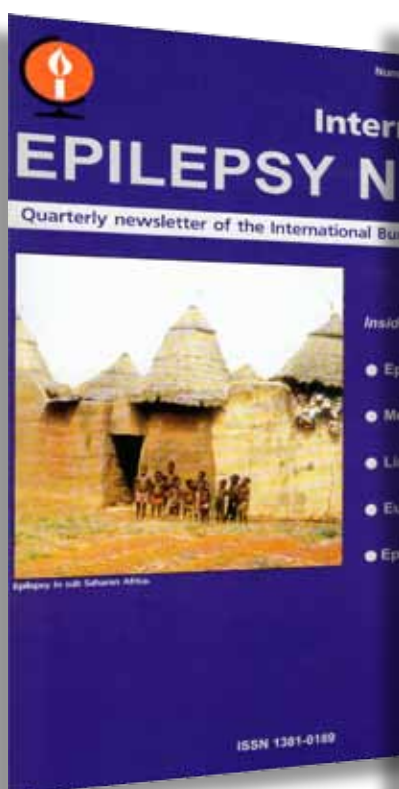
2005-2013



whom English was not a first language. The big change, however, was a move to full colour throughout! Photographs became more important in setting the tone of articles and agency photographs would henceforth be used on a regular basis. As the first elected President of IBE, when Susanne Lund took on her new role in 2005, she appointed Carlos Acevedo (Chile) as Editor, with Ann Little, once again, remaining on as Co-ordinator. The style of the magazine would, again, be reworked with a redesigned contents page and the inclusion of regular articles in Spanish with English translation. A more significant redesign was introduced at the beginning of 2011, the year of IBE's Golden Jubilee. This was facilitated by the

purchase of a more professional design software package that allowed more scope in formatting and layout of pages. Carlos Acevedo remained on as Editor, at the invitation of Mike Glynn, when he was elected IBE President in 2009, and is now coming to the end of eight years as IBE News Editor. Which bring the history of the newsletter up to date! Following election of the International Executive Committee for the term 2013-2017, it will be the duty of incoming President, Athanasios Covanis, to appoint the next Editor, who will be the voice in print of IBE for the next four years. Over its 50 year history, the newsletter has undergone many changes of format and size, from the first two page 'news-

letter' produced on IBE letterhead by George Burden on a manual typewriter, to a 20-page A4 full colour magazine that is printed commercially and sent around the world to more than 120 countries, four times annually. Copies are sent to IBE members and associates, chapters of the International League Against Epilepsy, medical libraries, sponsors and friends, and to a wide range of subscribers. Preparation of the magazine has also changed with the introduction of new technology and publishing software. It is not known how George Burden produced copies and dispatched that first newsletter to chapters, but, it is likely that he used a Getsetner machine and Royal Mail! As recently as the mid-1990's the newslet-





ter was prepared and printed by Paswerk, a sheltered print company connected to SEIN Epilepsy Centre in the Netherlands, was using the then standard bulky acetate sheets.

The timeframe from start to finish took several weeks, with hardcopy proofs to be checked and corrected. Marylyn Hills, wife of Mike Hills - a member of the IBE Executive Committee from 1993 to 2005 - proofed each copy of the magazine at her home in New Zealand.

The introduction of the internet and email, which became more widely available in the late 1990's was to bring about a sea-change in production of the newsletter. No longer was it necessary to send photographs and typed (or, indeed, handwritten)

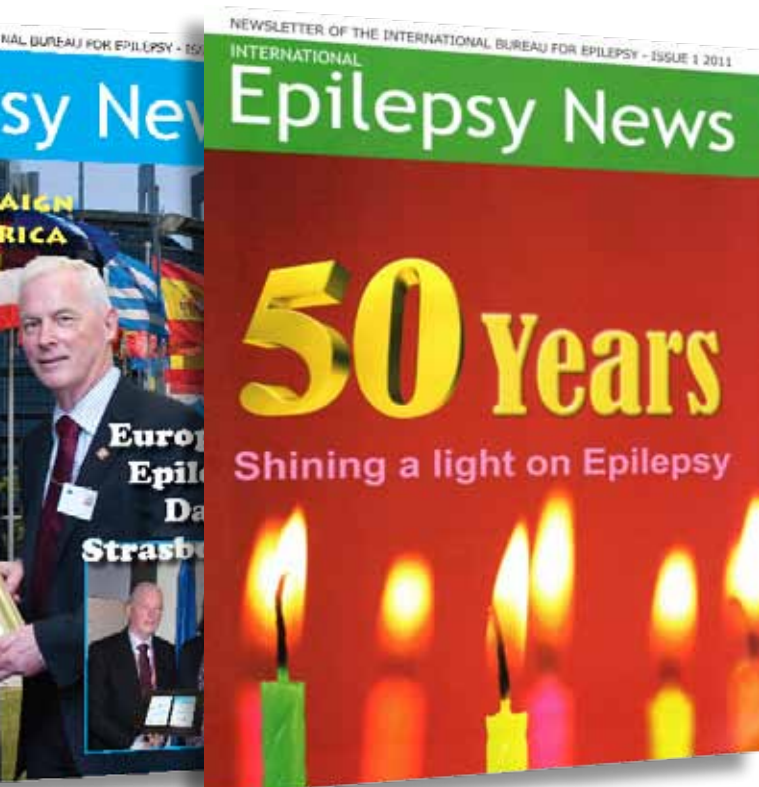
articles by post. It became commonplace for content to be sent in electronic format. In addition, in more recent years, training in publishing software has allowed the magazine to be prepared in-house to print ready stage, saving both on time and money, before being sent electronically to the printing house. A proof is received within 24 hours or, more often, within a couple of hours! Less than one week later, the newsletters are packed and dispatched globally, using a cost effective postal service.

IE News is available also for download on the IBE website and is included in the delegate bags at each regional and international congress. Which is why you may be reading this article as you attend the

30th International Epilepsy Congress in Montreal!

Given the ongoing acceleration in the development of new technology, who knows what the next 50 years will bring. What is certain is that the methods we currently use to publish IE News will seem as archaic to those coming after us as the old-fashioned typewriter is to us today! The only problem is: we won't be around to witness it!

At this time of celebration, IBE would like to express its gratitude to all those who have given willingly of their time, their energy and their experience thereby ensuring that International Epilepsy News maintains a consistently high standard.



Newsletter covers, clockwise, from top left:

1. Epilepsy International Newsletter, December 1978: pictured is Prof Juhn Wada who receives the Lifetime Achievement Award at the congress in Montreal
2. Epilepsy International News, April 1979
3. Noticias Epilepsia Internacional: Spanish translation, undated but contents suggest publication in early 1980's
4. International Epilepsy News, September 1985
5. International Epilepsy News, March 1988: celebrating 25 years of the newsletter (also shown on front cover page)
6. International Epilepsy News, Issue No 111, March 1993: first full colour cover
7. Japanese translation of International Epilepsy News, No 131, 1998
8. International Epilepsy News, Issue 1-2011: highlighting IBE's Golden Jubilee celebrations.
9. Issue 4-2011: Marking the 1st European Epilepsy Day. The first issue in the current design of the magazine.
10. Issue 1-2005: Special issue focussing on IBE's first elections to elect the International Executive Committee 2005-2009
11. Issue 2-2004: celebrating the 3rd Latin American Epilepsy Congress, Mexico City
12. Issue 132- July/August 1998: Rajendra Kale's radical redesign.

A Long Way to Go: Epilepsy Care in China

Report by Ding Ding and Shichuo Li, China Association Against Epilepsy CAAE

Photo: Father and daughter in rural China

China, the second largest economy in the world, remains a low-and-middle-income country (LAMIC) in World Bank terms due to its huge population. Of the 1.3 billion people living in China, about 9 million have epilepsy, of which 6 million have active epilepsy. In addition, a further 400,000 new cases are diagnosed each year. Unfortunately, 65% of these patients receive no treatment; while others are inadequately treated due to deficiencies in health-care resources and delivery.

Epilepsy brings a heavy burden to people with epilepsy and their families economically, psychologically and, also, socially.

Since the establishment of China Association Against Epilepsy (CAAE) in 2005, the scientific and psycho-social treatment of people with epilepsy in China has been improving rapidly and the disease has been receiving more and more attention both from the government and the public.

As part of the Global Campaign Against Epilepsy, and under the auspices of the World Health Organization and the Ministry of Health of China, a demonstration project was implemented from 2000 to 2004 in rural China.

An intervention trial was undertaken in 8 rural counties in 6 provinces, covering a population of 3 million people. This project was expanded to 135 counties in 18 provinces at the end of 2012, covering 74.95 million people in rural the population. A total of 135,764 people with epilepsy were screened under this project; 74,862 were treated with Phenytoin and 8,020 with Valproic acid, free of charge. After treatment, about 25% of people with epilepsy were seizure-free and the condition of a further 45% had improved. This is also a good experience for LAMICs.

Meanwhile the CAAE organized a number of activities to eliminate social discrimination

and prejudice against people with epilepsy, to safeguard their lawful rights, and to increase their knowledge on epilepsy.

In July 2007, the self-help “Seahorse Club” of people with epilepsy was founded in Shanghai, under the Patients Self-help Cluster of CAAE. The Club held group meetings for people with epilepsy, invited experts in epileptology to deliver lectures on epilepsy, and provided free medical consultations.

Since late 2007, the Club has conducted a series of “art and epilepsy” activities, such as art competitions and handcraft making courses, both for people with epilepsy and for their carers, in order to improve their capabilities.

Of the 1.3 billion people living in China, about 9 million have epilepsy

In 2010, the Club established the Self-help Art Studio for people with epilepsy, with the support of IBE’s Promising Strategies Program. The artworks were exhibited and published as calendars, book covers, greeting cards, and albums.

However, there are still challenges to be faced in the next decade in China in respect of patient care.

The diagnosis and treatment skills of primary care physicians are heavily lacking, and people with epilepsy themselves do not have other resources to access epilepsy knowledge. Some people with epilepsy have poor adherence to standardized treatment with anti-epileptic drugs (AEDs), and monitor plasma concentration and adverse events regularly. Most people with epilepsy think that it is inconvenient to see doctors because of long waiting times and traffic problems. Another main reason

is that they worry about recurrent seizures and medical costs. The key problem is not the gap between provinces, but the gap between urban and rural areas. For people with epilepsy living in urban areas, accessing efficient AEDs is their most important requirement, while for those living in rural areas, accurate diagnosis and cheap AEDs are their basic needs. Thus, the goal of epilepsy management is to ensure that people with epilepsy remain as free from seizures as possible with efficient but cheap AEDs and with treatment side effects minimized. To achieve this goal, training of primary care physicians to improve diagnosis and treatment skills is a first priority.

Epilepsy has been in a culturally challenging condition throughout Chinese history. People with epilepsy receive unfair treatment or face discrimination, and often experience severe mental stress due to stigma. Most are reluctant to open themselves to education, employment and marriage, mostly due to a lack of relevant epilepsy knowledge and the negative impacts of traditional customs or superstitious ideas. Therefore, public education on epilepsy should be as important as the care of people with epilepsy themselves. It requires us to make strategic plans in terms of subgroups of the population, for example, children, students, teachers, farmers, doctors, social workers, etc. This is a tough task that needs our continuous and long-term efforts.

Finally, to quote a very famous Chinese proverb: “a journey of a thousand miles begins with single step”. We believe that epilepsy care in China will improve with the contributions and efforts of all related domestic and international organizations, institutions and warm-hearted people. People with epilepsy should and could enjoy their life in China!

CONGRATULATIONS! IBE Vice President awarded Michael Prize

IBE sends warm congratulations to Dr Ding Ding, China on her selection to receive the Michael Prize 2013.

The Board of Trustees of the Michael Foundation, on the recommendation of the judging committee, unanimously decided to award Dr Ding, PhD, MPH, MD from Fu Dan University in Shanghai, China. Dr Ding is incoming IBE Vice President Western Pacific and will begin her term of office at the General Assembly on Wednesday 26th June.

Dr Ding is currently a member of the IBE Research Task Force and has been a champion to the Seahorse Club in Shanghai, a self-help group of people with epilepsy. With Dr Ding's support, the Seahorse Club created an Artists Studio, with support from the IBE Promising Strategies Program, which has

provided a successful outlet for people with epilepsy to enjoy handcrafts while sharing their experiences of living with epilepsy.

Since 1963, the Michael Foundation awards the Michael Prize biennially, which is presented at the International Epilepsy Congress. It is one of the most prestigious international awards and is given for the best contribution to the promotion of scientific and clinical epilepsy research.

The prize will be officially awarded at the Opening Ceremony of the International Epilepsy Congress in Montreal on Sunday 23 June, 2013; the traditional Michael Lecture will be given by Dr Ding - on Monday 24th June at the Prize Symposium from 16:30 - 17:30 hours.



EPPY

the smartphone app for people with epilepsy

The Dutch Epilepsy Foundation has recently developed a new smartphone app, called “Eppy”, in collaboration with Kempenhaeghe Epilepsy Centre and the pharmaceutical company GlaxoSmithKline, which is specially designed for people with epilepsy.

Control

“Eppy” aims at helping people to have more control over their epilepsy. Users can keep track of their seizures and of the factors they think contribute to their seizures, such as stress or fatigue. It works everywhere and at all times. Medication schedules can be uploaded and the user will receive a reminder when it is time to take medication or when it is time to pick up a prescription up at the pharmacy. “Eppy” also enables the user to make detailed

reports on epilepsy related events over a certain period of time, which helps prepare for visits to the doctor. It is even possible to allow the doctor access to this information. But “Eppy” delivers even more!

Special function

“Eppy” has an alarm function specifically designed for people who know when they are about to have a seizure. An alarm button can be pushed, after which a message appears instructing bystanders on what to do or whom to call. They can call the persons the user has indicated. A user may give another person permission to temporarily keep track of his or her location. Parents or friends are able to identify user's whereabouts on their computer. This gives a feeling of security to the person with epilepsy who, otherwise,

might be anxious when going out alone.

Interested?

“Eppy” is available in European app stores and can be downloaded for free. Both Dutch and English versions are available. There is also animation video available on www.epilepsiefonds.nl/eppy/animation that explains what “Eppy” can do for people with epilepsy.

The Dutch Epilepsy Foundation would like to contact organisations that are interested in Eppy or other educational materials. The foundation has a broad range of materials that vary from basic information on all topics related to epilepsy, to DVD's and lesson plans for schools. It is also considering translating its materials into other languages if demand is there.

Contact: boer@epilepsiefonds.nl



REGIONAL EXECUTIVE COMMITTEES

2013-2017

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In addition to the three elected positions of Chair, Vice Chair and Secretary, the European Regional Committee, with in excess of 50 Full and Associate Members (more than twice the number than in any other region) has two additional elected Members on its Regional Executive Committee.

Meet IBE's Regional Executive Committees!

In addition to its International Executive Committee, IBE has seven regional committees, representing members in those regions.



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WESTERN
PACIFIC

Highlights from the third European Epilepsy Day

Organised by Epilepsy Advocacy Europe - the joint task force of IBE and ILAE and celebrated by epilepsy associations across Europe



To mark European Epilepsy Day, the Dutch Epilepsy Foundation, Dutch League Against Epilepsy, and epilepsy centres SEIN and Kempenhaeghe had the chance to sound the gong that heralds the daily start of trading at the Amsterdam Stock Exchange. This also provided the opportunity to highlight the impact of the disease on those affected by it. Miryanna van Reeden, actress and ambassador for the Dutch Epilepsy Foundation, had the honour to sound the gong on behalf of the organizations. Speaking at the event, Miryanna said "What I find so devastating is the unpredictability of the disease. People who have epilepsy can have a seizure at any time. This has a huge affect on their daily lives, and I find it heart rendering. One would think that modern medicine could find a solution for this. The fight against epilepsy deserves more attention.



As a special event to highlight European Epilepsy Day, the Serbian association - Doctors for Support - collaborated with its partners to stage a play called "Charms of the Forest" to entertain children attending the Clinic for Neurology and Psychiatry and invited guests.

Educational materials were handed out in addition to treats such as bags of sweets, soft drinks and balloons.

Over 100 people, including children who suffer from epilepsy, their parents, medical professionals and epilepsy supporters gathered in the Clinic's Amphitheatre at the Epilepsy Association to enjoy the performance.



NORWAY

In Norway, European Epilepsy Day 2013 was marked in Oslo by the opening of an outdoor photo exhibition. The exhibition ran for two weeks, and featured the best 30 entries from the photo contest "epilepsi - uten ord" ("Epilepsy - Without Words"), which the association organised last year.

On European Epilepsy Day itself, the association used teams of actors to attract public attention by performing seizures in public places. There was also a competition for visitors to the exhibition; the winning prize being one of the photographs.

Pictured left, are some of the images from the exhibition, on white display boards that stand out against the dark 'grey light' of a Norwegian winter's day.

EUROPEAN PARLIAMENT BRUSSELS



EED 2013 in the European Parliament (from left): Jim Higgins MEP, Francisco José Millán Mon MEP, Filip Kaczmarek MEP, Gay Mitchell MEP, Anna Záborská MEP, Veronika Mitykó, a young Hungarian gymnast who has epilepsy; Pat The Cope Gallagher MEP; Sean Kelly MEP; Kristzina Danczik (mother of Veronika) and Judit Jerney, President of the Hungarian Epilepsy League.

The Rose of Tralee 2012, a long running annual Irish pageant that takes its name from a traditional song, gets a kiss from a young wellwisher at the launch of Epilepsy Ireland's Valentine Rose appeal.

European Epilepsy Day was also used by the association as the perfect time to announce its rebranding from Brainwave to the more recognisable Epilepsy Ireland.



Local chapters of Epilepsialiitto organised awareness events in public areas

finland

Epilepsy and Employment was the European Epilepsy Day slogan of the Finnish Epilepsy Association - Epilepsialiitto. The association had numerous activities organised, including video interviews with people with epilepsy, and a national education day for healthcare professionals, employment agencies and pension insurance companies.

European Epilepsy Day started with a road show, in which the local chapters of Epilepsialiitto organised awareness events in public areas, such as cafes and local markets, where information and advice on epilepsy issues were provided.

These events and activities will continue to be held throughout the year around the country: in the capital Helsinki, along Baltic Sea coast, north to Lapland, and across arctic villages. These public platforms will be open to everyone and the association is actively recruiting new volunteers become involved.



THE HISTORY OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY



ESTABLISHED 1909

Part Five: 1965-1973: Separation Anxiety

As discussed in Part 4 (Issue 3-2012) the establishment of IBE, initially as the social arm of ILAE but, by 1967, as an independent organisation with its own constitution, was approved by the 1961-1965 Executive of ILAE. The 1965-1969 Executive was elected at the ILAE AGM during its quadrennial meeting in Vienna in 1965 in conjunction, as usual, with the International Congress of Neurology, the first Congress I ever attended. The new President was Albert M Lorentz de Haas from the Netherlands, but sadly he died in 1967 and was succeeded briefly by Jerome K Merlis (USA). Henri Gastaut (France) was now in his third term as Secretary-General and became an increasingly influential figure in the ILAE.

Gastaut was the prime mover in trying to bring some order and global consistency into the definition and classification of seizures and epilepsies. Beginning with an International Symposium in Marseilles in 1964, a draft international classification of seizures was the main scientific theme for a joint session of the ILAE together with the Congresses of Neurology and Encephalography in Vienna a year later.

Gastaut now sought formal approval of the

ILAE by establishing the first ever ILAE Commission on Terminology and Classification to finalise the proposals and obtain the approval of the ILAE Executive and AGM. The ILAE Clinical and Electroencephalographic Classification of Seizures was published in *Epilepsia* in 1970.

This and its revised form in *Epilepsia* in 1981 have been among the most influential of ILAE activities and publications. Successive ILAE Commissions in 1985 and 1989 published initial and revised ILAE proposals for the more difficult and still ongoing task of the Classification of Epilepsies and Epileptic Syndromes.

Gastaut was finally elected President together with the 1969-1973 Executive at the ILAE Annual General Meeting (AGM) in conjunction with the Congresses of Neurology and Neurosurgery in New York in September 1969. Including his four years as Past-President from 1973 to 1977, he eventually became the League's longest ever serving Officer from 1953 to 1977 i.e. 24 years.

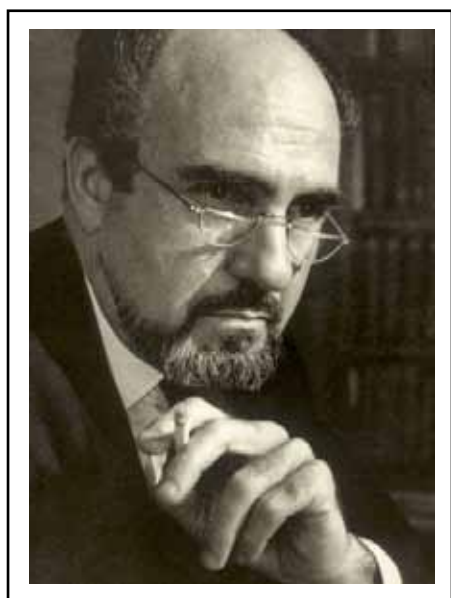
The new Secretary General was Otto Magnus from the Netherlands. Magnus *Henri Gastaut (1915-1995) from France, the longest serving officer in the History of ILAE, i.e. 24 years from 1953-1977.*

had agreed to edit *Epilepsia* on the death in 1967 of his fellow countryman, Lorentz de Haas, who had continued as Editor while he was President, as had Lennox in the past. With Magnus now Secretary General, Margaret Lennox-Buchthal from Denmark became Editor.

This Executive, with several strong personalities, did not function well and Magnus eventually resigned a year early in 1972.

There were several sources of tension. At the time, the Executive mainly concentrated on its scientific meetings and on *Epilepsia*. Magnus was motivated to bring the League to developing countries. Lennox-Buchthal and Magnus disagreed over the performance of Elsevier, the Dutch publishers of *Epilepsia*. David Daly (USA), in his second term as Treasurer, wished to exert more control over the League's finances. He objected to others, such as Magnus, raising money from generous Dutch sources for League purposes without more accountability.

The League, however, had limited resources of its own, not least because of poor communication with its Chapters, many of whom failed to pay their dues. In addition to the 19 countries listed in part 4 in this series, five new Chapters had





*Albert M Lorentz de Haas (1911-1967).
The only President of ILAE to die during his
Presidency*

been added by 1973 i.e. Czechoslovakia, Denmark, Norway, Portugal and Spain, making a total now of 24.

In the meanwhile, there had also been ambiguities and tensions over the relationship between the ILAE and IBE which had become an independent organisation in 1967. Some had objected to IBE appointing medical doctors to their Executive, which they felt confused and undermined the objectives of the separation.

However, in Europe ILAE and IBE began to work well together in establishing joint scientific and social conferences, firstly in Paris in 1967 and then in Dunblane, Scotland, in 1968, where I first met Harry Meinardi.

After the 1969 International Congress in New York these European Conferences continued in Marienlyst (1970), Amsterdam (1971) and London (1972). At the International Congress in Barcelona, in 1973, the relationship of ILAE and IBE was set on firmer and clearer foundations

by the establishment in the new 1973 Constitution of the ILAE of interlocking Executive Committees, with the President and Secretary-General of each organisation serving on the Board of the other.

This however also set the stage for a soon to be proposed re-integration of ILAE and IBE within just a decade of their separation! This will be the subject of the next instalment.

References:

1. Shorvon S, Weiss G, Avanzini G, Engel J, Meinardi H, Moshé S, Reynolds E, Wolf P. International League against Epilepsy 1909-2009: A Centenary History. Chichester, Wiley-Blackwell 2009.
2. Commission on Classification and Terminology of the International League against Epilepsy. Proposal for revised clinical and electroencephalographic classification of epileptic seizures. *Epilepsia* 1981; 22; 489-501.

March is Epilepsy Awareness Month in Hong Kong and throughout the month Enlighten-Action for Epilepsy engaged with the public in various ways to demystify the condition and eliminate the pervading myths and misconceptions in Hong Kong.

“If we want to improve the quality of lives of people with epilepsy, building awareness is the key,” said Claudia Schlesinger, co-founder and CEO of Enlighten-Action for Epilepsy.

Grand Hyatt Hong Kong’s 3D cake made in the image of Enlighten’s new soft toy - Ellie the Epiphant - caught the eyes of many, encouraging them to read about the campaign.

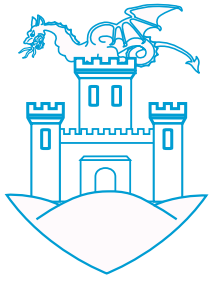
The entire Hong Kong community joined forces to show support. At the Lantau Beer Dash, a local charity run, we had a team of supporters running in purple wigs and tutus, and a long-standing volunteer hosted ‘Bill’s Bash’ on Lamma Island.

One of Enlighten’s supporters, Paul Niel, set off on a 9 week expedition to climb Mount Everest and Lhotse and decided to raise money for Enlighten. Thanks to Paul, the epilepsy awareness message will reach the summit of the tallest mountain in the world!

Enlighten-Action for Epilepsy is amazed at the support and success of the campaign and looks forward to planning next year’s activities.



**ELLIE the Epiphant
and a trunkful of
events in Hong Kong!**



13TH EUROPEAN CONFERENCE ON

Epilepsy & Society

LJUBLJANA, SLOVENIA

28TH - 30TH AUGUST 2013



Break down the barriers and Stand up for Epilepsy

With the European Conference on Epilepsy & Society 2013 now just a few months away, some deadlines are fast approaching so don't miss out!

Bursaries

A limited number of bursaries are available, granted on the basis of a written submission. Closing date is 8th July.

Advocates for Epilepsy Workshop

This is an exciting new workshop concept, designed to raise awareness and improve patient care through collaborative practice. The workshop will take place on the 28th of August, prior to the main programme

of 28th – 30th of August, 2013.

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

Poster Submission

Have you something interesting to share? Consider submitting a poster discussing social aspects of epilepsy, or detailing the work of your national member association. Special emphasis is being placed on posters and you are encouraged to prepare and submit your latest



work by the deadline of Monday 8th July.

Further information on the conference programme, and other activities, is available at www.epilepsyandsociety.org.



IBE in KUALA LUMPER

Incoming IBE Treasurer, Robert Cole (pictured far left) and Executive Director Ann Little were delighted to have the opportunity meet with members of the Malaysian Society of Epilepsy in Kuala Lumpur in March. The Society is the IBE member association in Malaysia.

Pictured middle of the photo is Rosalind Chee, the association's Secretary. Magrette Selvy is second from right and Kheng Seang Lim is pictured far right.

News from Russia

Prof Voronkova Kira, Vice President of the *Association of Doctors-Epileptologists and Patients* in Russia wrote to tell us about a recent all-Russian Conference organised by the association, which took place in St Petersburg. The meeting centred on the psychiatric problems experienced by some people with epilepsy. The photo, right, shows a section of the audience at the conference.

Epilepsy information and advice is also provided to people with epilepsy in Moscow, St Petersburg, Siberia and in other regions of the Russian Federation.

The association, which works closely with the IBE Full Member in Russia, has applied for IBE Associate Membership and IBE hopes that the ratification process will be completed prior to the congress in Montreal.



2013 MONTREAL

23rd - 27th JUNE, 2013

30th INTERNATIONAL EPILEPSY CONGRESS



FOR YOUR MONTREAL DIARY!



IBE General Assembly

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



The Traveller's Handbook

For people with epilepsy

Several years ago, the IBE Travel Commission developed an **Epilepsy Passport**, published to resemble a regular travel passport, which was full of tips, precautions and information for people with epilepsy who were travelling abroad. The booklet had information in a number of languages and proved to be extremely popular and was much requested. In more recent years, a follow up

Traveller's Handbook was introduced, supported by UCB Pharma and, once again, there was huge demand for the publication. Now that we are well ensconced in the electronic age, it makes sense to update the document to an electronic only production, which IBE has done, thanks again to the provision of an educational grant from UCB. The **Traveller's Handbook** CD, which

has information in no fewer than 20 languages, can be downloaded onto a Smartphone or can be accessed on a computer. To get a copy of the CD, visit the IBE booth in the Exhibition Area at the congress. For those of you not with us in Montreal, you can download the material from a newly developed dedicated webpage: www.ibe-travelhandbook.org

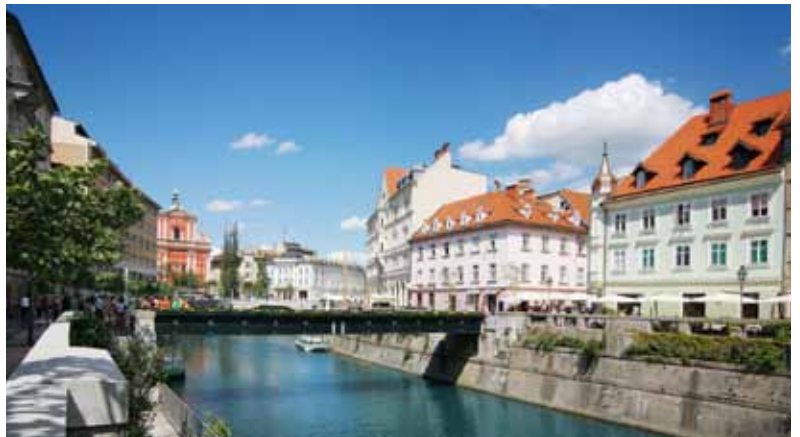
FUTURE CONGRESSES

**13th European Conference
on Epilepsy & Society**

LJUBLJANA, SLOVENIA

28th - 30th August 2013

www.epilepsyandsociety.org



**10th Asian Oceanian
Epilepsy Congress**

SINGAPORE

24th – 27th August 2014

Website coming soon



Just announced!

**31st International
Epilepsy Congress**

ISTANBUL, TURKEY

6th - 10th September 2015



Latest News!

**2nd African Epilepsy
Congress**

SOUTH AFRICA

More details coming soon!



Congress Secretariat: 7 Priory Hall, Stillorgan, Dublin 18, Ireland
Telephone: ++353-1-20-567-20 Email: info@epilepsycongress.org

www.epilepsycongress.org