

# Western Pacific Region Report

# **STRUCTURE**

## Members in the Western Pacific Region;

1. AUSTRALIA 2. KOREA 3. MALAYSIA	Joint Epilepsy Council of Australia Ltd Korean Epilepsy Association Malaysia Society of Epilepsy
4. MONGOLIA	Mongolian Epilepsy Association
5. NEW ZEALAND	Epilepsy New Zealand
6. CHINA	China Association Against Epilepsy
7. JAPAN	Japan Epilepsy Association Inc.,
8. PHILIPPINES	Epilepsy Awareness and Advocacy Inc.,
9. SINGAPORE	Singapore Epilepsy Foundation
10. TAIWAN	Taiwan Epilepsy Association

#### Western Pacific Regional Executive Committee:

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

#### IBE International Executive Committee:

Vice President, Western Pacific Shunglon Lai

# AIMS OF THE WESTERN PACIFIC REGIONAL COMMITTEE

- To provide a forum for IBE members within a defined geographical region;
- to pursue and co-ordinate at a regional level the implementation of the policies and plans of IBE;
- to identify regional issues of relevance and significance to members and to develop plans and policies to address these;
- to consider issues which fall within the scope of the above which are either referred to the Western Pacific Regional Committee by the International Executive Committee or which the Western Pacific Regional Committee itself concludes are appropriate topics for its consideration and to report its deliberations and recommendations to the International Executive Committee.

#### POLICY STATEMENT

In June 2009 the new IBE Western Pacific Regional Executive Committee (WPREC) was appointed. The WPREC is working hard to coordinate IBE activities, organise forums, increase membership, identify significant regional issues and build on the work of previous executives to continue to raise epilepsy awareness in the region.

#### **COMMUNICATION**

We have developed good email communications with most members of the Western Pacific. Meeting face to face has enhanced relationships. We are encouraging frequent dialog.

# THANK YOU

Thank you sincerely to Ann Little and Vânia Silva for their support, advice and assistance. It is greatly appreciated. We also thank IBE Vice President, Western Pacific, Shunglon Lai for his tireless work which has greatly increased epilepsy awareness and provided education over many years in our region.

#### ACTIVITIES in 2009

Since the 7<sup>th</sup> Asian & Oceanian Epilepsy Congress in Xiamen, China in May 2008, during which the main activity of the WPREC was the Special Program for People with Epilepsy, the following activities have occurred:

#### Joint Meeting

A joint meeting of the IBE South East Asian and Western Pacific Regional Executive Committees was held in Budapest, Hungary at the IBE International Epilepsy Congress on 30<sup>th</sup> June 2009. Robert Cole, incoming Chair, WPREC chaired the meeting and 12 participants attended.

## Main Activity

Our main activity in 2009 was our focus on Vietnam with a view to establishing a new chapter there. Shunglon Lai visited Vietnam accompanied by Dr Li and conducted a Workshop on the Medical and Psychosocial Issues of Epilepsy and to establish a self-help group. He exchanged his experiences in China, Taiwan, Japan, the Philippines and Mongolia. Meetings took place in both Ha Noi and Ho Chi Min City, November 26-30. The concept was to introduce models from neighbouring countries to enable Vietnam to establish their own model for helping people living with epilepsy.

#### **CLAN** Collaboration

Dr Kate Armstrong, B Med DCH MPH, President and Founder, CLAN (Caring & Living As Neighbours) (<u>www.whatisclan.org</u>), contacted us in October 2009 because they were asked to help young people with Epilepsy in Vietnam. We are very pleased that we have formed this new relationship and hope that we can partner with CLAN in their epilepsy activities.

#### Philippines Visit

Shunglon-Lai attended the Epilepsy Awareness & Advocacy Inc. (EAAI) Epilepsy Lay Symposium and the Philippine League Against Epilepsy (PLAE) Epilepsy Congress by invitation. His presentation was entitled: "International Bureau for Epilepsy: what it does for persons with epilepsy".

#### Meeting with New Zealand

Joint Epilepsy Council of Australia met with Epilepsy New Zealand CEO, Frank Gouveia and Mr Mike Hills in Melbourne, May 2009 to explore ways of sharing ideas and resources between our organizations.

#### IBE inquiries to Pacific Island Countries

In December 2009, the IBE wrote to Departments of Health in all countries where IBE does not have representation, enquiring about details on national epilepsy associations.

#### Meeting with Dr H V Srinivas

WPREC Secretary, Denise Chapman met with IBE South East Asia Region Chair, Dr. H V Srinivas in Sydney, December 2009 to discuss progress in the regions and to build relationships.

#### ACTIVITIES in 2010

#### Main Activity

Our major activity in 2010 was the 8th Asian & Oceanian Epilepsy Congress (AOEC) in Melbourne 21-24 October 2010. Australia hosted this major event which provided another opportunity to increase community awareness of epilepsy to help change attitudes and to help reduce stigma.

The Special Program for people with epilepsy titled "Epilepsy & Society" was a highlight of the Congress and was held on Thursday 21 October and experienced the largest attendance ever, with 234 delegates participating. Olympic cyclist Marion Clignet presented and she spoke about "exercise, diet and AED's" and "epilepsy, sport and exercise".

The major highlight of this day was the presentation of awards for "Outstanding Persons with Epilepsy". This Award was presented to very worthy recipients, nominated by their respective Chapters, and our IBE International President, Mike Glynn, presented the awards at the conclusion of the "Epilepsy & Society" day.

#### Joint Meeting

A joint meeting of the IBE Western Pacific Regional Committee & South East Asia Regional Committee was held in Melbourne, Australia during the 8<sup>th</sup> AOEC on Friday 22 October 2010. Chairs were Robert Cole (WP) & Dr H V Srinivas (SEA) and 13 participants attended. A cocktail party was hosted by the WPREC following this meeting.

#### Western Pacific Regional Meeting

The WPR also met during the 8<sup>th</sup> AOEC on Friday 22 October. The Chair, Robert Cole convened the meeting with nine attendees representing 7/10 Western Pacific members. Apologies were from Korea, Malaysia and Mongolia. The main issues in the Western Pacific Region included funding, employment, better access to treatment via referral programs, having epilepsy considered as a mental health issue and a lack of social workers in the community who understand epilepsy.

#### Meeting with Epilepsy Service staff

Epilepsy Foundation Victoria hosted a special day on Wednesday 20 October. The aim of meeting was to bring epilepsy workers from across Australia and New Zealand together to share their knowledge, ideas and priorities whilst in Melbourne attending the 8<sup>th</sup> AOEC. Staff from every state in Australia attended and also New Zealand added staff members which totaled fifty (50). A dinner was held to continue networking which was well attended.

#### Meeting with Japan

The Japan Epilepsy Association hosted a special meeting on Saturday 23rd Oct with delegates from The Epilepsy Foundation of Victoria and Epilepsy New Zealand to discuss service provision. They discussed "Education for Paramedical staff (Mainly nurses)", medical education and education regarding the welfare system.

# PLANS FOR 2011/2012

# 9<sup>th</sup> Asian and Oceanian Epilepsy Congress (AOEC) & Epilepsy & Society Symposium Programme

The 9<sup>th</sup> AOEC will be held in Manila in 2012. The Western Pacific Regional Executive Committee will be highly involved with the planning during 2011 in the lead up to 2012. The Epilepsy & Society Symposium will have to be well planned and it is estimated that 200+ people could attend including local PWE and Health care professionals for their professional development.

# Philippines Visit to Plan the 9<sup>th</sup> AOEC Epilepsy & Society Symposium Programme

Assistance needs to be provided to the local Philippine chapter, Epilepsy Awareness & Advocacy Inc. to conduct the Epilepsy & Society Symposium and to assist with developing an interesting programme. Funding strategies must be developed to facilitate maximum attendance including commencing general fundraising for the purpose of accumulating funds to subsidise local attendees.

# Increasing Western Pacific Membership - New Members

# IBE Chapter in Vietnam

During the Western Pacific Regional (WPR) Committee meeting it was agreed that we must progress the establishment of an IBE Chapter in Vietnam and to provide more training. We are still very eager to conduct a follow up meeting in Vietnam. We plan to ask Shunglon Lai to progress the work that he and Dr Li have already done.

# IBE Pacific Islands Chapter

Also during the WPR Committee meeting it was agreed that we must progress the establishment of an IBE Pacific Islands Chapter. The Cook Islands have a health system but no Neurologists. It was suggested bringing Fiji, Tonga, Samoa etc. to New Zealand to introduce them to the IBE/ILAE and for New Zealand to act as "big brother" member. The cost will be a major factor. New Zealand agreed to explore epilepsy in Pacific Islands to develop relationships because of their close proximity and the work they have already begun.

# IBE Chapter in Laos

Also during the WPR Committee meeting it was noted that Laos provides another opportunity to add to membership. The Global Campaign Against Epilepsy is key and a demonstration project could be established. It is proposed that we visit Laos and assist them with training and support with a view of establishing a Laos Chapter.

# IBE Chapter in China

Also during the WPR Committee meeting we received a report on the developments in China. China has the largest population of the ten (10) members of the Western Pacific Region. We propose to further support China by conducting health education and awareness lectures. Our plan is to fund Western Pacific, Vice President, Dr Shunglon Lai to travel to China in 2011 to further enhance the work that he has already commenced.

#### Development of shared training resources

Also during the WPR Committee meeting considerable discussion took place on producing and sharing training resources so that savings could be made on printing via economies of scale and benefit from standardising materials for consistency. Training materials are needed by every member. We plan to develop common training resources and propose to allocate funds to achieve this goal.



Robert ColeChair- IBE Western Pacific Regional Executive CommitteeChair- IBE Editors NetworkCo-Chair- 9<sup>th</sup> Asian & Oceanian Epilepsy Congressrcole@epilepsycentre.org.aurcole@jeca.org.au

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