



IBE Editors Network

International Bureau for Epilepsy



7th ASIAN & OCEANIAN EPILEPSY CONGRESS

Xiamen International Conference and Exhibition Centre

Xiamen, CHINA, 15-18 May 2008

www.epilepsyxiamen2008.org

MINUTES OF MEETING

**Saturday 17th May, 18.30 – 20.00hrs.
Meeting Room: 305 on Level 3 of the XICEC**

**In the Chair: Robert Cole
Minutes: Denise Chapman**



Front L to R: Ann Little, Jacinta Cummins, Denise Chapman, Anthony Zimba, Dr M M Mehndiratta, Robert Cole, Susanne Lund, Carol Ireland, Dr Vinod Saxena, Dr Allison Clarke and Dr Christine Walker

WELCOME

The Chair welcomed attendees:

1.	Susanne Lund	IBE President
2.	Ann Little	IBE Executive Director
3.	Dr Vinod Saxena	India
4.	Dr M M Mehndiratta	India
5.	Anthony Zimba	Zambia
6.	Dr Christine Walker	Australia
7.	Dr Allison Clarke	Australia
8.	Carol Ireland	Australia
9.	Denise Chapman	Australia
10.	Jacinta Cummins	Australia
11.	Robert Cole	Australia

MEMBER REPORTS (around the table)

Dr V Saxena

- Dr Saxena reported that he has produced four Epilepsy India Newsletters since our last meeting in Singapore
- These were both emailed and posted
- The Indian Epilepsy Association (IEA) is organised in Chapters and each is asked to contribute
- Dr Mehndiratta coordinates the ILAE/IBE information
- Costs are met partly from the IEA Trust Fund, from pharmaceutical companies and from paid advertising
- Only 25% of their members have access to the Internet
- This publication is also used to promote conferences, announcements and meetings
- Forthcoming events are published well in advance
- Dr Saxena reported that Epilepsy India has been in existence for more than 30 years. IEA has improved the newsletter quality and now upload it to the website www.epilepsyindia.org.

Jacinta Cummins

- Jacinta Cummins reported that Epilepsy ACT uses the Epilepsy Report and inserts pages of information that are specific to the ACT
- They send out 300 magazines each time plus 150 are distributed to Federal Politicians

Carol Ireland

- Carol Ireland reported that Epilepsy Action produces a donor newsletter
- They publish the "360 Degrees" magazine to their broader client group including consumers and the acute care sector
- They co-brand a newsletter in Western Australia with the Epilepsy Association of Western Australia
- Their publications are on their website
- Permission is given to use their material
- Magazine has a distribution of 10,000 and publishes quarterly

Ann Little

- Ann Little reported that IBE's International Epilepsy News is published quarterly
- Each issue is now uploaded to the IBE website www.ibe-epilepsy.org. The current issue will be available on the Members Section, while previous issues are available to all visitors to the site
- Ann requested reports from all Associations to add to the information published in IE News
- There is a need to publish stories from all over the world
- The current survey had not had a high response from readers of the hard copy magazine, although a percentage of Members had responded to the questionnaire when it was circulated electronically.

Anthony Zimba

- Anthony Zimba reported that he has difficulty finding stories
- South Africa publications are very good, Namibia produces two issues per annum and Swaziland also produces a newsletter
- Zambia has just produced their first issue!
- They started with a calendar, information and fundraising
- They will improve this newsletter and their fact sheets
- They plan a Zambia conference next year which is a local initiative
- They aim to produce a newsletter every month

Susanne Lund

- Susanne Lund reported that The Swedish Epilepsy Association produces a 24 page national magazine which is distributed to 8,000 members
- MP's, doctors and health care workers are included in the distribution
- It consists of good news stories, articles, interviews and small news items etc.
- They circulate to 42 local branches in Sweden
- Members are satisfied with this national magazine
- It is now read more because of the local branch news
- Members pay a subscription and the national magazine is part of the membership benefit
- This highlights the need to have the Editors Network section of the IBE Website password protected to ensure that only editors have access
- Associations who provide members with a newsletter as part of their membership fee must ensure that their members rely on them to provide their newsletter

Denise Chapman

- Denise Chapman detailed the publication of "The Epilepsy Report"
- This is a national magazine produced by Epilepsy Australia which is a coalition of Epilepsy Associations from around Australia
- This magazine is also circulated internationally
- Distribution is 10,000
- Epilepsy Australia had developed a brand new comprehensive website: www.epilepsyaustralia.net
- It contains very detailed information, resource and links

- Editors Network members are urged to visit this site and to download the information for their use
- Denise Chapman can assist you further with additional information and can be contacted at: DChapman@epilepsyaustralia.net

Robert Cole

- Robert Cole reported that The Epilepsy Centre published their newsletter quarterly
- It is now in full colour
- The circulation is broad including to international colleagues
- The only epilepsy research team in South Australia, based at the Flinders Medical Centre, is now providing articles
- Communicating this information is vital to ensure that all epilepsy stakeholders are fully informed
- He noted that many charities in Australia are now ceasing to produce costly Annual Reports and opting to publish them on their websites instead
- Previous Editors Network discussions confirmed that there is still a need for both electronic and hard copy publications
- It is clear that many people still like hardcopy newsletters, however, over time as more consumers gain access to the internet, we will be able to convert to electronic publications

IBE WEBSITE DEVELOPMENT (Editors Network)

- Ann Little advised that the new IBE website was well established and that the Members and Editors Network sections were still being worked on.
- She stated that the Members Section was designed to be used for downloading forms, procedures, Constitution, dues forms, financial statements and summaries of Executive Committee Minutes.
- Members will be supplied with a password to access this section of the IBE Website.
- Members were asked to offer other suggestions that could be incorporated into this section.
- She noted that this section would experience high usage during elections.
- Ann also reported that access to the Editors Network is available through the link to Networks, which can be found towards the bottom of the right hand column on the Homepage.
- With regard to images on the site, the copyright issues are dealt with by an "Opt in/Opt out" box on the Dues Form, similar to the tick box on the Registration form
- Robert Cole raised the question of the Visitors Comment facility to establish traffic to the Editors Network which was originally suggested.
- Robert also raised the issue of data storage on the IBE site.
- Ann Little clarified that large files for download were uploaded to a separate ftp site, although photos were uploaded directly to www.ibe-epilepsy.org
- Robert Cole will provide some Rules of Usage which will be displayed on the opening page of the Editors Network

IBE WEBSITE FEEDBACK

- The new IBE website was now well established and in full use and members were pleased with its function and resources.
- Dr Mehndiratta advised that he is a strong supporter of electronic newsletters because of the time and cost savings involved in physical printing. He stated that Epilepsy India now had a large database available for electronic communication

EFFECTIVE COMMUNICATION

- Robert Cole sought determination of the effectiveness of the communication between Editors' Network members. It was noted that all were happy with email discussions and feedback.

ANY OTHER BUSINESS

- Anthony Zimba from Zambia promoted his association's DVD which was presented in Singapore. He stated that he has copies still available @ US\$30.

NEXT MEETING (face to face)

The next face to face meeting will be held at the 28th International Epilepsy Congress, Budapest, HUNGARY, June 28th – July 2nd 2009.

There was no other business and the meeting closed at 7.30 pm.



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



International Bureau for Epilepsy