



# Editors Network Meeting

International Bureau for Epilepsy

## 2013 MONTREAL

23<sup>rd</sup> - 27<sup>th</sup> JUNE, 2013

30<sup>th</sup> INTERNATIONAL EPILEPSY CONGRESS



## MINUTES OF MEETING

30<sup>th</sup> International Epilepsy Congress  
Montreal, CANADA  
24 June 2013

<http://www.epilepsymontreal2013.org>

## **CALLING ALL NEWSHOUNDS!**

### **IBE Editors Network Meeting**

**Monday 24th June 2013**

**Time: 11:30 - 13:00 Venue: Room 518A**



If you edit your association's magazine or newsletter, this is a great opportunity to network with editors from IBE member associations around the world. Do come along - we'd love to meet you!

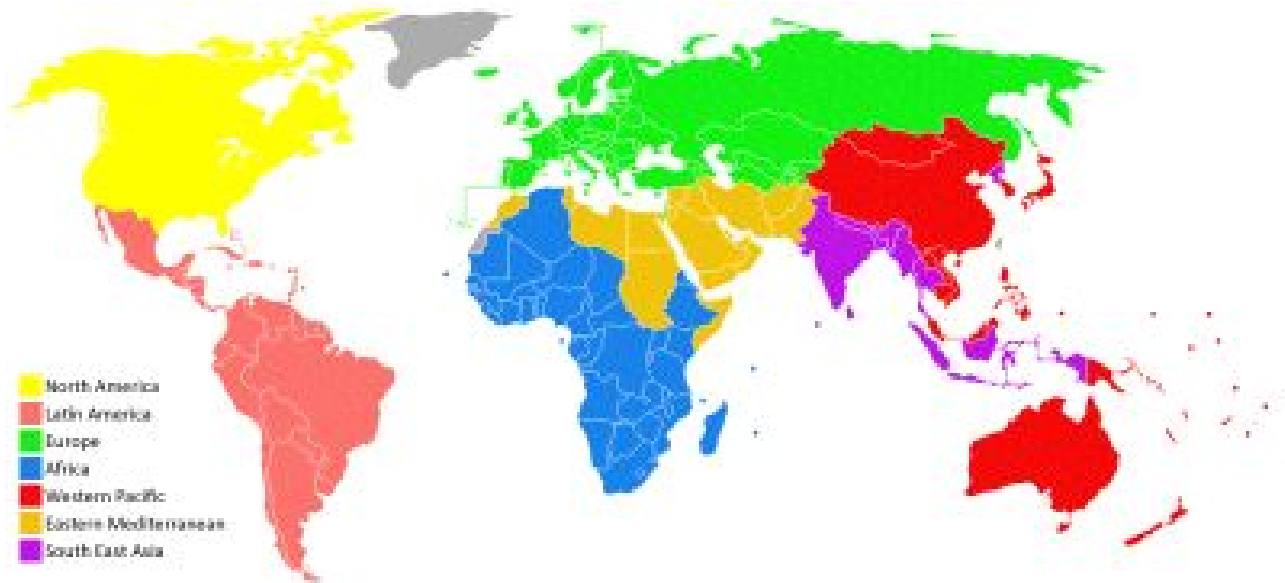
### **Welcome**

- The meeting commenced at 11.30am

### **The Chair welcomed attendees:**

- |     |                    |                                  |
|-----|--------------------|----------------------------------|
| 1.  | Robert Cole        | Australia, IBE Treasurer (Chair) |
| 2.  | Ann Little         | Ireland, IBE Executive Director  |
| 3.  | Dr Hidemoto Kubota | Japan                            |
| 4.  | Michael Alexa      | Austria, EREC Vice Chair         |
| 5.  | Mike Glynn         | Ireland, outgoing IBE President  |
| 6.  | Peter Murphy       | Ireland                          |
| 7.  | Frank Gouveia      | New Zealand, WPREC Vice Chair    |
| 8.  | Dr Kheng-Seang Lim | Malaysia                         |
| 9.  | Anthony Zimba      | Africa AREC Vice Chair           |
| 10. | Sari Tervonen      | Finland, IBE Secretary General   |
| 11. | Nikki Porter       | Canada                           |
| 12. | Shuistu Harada     | Japan                            |
| 13. | Akiko Okada        | Japan                            |
| 14. | Rosey Panelli      | Australia, Chair IBE Task Force  |

## Member Activity Reports (around the table)



### Austria

- Michael Alexa, Austrian IBE Member Association, has been re-elected after four years as the Vice Chair, European Regional Executive Committee
- The EPIFocus newsletter is a publication of the European Regional Committee. It is circulated electronically to IBE members in Europe and is also available on the IBE website. The aim of the magazine is to encourage members in Europe to submit information about their activities and to promote activities of the European Regional Committee. Michael has gathered content when he acted as Secretary previously and will now assist their new Secretary, Dr Ljubica Vrba (Slovenia) to gather the content. The layout and design are done by Ann Little at the IBE office. Five issues have been produced to date
- ZAK, the newsletter of the Austrian association, is provided free of charge to patients and distributed at training sessions. People can subscribe on their website home page to receive summaries  
The Austrian Epilepsy Association website includes scientific articles, community articles, results of surgery and reports on conferences in its newsletter ZAK. You find selected articles online:  
[http://www.epilepsie.at/php/zeitschrift\\_fuer\\_anfallkranke\\_27,13896.html](http://www.epilepsie.at/php/zeitschrift_fuer_anfallkranke_27,13896.html)

### Africa

- Anthony Zimba, IBE Vice President, Africa Region and also representing Zambia stated that one newsletter was produced by the IBE African Regional Committee whose editor is their former executive committee member, Jacob Mukubate based in Zimbabwe. The other two newsletters were produced by the Epilepsy Association of Zambia and the editor is Betty B Nsachilwa who is their Association Secretary. The regional newsletters were posted on the IBE website

- The Epilepsy Association newsletter was printed in hard copy only
- They have established a new member association in Malawi
- They have held their first African Congress in Nairobi and will hold the second in Cape Town in 2014
- They are still constructing their website

### Japan

- Dr Kubota, Vice President of the Japan Epilepsy Association Inc. (JEA) advised that they continue to provide services and issue 7,000 – 8,000 copies of their newsletter quarterly and also produce an electronic version which is available on their website: <http://www.jea-net.jp>
- In April 2011 six children died as a result of a car accident caused by the driver who had a seizure. He received seven years gaol for carelessness. He also revealed that he had caused another accident previously. A petition of 150,000 names was submitted to the Chairman of the National Public Safety Commission which saw the Japanese Government amend their Traffic Act with a penalty of US\$300,000 or one year in gaol
- JEA lobbied to successfully bring about this change but the media coverage caused negative fears and drew attention to epilepsy in a negative way. The media created hatred against epilepsy and misled the public. There is no evidence that the car accident rate is higher with people living with epilepsy
- Counselling is key to raise awareness and responsibility

### Malaysia

- Dr Kheng Seang Lim advised that websites are often hacked with spam messages so they closed it. Facebook allows much easier communication with clients
- He recommends holding a forum on Facebook The Forum forms a trail of comments including driving licence issues
- Information is easy to share using different languages
- Newsletters enable relevant local issues to be added. They have no website and 40 – 50% of people don't have the internet or use it, and prefer information in hard copy

### Canada

- Dr Nikki Porter from the Canadian Epilepsy Support Centre advised that they represent and assist epilepsy associations to produce newsletters biennially, which are also on their website. She writes specialty articles for publication. They inform by using Facebook and Twitter promoting upcoming events
- They are still working out how to manage conversations on Twitter
- They have a close relationship with the epilepsy unit in London Healthsciences centre  
[www.epilepsysupport.ca](http://www.epilepsysupport.ca)

## Ireland

- Peter Murphy advised that Brainwave has changed its name to Epilepsy Ireland to better describe what they do using this new name. This change was to get epilepsy more prominent and they launched the name change to coincide with European Epilepsy Day in February. Advertising was executed and they conducted text fundraising. Their 1,000 study gained media coverage and focused on the epilepsy myths
- They received good exposure on Ireland's popular Friday night chat show, the Late Late Show when Warren Gatland and Rick O'Shea (Irish radio presenter) talked about epilepsy. Gatland has a son with difficult epilepsy and Rick O'Shea is a person living with epilepsy
- They have generated an awareness campaign on generics because their Government is trying to introduce automatic generic substitution
- Their website was redone for the name-change and is an important communication tool. They are focusing on using videos to communicate and advise on generic substitution and other issues. They have so far signed up 100 "media volunteers" who are willing to share their stories in the media. [www.epilepsy.ie](http://www.epilepsy.ie)

## New Zealand

- Frank Gouveia, Vice Chair, Western Pacific Regional Executive Committee advised that his organisation has recently spent a lot of time on internal cleansing and dealing with politics. They have reopened communication lines with great success. He produces an electronic newsletter and reprints at a cost of NZ\$27,000 to NZ\$30,000 per annum. Printed newsletters are better because the life expectancy is greater. They use Facebook but not Twitter because it is not popular in New Zealand. They research other epilepsy websites to get content
- He has adopted the US "Talk About it Campaign" on prime time television and gained free to air spots very successfully for their November campaign
- They are moving more towards electronic communication with a social content and looking at smart phone apps. Their Newsletter is more social than clinical. They have updated their website to incorporate the colour purple. [www.epilepsy.org.nz](http://www.epilepsy.org.nz)

## Finland

- Sari Tervonen, IBE Secretary General detailed that the Finnish Epilepsy Association produces a popular magazine and have internet discussion groups and are developing internet services
- They are changing the way that they work with volunteers because it is very challenging working with them at a local level, particularly with those that have refractory epilepsy
- They have recruited people living with epilepsy to tell their stories and to describe their own feelings. They offer this to magazines and sometimes people with epilepsy are interviewed and an epilepsy expert is also invited
- They have obtained free air time on national TV recently



- They are airing short 20 second stories that are presented in a humorous way by an actress which is appealing to the audience. They need to be more promotionally minded to increase epilepsy awareness
- The electronic media is challenging  
[www.epilepsia.fi](http://www.epilepsia.fi)

### **IBE**

- Ann Little, IBE Executive Director stated that the new website has been operating since our Rome Congress. It has new features and video clips. They use Facebook and Twitter but Twitter is less popular
- The IBE publishes International Epilepsy News quarterly which is distributed to 130 countries. They send out Facebook updates to direct traffic to the website
- They survey members and the site contains a password protected “Members only” section. There are sections on all Commissions and the IBE Editors Network. Ann Little requested photos and short stories  
[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

### **Australia**

- The Joint Epilepsy Council of Australia and Epilepsy Australia produce The Epilepsy Report which is published twice yearly
- They are using social media and sourcing content
- The South Australian Purple Day in the Park Walk was hugely successful with over 14,000 Facebook shares  
<http://www.epilepsyaustralia.net>

### **How can we increase our Social Media presence?**

- Considerable discussion took place.  
Frank Gouveia suggested that Facebook will never replace newsletters. Gathering “Likes” is a slow process and it took 14 months to gain their first 1,000 members but the second 1,000 joined in four months. Competitions and give-aways attract members to Social Media sites which can be linked to competition sites. Our sites must be promoted and marketed
- Rosey Panelli stated that Social Media can be linked to articles eg. EpiTed and SUDEP. Share a link to the page on your own website and it works better with a colourful photo. Some articles and posts can go “viral” which results in incredible reach
- Michael Alexa recommended linking social media sites to each other including our members sites to automatically increase reach
- Dr Kheng Seang Lim stated that while English is the standard language, translations of useful information in IBE website should be provided in local languages with the help of local chapters, although accurate translations can be difficult to achieve. Permission needs to be gained to translate articles into local languages.

- SUDEP, the Global Conversation has its own Facebook page and should be linked to the IBE website. SUDEP is a good article for IE News
- It was suggested to create a list of all links and to list them on the IBE website
- Articles from International Epilepsy News can be published on Facebook
- Dr Nikki Porter stated that Social Media can be used to create a page to support newly diagnosed people via conversation groups to connect these members
- It was also suggested to recruit Editors to translate scientific articles
- Considerable discussion took place on translating articles. Ann Little stated that IBE had articles translated into other languages. It was noted that the IBE Travellers Handbook was printed in other languages
- Frank Gouveia asked if we are a translation support group? In our countries there are a number of Asian people requesting information in their languages. Is there a way we can set up a way to share resources?
- On Facebook the Taiwan Epilepsy Association articles come with a translation button which converts to relatively good English
- Sari Tervonen suggested sharing small stories with links. Articles must be short, entertaining, touching and easy to read
- Ann Little suggested creating a repository on the IBE website in PDF format in other languages with acknowledgement of the source

## IBE'S SOCIAL MEDIA

Social media is a recent arrival  
to our communications network  
- so it's still all new and exciting!



Find us on FACEBOOK



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 Tweet us on Twitter!  
@IBESocialMedia

Visit us at  
[WWW.IBE-EPILEPSY.ORG](http://WWW.IBE-EPILEPSY.ORG)



## How can we source content for IE News, IBE Website & Newsletters?

- A short discussion took place on the need to source good content and to share with other Editors

## How can we report the 30<sup>th</sup> International Epilepsy Congress – Montreal?

- The chair requested that all members report this Montreal Congress on their websites, newsletters and other publications
- He suggested reporting on the Michael Prize which was awarded to Professor Ding Ding from China
- He also requested the 10<sup>th</sup> Asian & Epilepsy Congress be promoted with electronic links provided as well as the IBE website and the European Conference on Epilepsy & Society Congress in Ljubljana 28-30 August 2013. <http://www.epilepsyandsociety.org/>

## Next Meeting (face to face) 10<sup>th</sup> AOEC, 24-27 August, Singapore 2014

- The next face to face meeting will be held at the 10<sup>th</sup> AOEC, 24-27 August, Singapore 2014  
<http://www.epilepsysingapore2014.org>



*“IBE has a vision of the world where ignorance and fear about epilepsy are replaced by understanding and care”.*



[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

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