



# Joint Meeting - Western Pacific Region & South East Asian Region

International Bureau for Epilepsy

2013 23<sup>rd</sup> - 27<sup>th</sup> JUNE, 2013  
**MONTREAL**  
30<sup>th</sup> INTERNATIONAL EPILEPSY CONGRESS



## **MINUTES OF MEETING**

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

<http://www.epilepsymontreal2013.org>

## Welcome to our two new Regional Executive Committees

- The meeting commenced at 2.30 pm

### The Chair welcomed attendees:

1.	Robert Cole	Australia (Co- Chair)
2.	Dr Hidemoto Kubota	Japan
3.	Dr Yuan-Fu Tseng	Taiwan
4.	Dr Hemav Rajbhandari	Nepal
5.	Dr M M Mehndiratta	India
6.	Frank Gouveia	New Zealand
7.	Dong Wei Wei	Taiwan
8.	Professor Ding Ding	China
9.	Dr Kheng Seang Lim	Malaysia

### Apologies:

Denise Chapman, Dr Srinivas

- The Co-Chair welcomed everybody and congratulated the two new Regional Executive Committees on their four year appointments

## Introductions and Member reports (around the table)



### South East Asian & Western Pacific Regions.

### **Nepal - Dr Hemav Rajbhandari**

- Nepal Epilepsy Association (NEA) has three Epilepsy centers, including one in Kathmandu serving more than 1500 epilepsy patients. NEA raises awareness about epilepsy and to provide holistic care to people living with epilepsy. NEA takes care of people living with epilepsy by distributing anti-epileptic drugs in subsidized rates and free to those patients who live under poverty
- NEA has produced a film which tells the true life story of “Juneli” a young girl who has epilepsy since her childhood, through her school years, to her wedding day and early married life. There are two different actors to play the part of Juneli, as she grows from a young child to a mature and beautiful young woman! According to Nepal Epilepsy Association
- Dr Mehndiratta congratulated Nepal and stated that this movie was very good. It is available on the Nepal Epilepsy website and on the IBE website and on YouTube:  
[http://www.youtube.com/watch?v=x2K96GQnjgU&feature=player\\_embedded](http://www.youtube.com/watch?v=x2K96GQnjgU&feature=player_embedded)
- Since Nepal is near to Singapore, NEA is planning to attend AOEC, Singapore with a big team

### **Japan - Dr Hidemoto Kubota**

- Their members are down from 7,500 to 5,000
- They have the power to influence politics
- A Constitutional change will occur enabling free membership to family members
- 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

### **Taiwan- Dr Yuan-Fu Tseng**

- They conducted a nationwide survey 20 years ago and public education. They have repeated this survey and public awareness programme again. The report still being analysed. It was a face to face questionnaire with a sample size of 6,000 people which was conducted in city and rural areas. Results will be compared to those 20 years ago with 2,000 people
- They focus on patients that are handicapped. They get work rights from the Government

### **China - Professor Ding Ding**

- Last year they established two Patient Centres in Beijing and Shanghai and now two more are planned (in Xi'an and Dalian)
- The Seahorse Club received Promising Strategies Project funding last year and have submitted their report
- June 28 is "International Caring Day for Epilepsy" each year and this year has a theme with "Realize the dream to cure epilepsy, start from compliance and diary". They want to teach PWE to follow what the doctor tells them and to record details and events in their patient's diary as much as possible
- There is no Facebook in China but they have other social media that patients can use to communicate, which are, MicroBlog and QQ. PWE living in cities most have Internet and can access it but in rural areas don't have this opportunity. However, in rural areas most can have a cell phone so it is used to send short messages to them
- They will conduct a survey nationwide with a 200,000 sample across 20 provinces which they hope to complete by the end of next year

### **Malaysia - Dr Kheng Seang Lim**

- Two different groups exist. The Council was formed by Doctors and they provide treatment guidelines
- Malaysian Society of Epilepsy is the lay leadership group and there is crossover. Dr Lim became involved in organising Support Groups now he is on the committee
- They want to Increase membership which is currently concentrated in the central part of Malaysia. No activities occur in other States.
- They have built networks via social media and have 100 members on Facebook. He recommends holding a forum on Facebook The Forum forms a trail of comments including driving licence issues
- Membership is growing from other states
- The treatment gap is quite wide
- They provide care to patients and members and are involved in promoting these days
- They use Facebook to promote Purple Day

### **INDIA – Dr Mehndiratta**

- The Indian Epilepsy Association was formed in 1971 and has 29 Chapters and close to 3,000 members
- National Epilepsy Day is usually organized on 17th November each with sporting activities, painting, games for children with an "Epilepsy and Women" and "Epilepsy and Employment" themes
- They have produced a CD in the national language Hindi which has been translated into English and eight other local languages
- IEA Chapters provide education and public awareness and distribute handouts. Various Chapters are likely to provided, with "Hope on wheels" vehicles which will have team ambulances that link up with urban and country areas. The Doctors and Nurses will collect data from a reach of 200,000

- Their website, [www.epilepsyindia.org](http://www.epilepsyindia.org) is doing very well and contains information about the association and its activities

### **New Zealand – Frank Gouveia**

- They have now been established for nearly 60 years and have an annual client base of approximately 15,000. New Zealand has a 4.2 million population
- They are well settled after working on a number of internal issues and now focusing on the development of their staff by improving their knowledge.
- New Zealand Social Media is well used and they have conducted two Purple Day events plus one successful “Talk About It” campaign featuring well known Hollywood celebrities.
- New Zealand has a funding contract with the New Zealand Government which provides 50% of their funding and is tendered for every three years. The Government undertakes a complete review
- to know about Epilepsy” and their 23 staff deliver the program

### **Australia – Robert Cole**

- Epilepsy Australia Ltd. and the Joint Epilepsy Council of Australia are still pursuing Federal Government funding and after the election they will reactivate their “Parliamentary Friends of Epilepsy” initiative which is designed to lobby
- The major focus is on fundraising to ensure the viability of both organisations. The Epilepsy Australia website is the main vehicle for fundraising and gets incredible results thanks to Executive Officer, Denise Chapman’s hard work.  
[www.epilepsyaustralia.net](http://www.epilepsyaustralia.net)

### **What are the main issues in our two regions?**

### **How can we further reduce stigma in our two regions?**

### **How can we work collaboratively together?**

### **What activities can we create in our two regions?**

- Frank Gouveia detailed that exchanging staff is a good idea but the organisational structures have to be similar. New Zealand is offering to host non-professional exchange staff and can help finance their stay
- New Zealand will sponsor two employees from Fiji and will train them in Epilepsy Care but they are not experienced in the New Zealand culture and might struggle with that
- Dr Mehndiratta said that in India they are not very involved in training Nurses
- Pharmacist, Nurses, Counsellors and Social Workers could be exchanged and trained for a three month visit and stay in others homes around the country and billet them out but airfares will have to be

raised by the person. Transportation, food and accommodation can be provided

- Dr Rajbhandari reported that Janita Keating from Epilepsy Foundation Victoria attended their camps and provided education as a volunteer during her annual leave at her own expense. She used Powerpoint to educate Nepalese patients in camps and she is coming on September 2013 to organize camps at three different places of Nepal
- Dr Lim confirmed that training one person is very useful because they can adopt new ideas. The mentoring system adoption program is a big area in Asia by share materials and ideas followed by training. Advocates are useful in Malaysia and they are adopting training modules. Some countries have a heavy focus on research and some have more resources.
- Dr Kubota said that Japan has a very diverse newsletter. All countries have the same goals and mentoring is a very good idea. He stated that we should have contact after this meeting and exchange descriptions of what each other organisation does.

**ACTION:** Develop descriptions of what each organisation does so we can develop a Mentoring Exchange Program and report at our next face to face meeting in Singapore

- Dr Mehndiratta stated that Care Givers, Social Workers and Counselors are the three people best to help and these services need to be enhanced in India.
- Professor Ding Ding suggested a one week training course for 20 people from different countries. Invite experts to train and provide a Certificate
- Frank Gouveia stated that in New Zealand they hold Epilepsy Information and Support seminars with specialists. They hold these seminars in schools, factories and in the community titled. "Everything you want to know about Epilepsy" and their 23 staff deliver the program
- Dr Mehndiratta suggested that IEA can conduct a course which is IBE supported and endorsed. We should conduct courses like the ILAE. The Indian Epilepsy Association awards a Diploma in "*Epilepsy Care*". They need to provide more education. He suggested two sessions, one for Counselors and one for Nurses. The IBE should endorse and support this type of activity
- Professor Ding Ding confirmed that Nurses need to be trained
- Dr Lim stated that the Certification should be internal and that a two hour session is needed to meet each other and interact

### **Share our 2013 Budget and Plans**

- The Co-Chair encouraged everyone to share their budgets and plans which will give other countries ideas and ways to collaborate

### **Next Meeting (face to face)**

- 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>

10<sup>TH</sup> ASIAN & OCEANIAN  
**Epilepsy**  
CONGRESS



**SINGAPORE 2014**  
24 -27 AUGUST

The meeting closed at 4.00pm.

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



International Bureau for Epilepsy  
[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)