



# Western Pacific Meeting

International Bureau for Epilepsy

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



## **MINUTES OF MEETING**

Epilepsy Congress, Montreal, Quebec, CANADA  
24 June 2013

<http://www.epilepsymontreal2013.org>

## Welcome

- The meeting commenced at 2.30pm
- Apology from Denise Chapman

### Welcome and Western Pacific Regional Committee Handover:

1.	Robert Cole	Australia (Chair)
2.	Ann Little	IBE Executive Director
3.	Rosey Panelli	Australia
4.	Dr Hidemoto Kubota	Japan
5.	Dr Shung-Lon Lai	Taiwan
6.	Dr Yuan-Fu Tseng	Taiwan
7.	Professor Ding Ding	China
8.	Dong Wei Wei	Taiwan
9.	ShawYu Wu	Taiwan
10.	Akiro Okada	Japan
11.	Keiji Tsurui	Japan
12.	Shuitsu Harada	Japan
13.	Graeme Shears	Australia
14.	Frank Gouveia	New Zealand

The Chair thanked the Western Pacific Region members for their support and participation over the last four years and the outgoing Western Pacific Regional Executive Committee (WPREC) for their hard work. He also thanked IBE Vice President, Western Pacific, Dr Shunglon Lai for his guidance and support.

#### IBE International Executive Committee

IBE Vice President, Western Pacific      Shunglon Lai

#### Western Pacific Regional Executive Committee

Chair:	Robert Cole
Vice Chair:	Yuan-Fu Tseng
Secretary:	Denise Chapman

The Chair welcomed and congratulated the new Western Pacific Regional Executive Committee. Note that their term will commence after the IBE AGM on Wednesday 26 June.

#### IBE International Executive Committee

IBE Vice President, Western Pacific      Professor Ding Ding

#### Western Pacific Regional Executive Committee

Chair:	Denise Chapman
Vice Chair:	Frank Gouveia
Secretary:	Yuan-Fu Tseng

- The Chair noted that the WPREC Budget had been approved by the IBE Executive and it is for 6 months to 30 June. The new committee needs to ensure that the current budget activities are completed and any unspent funds are carried over. This needs the approval of the IBE Treasurer

### **BUDGET SUMMARY**

<b><u>ACTIVITY</u></b>	<b><u>COST</u></b>
Reprint the SUDEP book for Australasian distribution	<b>US\$4,000</b>
Reprint Epilepsy Carers Handbook (China)	<b>US\$2,000</b>
Quality Life program expansion in Mongolia seed funding	<b>US\$2,000</b>
Proposed Vietnam Chapter establishment revisit Laos	<b>US\$1,200</b>
Proposed IBE Chapter in Tibet conference	<b>US\$1,500</b>
<b>TOTAL</b>	<b>US\$10,700</b>

- The SUDEP Book has been reprinted. The Epilepsy Carers Handbook project needs to be completed. Need to follow up with Mongolia on their progress. Dr Shunglon Lai visited Laos in February and will claim back his expenses. Dr Shunglon Lai and Professor Ding Ding will still visit Tibet but have been delayed due to bad weather
- The Chair advised to carry over these expenses if the activities have not been completed
- Congratulations to Professor Ding Ding for winning the prestigious Michael Prize

A minutes silence was held to honour the death of **Dr Mike Hills** of New Zealand

### **Brief Reports (around the table)**



**Western Pacific Region.**

### **NEW ZEALAND - Frank Gouveia**

- The Epilepsy Fiji Association have lodged an application as a Not For Profit organisation with the Fijian Government which is hopeful to be approved in October. Processes have moved slowly because Fiji is under Military Rule. Fiji will be established as an IBE Regional Member and Dr Achara is leading the application with the Senior Health Specialist from the Ministry of Health, Dr Neil Sharma
- There is no Neurologist practicing in Fiji
- It is business as normal in New Zealand as they continue to fight stigma

### **AUSTRALIA – Graeme Shears**

- Australia has a close working relationship with the ILAE and IBE on joint research which is achieving better integration between the medical and non-medical groups
- The Australian Epilepsy Research Register longitudinal study is progressing to Wave 3 which will shortly be completed. Over 850 people have joined the register to date
- This study is reporting on the impact of epilepsy. Two Wave 2 reports have been produced and published in “Epilepsy & Behavior”
- Dr Rosey Panelli has been leading research into epilepsy deaths but more funding is needed. This is disappointing given the importance of the project. They have access to the Coroners national online data base to research SUDEP deaths. This is an important project. Bereaved families are participating in an online survey
- The Australia Federal Government has legislated and introduced a National Disability Insurance Scheme. Epilepsy Foundation Victoria received A\$250,000 to produce a set of tools to help support provider agencies to assist intellectually disabled people, of which, 30-40% have epilepsy. The Government has now doubled the amount of funding from A\$7–14 billion for this initiative
- The Australia Pregnancy Register continues to grow which is led by Professor Frank Varja

### **JAPAN – Dr Hidemoto Kubota**

- 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

- Progress is being made in Japan following the devastating Tsunami. Homes and buildings are under reconstruction and people are relocating but it will take years to achieve. Towns are being reconstructed at same place or moved to higher ground. The decisions are under discussion with the local people
- They have had a collaborative meeting with the Japan Epilepsy Society and decided that National Epilepsy Month will be held in October which is Purple month. <http://www.jea-net.jp>

### **TAIWAN – Dr Yuan Fu Tseng**

- The new President of the Taiwan Epilepsy Association, Dong Wei Wei was introduced
- Their “Stand up for Epilepsy” activity was very successful which involved Super marathon athletes. The activities were well reported in the IE News
- 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
- PWE who are drug resistant can qualify for disability assistance but since July the Government changed the law and some people have lost certification. As a result they have lost their jobs and their financial resources so the Taiwan Epilepsy Association is fighting to have this rule rejected and hope that people can have basic support reinstated through the reclassification of disability
- Some people with poor control cannot get jobs so many are unemployed. They are thinking of building a workshop, or shelter or perhaps a bakery. They will conduct major fundraising in August which is already arranged this so it should be successful. It was suggested that the IBE Treasurer and IBE Vice President, Western Pacific visit to see what is created. They hope to assist 20 people initially and then build from that. This project will provide employment

### **CHINA – Professor Ding Ding**

- Ding attended on behalf of Dr Li
- Last year they established two Patient Centres in Beijing and Shanghai and now two more are planned (in Xi'an and Dalian)
- 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

- The Seahorse Club received Promising Strategies Project funding last year and have submitted their report
- Their “Epilepsy Caring Handbook” has passed first proofing and should be out soon
- They have also hired a special company to manage the website which has been covered by UCB China funding

## **MALAYSIA**

- The Chair and Ann Little visited Kuala Lumpur and met with the local Association. They seem to have sorted problems and Dr Lim is the leader of the IBE side and we are now in regular communication via email. Rosalind Chee and Magrette Anthony-Selvy also involved

### **What are the main issues in our region?** **How can we further reduce stigma?**

- The Chair stated that there is a need to recruit new members. We have been working to enable new IBE members in Laos, Vietnam and Fiji. Also we need to reduce stigma through projects. Facebook communication and demonstrations which are avenues to consider
- Graeme Shears stated that the core issue is to create an understanding of the condition in the community. Epilepsy is a complex condition, so gaining understanding is difficult. Creating an understanding needs to start at primary school with young children because they have no fear or preconceptions. Then year by year we can start to change things. If we start with children the families will also pick up part of that as well
- He gave an example of a teacher who saw evidence of epilepsy in a student and advised parents. When checked, it turned out that the child had a tumour and his life was saved
- Dr Kubota stated that they run a school programme which is effective. They will have another seminar next summer for non-medical professionals. Over 900 persons attend each year. Stigma has not disappeared. They will undertake a survey on stigma this year or next. Staff do not visit schools in Japan
- Graeme Shears stated they are working with schools and looked at how materials might be used in the curriculum e.g. “How the brain works”. A booklet is being prepared in Australia but not completed yet
- Frank Gouveia stated that education is important but there is always a lack of funding. There is also a lack of Neurologists etc. but, in the case of Laos, they have no Neurologists
- The IBE and ILAE should work together to try to get epilepsy education into the Education Ministry curricula. The IBE is restricted because Governments tend to listen more to the medical profession. In Australia they work closely together but it is not always the case in other countries. If the IBE could forge that relationship through Task Forces to have education on epilepsy included in school curriculum

## How can we increase regional membership? (Vietnam, Laos and Tibet)

- We need to encourage new members
- Graeme Shears advised that a member of his team visited Nepal on her annual leave and provided assistance and education. She intends to repeat this voluntary education
- We should develop a list of non-members in the region and try to find out which ones have Neurologists from the ILAE who provide services
- Vietnam, Cambodia, Brunei and Laos are all possible new members. We should cross reference with the ILAE to build on their membership relationships. East Timor is also a possible member and we should liaise with Dr Ernie Sommerville

## What activities can we create in our region?

- Exchange programmes are a great initiative with other IBE member associations in the region
- Professor Ding Ding recommended Fellowships to support people going abroad. The airline cost must be funded and an exchange program for physicians and nurses for three months training can be provided. This system can also accept people from other countries such as Laos

## 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>



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