



Editors Network Meeting

International Bureau for Epilepsy



SMX CONVENTION CENTER



MINUTES OF MEETING

9th Asian & Oceanian Epilepsy Congress
Manila, PHILIPPINES
22 March 2012

<http://www.epilepsymanila2012.org>

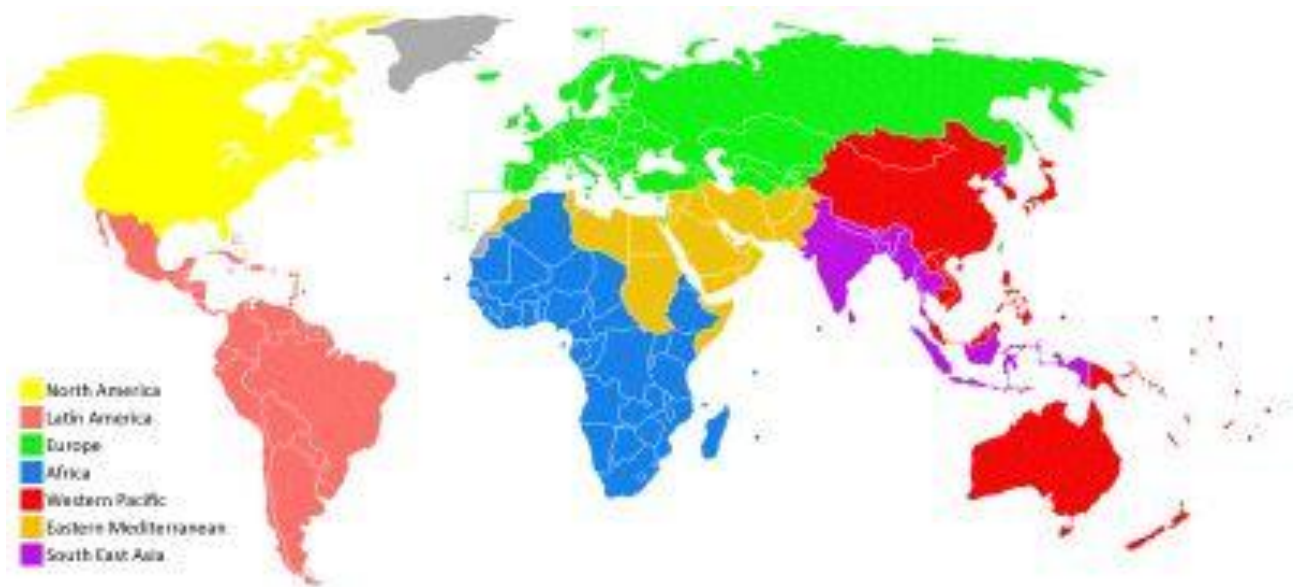
Item 1: Welcome

- The meeting commenced at 11.00am in the IBE President's Boardroom

The Chair welcomed attendees:

1.	Robert Cole	Australia (Chair)
2.	Ann Little	IBE Executive Director
3.	Dr H Kubota	Japan
4.	Dr Shung-Lon Lai	Taiwan
5.	Dr Yuan-Fu Tseng	Taiwan
6.	Michael Alexa	Austria
7.	Professor Ding Ding	China
8.	Mike Glynn	IBE President - Ireland
9.	Jeannie Khonghun	Philippines
10.	Carmella Pajarillo	Philippines
11.	Mary Margaret Colayco	Philippines
12.	Ariel M Oamil	Philippines
13.	Carlos Acevedo	Chile
14.	Denise Chapman	Australia

Item 2: Member Activity Reports (around the table)



Japan

- Dr Kubota, Vice President of the Japan Epilepsy Association Inc. advised that they have established consultation booths and a display centre at a major Railway Station in Japan. They encourage patients to speak to the public and tell their stories. The consultation booths are staffed by volunteers monthly on Sundays. They display the giant “Akaira” logo Enlightenment 6.

They post newsletters to members. They collected US\$7 million in donations for the Tsunami and earthquake appeal.

They are conducting a survey on AED’s which will be finalised in April
<http://www.jea-net.jp>

Taiwan

- Dr Yuan-Fu Tseng of the Taiwan Epilepsy Association reported that they produce their newsletter monthly and it contains details of the activities of people living with epilepsy. Their Facebook page with over 350 friends is functioning well and a friends group has been formed. Dr Tseng highlighted the need for accuracy on the internet. Often people publish facts which are incorrect or misleading. There is no way to control; what people write but it is a concern as Facebook and the internet grow in popularity.

Dr Shung-Lon Lai, IBE Vice President, advised that some chapters are using their own languages to communicate with stakeholders. Websites are in English which poses a problem because the translation tools are not good. Facebook causes issues too and is not available in China. <http://www.epilepsyorg.org.tw>

Ireland

- Mike Glynn advised that Brainwave, The Irish Epilepsy Association publishes their Epilepsy News in hard copy and electronically.
- They are expanding the social media and setting up Social Groups online which will operate as a type of online support group network which will commence in the Autumn after launching at their national conference.

Brainwave uses radio to create awareness of the burden of epilepsy and reduce stigma as well as to direct traffic to their website.

Brainwave received free newspaper full page advertising worth 100,000 Euros and also spent some 35,000 Euros on radio advertising during the fortnight around European Epilepsy Day 2012 in February.

www.epilepsy.ie

Chile

- Carlos Acevedo, IBE Secretary General advised that as Editor of International Epilepsy News, he is informing all the IBE Chapters of achievements in their countries as well as regional and international congresses.

He also reports relevant articles, activities and interviews. The IE News is easy to read and also conveys IBE and ILAE history and progress. Fortunately there are now more articles than can be printed. Sourcing information has been a problem in the past but this has now changed.

Ann Little, IBE Executive Director stated that they now have many articles to choose from and the IBE Jubilee and the International Epilepsy Congress in Rome provided a lot of information. The IE News is also available electronically

<http://www.ligaepilepsia.cl>

China

- Professor Ding Ding advised some exciting news. China has now opened two new patient centres in Beijing (for children) and Shanghai (for adults) which are supported by UCB.

They have good coordination which has enabled this to happen and have rented space.

The centre of adults with epilepsy was supported by the Shanghai Local Government and is open every Saturday on a two months trial.

Their opening ceremony for International Epilepsy Day on 28 June was a big achievement and was based on art and craft.

They participated the project of "Stand up for Epilepsy" and submitted the photo: the most successful Chinese amateur boxer with people with epilepsy

All the patients who participate in the Seahorse Club program are very happy.

Their newsletter is routinely published.

There is no Facebook in China so micro blogs are widely used.

The Seahorse Club has a micro blog which is excellent for young patients and those with iPhone access.

Older people are not familiar with technology and therefore hardcopy information is still the preferred information channel.

The UCB website, <http://www.livebeyondepilepsy.com/home> has a Chinese version and links to other websites.

http://www.epilepsy.com/epilepsy/sudep_china

<http://www.caae.org.cn>

Philippines

- Jeannie Khonghun was joined by three officers: Carmella Pajarillo, Mary Margaret Colayco and Ariel M Oamil. She and advised that their Facebook page is fast growing, particularly with younger people. They produce hard copy newsletter because older people do not have computers or cell phones.

They partner strongly with hospitals and the Philippine League Against Epilepsy. Through the doctors they reach patients. They have experienced a big increase in membership and their numbers are still growing.

They hold an annual Epilepsy Conference in Pampanga. There are 18 chapters in the Philippines and there are many small islands which are difficult to reach and to engage with patients

Austria

- Michael Alexa presented his EPI Focus newsletter which is very comprehensive.

The Austrian Epilepsy Association newsletter includes scientific articles, community articles, results of surgery and reports on conferences in its newsletter ZAK. You find selected articles online i.e. http://www.epilepsie.at/php/zeitschrift_fuer_anfallkranke_27,13896.html but not the whole ZAK!

Australia

- The Joint Epilepsy Council of Australia and Epilepsy Australia produce The Epilepsy Report which is published twice yearly <http://www.epilepsyaustralia.net>

Item 3: Social Media discussion

- Considerable discussion took place.
Mike Glynn stated that Facebook is used 24/7 by many young adults and has a large following. It is noted that it is impossible to monitor what is published.
Denise Chapman also stated that it is impossible to manage what is published and the accuracy of the content on epilepsy. Noted that you can send private messages but you cannot moderate it. Facebook is very time consuming and it would be a full time position to moderate your site.
Epilepsy Action UK had three people moderating their site at one time. Facebook has become too big to manage.
Michael Alexa commented on the Philippine newspaper article “Hide your Diseases”.

Jeannie Khonghun advised that they give students advice and tips at graduation. Discrimination in the workplace is still a major concern and they advise people what to say on their applications.

Ann Little suggested that more time be allocated to Editors Network meetings eg. 1.5 hours and that perhaps the reports could be sent in advance which would save time

Item 4: Sourcing content for IE News, IBE Website and Newsletters

- This item was noted but not discussed because of lack of time

Item 5: Reporting 9th AOEC, Manila

- The chair requested that all members report this Congress on their websites, newsletters and other publications

Item 6: Promoting 30th International Epilepsy Congress

- Robert encouraged members to heavily promote the forthcoming 30th International Epilepsy Congress, Montreal, Quebec, CANADA 23–27 June 2013

Item 7: Other business

Item 8: NEXT MEETING (face to face)

- The next face to face meeting will be held at the 30th International Epilepsy Congress, Montreal, Quebec, CANADA 23–27 June 2013
<http://www.epilepsymontreal2013.org>



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



www.ibe-epilepsy.org

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