



**Western Pacific Regional Committee & South East  
Asia Regional Committee Joint Meeting**

International Bureau for Epilepsy

8<sup>TH</sup> ASIAN OCEANIAN  
**EPILEPSY**  
CONGRESS  
21–24 October 2010  
Melbourne, Australia



**MINUTES OF MEETING**

**8<sup>th</sup> ASIAN & OCEANIAN EPILEPSY CONGRESS**

Melbourne Convention and Exhibition Centre  
Melbourne, AUSTRALIA

Friday 22 October at 7.00pm to 8.00pm in Room 107 Level 1 MCEC followed by a  
cocktail party

**Chairs: Robert Cole (WP) & Dr H V Srinivas (SEA)**

**Minutes: Denise Chapman**

## **Item 1: Welcome**

The meeting commenced at 7.00pm

### **The Chairs welcomed attendees:**



- |     |                          |                           |
|-----|--------------------------|---------------------------|
| 1.  | Mike Glynn               | IBE President             |
| 2.  | Denise Chapman           | Australia (WP Secretary)  |
| 3.  | Robert Cole              | Australia (WP Chair)      |
| 4.  | Dr Yuan-Fu Tseng         | Taiwan (WP Vice-Chair)    |
| 5.  | Grace Tan                | Singapore (IBE Treasurer) |
| 6.  | Dr H V Srinivas          | India (SEA Chair)         |
| 7.  | Dr H Kubota              | Japan                     |
| 8.  | Dr Hubert Barennes       | Laos                      |
| 9.  | Orla Gilroy              | Hong Kong                 |
| 10. | Jeannie Desiree Khonghun | Philippines               |
| 11. | Frank Gouveia            | New Zealand               |
| 12. | Dr M M Mehndiratta       | India (SEA Vice-Chair)    |
| 13. | Shuitsu Harada           | Japan                     |
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The meeting welcomed Dr Hubert Barennes from LAOS. Dr Barennes is an Epidemiologist heading the Francophone Epilepsy Project in Laos. Dr Barennes spoke about the prevalence of epilepsy in Laos of 7.7% and huge treatment gap around 90% with only one trained neurologist based in Vientiane. GPs are not trained to manage PWE and only few PWE are seen in outpatient departments of hospitals.

## **Item 2: Addressing Stigma in our Regions**

### **Grace Tan**

- Singapore is considering following Hong Kong's lead in changing the Chinese name for epilepsy because it is less stigmatised
- Epilepsy is classed as mental disorder in Singapore as well
- They will raise this with the Ministry of Health & Education Board of Singapore

### **Dr H V Srinivas**

- In India among the lay people, epilepsy is still associated with mental illness
- Until 1999 Epilepsy bracketed with mental illness and therefore did not form a legally sanctioned marriage. In 1999 the law was repealed and now epilepsy is not a ground for divorce
- PWE are not seen as normal members of society
- There is a need to transfer medical knowledge that epilepsy is eminently treatable in great majority, to the public, and to dispel myths and prejudice
- The awareness campaign can be augmented by roping in PWE Celebrities

### **Dr Kubota**

- In Japan, epilepsy is legally classified as a mental illness
- Japan Epilepsy Association empowers PWE to overcome disease and to increase public awareness
- Lack of money is always an issue
- This year a major newspaper campaign occurred with an article on epilepsy for seven consecutive days
- In Japan it is legislated that 1.8% of jobs be given to PW disabilities

### **Mike Glynn**

- In Ireland, epilepsy is aligned with physical and sensory conditions but has more in common with people with mental health conditions
- As things improve economically, stigma reduces
- There is no quick fix, stigma will be reduced over time
- We need to expunge the use of the term 'epileptic' in the media
- The Scarlet E article in IBE news has been published in Spanish

### **Denise Chapman**

- In Australia PWE are more likely to be discriminated against in the workplace and in getting employment

### **Yuan-Fu Tseng**

- In Taiwan, epilepsy has been considered a neurological disease for a long time. There is still discrimination in employment

### **Jeannie Desiree Khonghun**

- In Philippines, myths around epilepsy still exist in rural areas
- Their goal is to empower PWE
- They will need to educate not only PWE, but also those around them

### **Orla Gilroy**

- The situation in Hong Kong, is similar to Singapore
- The Chinese character/name has been changed. The 1<sup>st</sup> character 'dian' means 'crazy' in Cantonese culture in Hong Kong and misleads people to regard epilepsy as mental illness. The new change of the first word as '腦' (nao), a simple and factual description of its biological nature referring to the "brain"
- An experience taking a client to hospital when they used the new name / then old name with an explanation and reaction was 'That's good'
- Attitudes still need work eg. an employee had a seizure at work and the whole office fell apart. Other employees won't use the same water cooler as a PWE because they fear that epilepsy is contagious!
- The old traditions in Chinese culture are very hard to change

### **Frank Gouveia**

- In New Zealand, stigma stems from ignorance and people don't look back in history for an explanation
- After discussion on stigma at the Congress, this now poses the question are we as organizations enabling stigma with signs on cars, staff jackets/ etc.?

### **Dr Hubert Barennes**

- In Laos, epilepsy is referred to as the 'Disease of the mad pig'
- There are sixty dialects in Laos which makes it hard to translate other descriptions
- Epilepsy is considered contagious
- Psychiatrists treat epilepsy in Laos (if it is treated at all)
- They only have one neurologist for the entire country

## **Item 3: Stigma Report – Chinese Name Change Anchor Hung**

Anchor Hung presented this report at the Epilepsy & Society Day previously. Orla Gilroy provided further comments in her report above.



## **Item 4: Other Major Issues**

Dr H V Srinivas:

Epilepsy is basically a clinical diagnosis and, there is a great need to train primary care physicians in diagnosis and management of common types of Epilepsy, which is now the focus of action in India.

Mike Glynn:

The Chinese name change is potentially a huge opportunity to influence government for systemic change. Frank Gouveia and Denise Chapman commented on the large Chinese populations in both New Zealand and Australia and that the new Chinese name should be incorporated into our literature.

Dr Kubota:

He commented on the need for standardised information citing that police in Japan did not understand automatisms in epilepsy. The US Foundation has a DVD for Police.

Grace Tan discussed the police training that they do in Singapore.

Orla Gilroy:

She inquired about the PSP program and sought assistance in how they might access this program in Hong Kong. Although Hong Kong has a high GNP, there are huge areas of poverty where the need is very great.

Risks associated with driving licences were discussed as well as risks from riding a bicycle. It was suggested that in the future PWE might be banned from riding bikes (and causing accidents).

Jeannie Desiree Khonghun:

She advised the meeting that a friend died after having a seizure while riding a bicycle on the road and was hit by a car. She felt it was more important to educate PWE about the risks.

## **Item 5: Ideas for working collaboratively together**

While the issue of stigma varies greatly across the regions, there are common points that, as a group, we could address including:

- Encouraging the adoption of the new Chinese name in countries that have a large Chinese population
- Sharing existing education resources eg. community training DVDs

## **NEXT MEETING (face to face)**

The next face to face meeting will be held at the **29th International Epilepsy Congress**, Rome, Italy, 28 Aug –1 Sept. 2011.

<http://www.epilepsyrome2011.org>





There was no other business and the meeting closed at 8.00 pm.

Members were invited to continue informal discussion over drinks.



*“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)