



Report

Western Pacific Region

International Executive Committee

2009

Western Pacific Region Report 2009 and 2010 Plans & Budget

STRUCTURE

Members in the Western Pacific Region:

1. AUSTRALIA	Joint Epilepsy Council of Australia Ltd
2. KOREA	Korean Epilepsy Association
3. MALAYSIA	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
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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.

OBJECTIVES OF THE WESTERN PACIFIC REGIONAL COMMITTEE

The Western Pacific Regional Committee will:

- Liaise with the Global Campaign Against Epilepsy, EUCARE, IBE's other Regional Committees and other IBE and ILAE Commissions, Task Forces, Working Groups, and special initiatives on issues of common interest;
- seek to encourage the development of new Full, Associate and Regional members in the region in countries where no Full, Associate or Regional members currently exist;
- support existing members within the region by providing a forum for the exchange of information, expertise and experience;
- organise meetings, seminars and workshops on a regional basis in line with the above;
- provide a regional representative voice for IBE members within IBE and externally to other regional bodies like regional governments.

POLICY STATEMENT

In June 2009 the new IBE Western Pacific Regional Executive Committee (WPREC) was appointed. We acknowledge and thank the outgoing committee, Dr Hidemoto Kubota, Dr Andrew Pan and Dr Yuan-Fu Tseng. We also thank IBE Vice President, Western Pacific, Shunglon Lai for his work which increased epilepsy awareness and provided education over the last four years.

The WPREC believes that we must develop closer relationships in the region and work hard to coordinate IBE activities, identify regional issues and to raise epilepsy awareness. Australia will host the 8th Asian & Oceanian Epilepsy Congress in Melbourne 21-24 October 2010 and this event will provide another great opportunity to increase community awareness of epilepsy to change attitudes and reduce stigma.

Members must develop closer relationships in the region to link East Asia with the Pacific. Increasing community awareness of epilepsy is critical to changing attitudes and demystifying the condition. Stigma will only be overcome by a solid public education program.

The WPREC will work 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.

THANK YOU

Thank you sincerely to Ann Little and Vânia Silva at the International Bureau for Epilepsy head office for their support, advice and assistance. It is greatly appreciated.

ACTIVITIES

Since the 7th 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 30th June 2009. Robert Cole, incoming Chair, WPREC chaired the meeting and 12 participants attended.

The 8th Asian & Oceanian Epilepsy Congress was discussed in detail and that promotion was important and that pre-congress events such as dragon boat racing, cycle event, etc., was considered. A meeting with ILAE also took place during the congress to finalise the programme and ideas were tabled for consideration.

People with epilepsy with limited means needed to be supported to attend. The Indian Trust would support some people to attend from India. In addition to attracting people with epilepsy and their carers to attend, other NGOs as well as teachers and other professionals will be encouraged to participate.

The next WPREC face to face meeting will take place during the 8th Asian and Oceanian Epilepsy Congress in Melbourne, Australia.

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 Hanoi and Ho Chi Min City, November 26-30. The concept is to introduce models from neighbouring countries to enable Vietnam to establish their own model for helping people living with epilepsy.

The goal was:

- To promote the epilepsy care and formation of supporting group for persons with epilepsy in Vietnam.

The objectives were to:

- To introduce the diagnostic aspect of medical care in epilepsy;
- to introduce the scope of psychosocial problems among persons with epilepsy;
- to enhance the perception of psychosocial problems among physicians taking care of persons with epilepsy;
- to introduce the concept, the model and the implementation of supporting group or self-help organisation;
- to discuss the solution of coping with psychosocial care for persons with epilepsy in Vietnam.

These two meetings were quite successful and the outcome is that they now know how to form a lay group from a hospital based level. They also intend to form a patient group. We are very eager to conduct a follow up meeting in order to progress establishing a Vietnam Chapter.

CLAN Collaboration

Dr Kate Armstrong, B Med DCH MPH, President and Founder, CLAN (Caring & Living As Neighbours) (www.whatisclan.org), contacted us in October 2009 because they were asked to help young people with Epilepsy in Vietnam. They have helped children with Diabetes, Autism and CAH and they focus on the maximizing quality of life for all children living with chronic medical conditions in resource-poor countries of the world.

We directed her to contact Shunglon Lai and he provided advice and assistance. 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. He spoke at the Epilepsy Lay Symposium and his presentation was entitled: "International Bureau for Epilepsy: what it does for persons with epilepsy".

Meeting with New Zealand

Joint Epilepsy Council of Australia had a very productive meeting with Frank Gouveia, Mike Hills and Verity Cosgrove (Epilepsy New Zealand National Services Manager) in Melbourne May 2009 to explore ways of sharing ideas and resources between our organizations. We look forward to working together to benefit the Western Pacific Region.

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. To date we have received one reply, which came from the Ministry of Health in the Marshall Islands. It is important to find new ways to enlarge our membership.

Recent changes to the IBE Constitution now allow for "Regional Organisations" to become IBE Full Members; "*Where a Full Member covers more than one country (a "regional organisation"), for the purposes of measuring the threshold, that member shall be counted as being one country.*"

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. The meeting was very successful and it is important to maintain contact and to exchange ideas.

Communication

We have sent several email communications to Western Pacific Members to encourage dialog and to establish links. The main obstacle, not only for Vietnam, but for some of the chapters is the language barrier because many do not speak English.

MEMBERS REPORTS

Australia

The Joint Epilepsy Council of Australia (JECA) has achieved considerable progress. Our Parliamentary Friends of Epilepsy Inquiry into epilepsy by the Federal Government was achieved in November 2009 at Parliament House, Canberra. It is the first ever inquiry and over 350 submissions were received. A Private Members Bill will now be presented to both Houses of Parliament and government departments containing key recommendations.

JECA international activities over the past year include:

- Study tour of UK epilepsy organisations (Graeme Shears & Dr C Walker);
- papers presented at Centre for Disease Control, SUDEP workshop in Washington, and 28th International Epilepsy World Congress in Budapest.

National activities of JECA report that they have:

- Continued the strategic lobbying of Federal government;
- worked with Epilepsy Society of Australia on the Vegus Nerve Stimulation (VNS) issue;
- met with over 50 federal politicians;
- met with the Prime Minister's Health Advisor;
- met with advisors to the Minister for Health and Ageing, Minister for Families, Housing, Community Services and Indigenous Affairs, Parliamentary Secretary for Disabilities and Children's Services;
- met with government departments including, Department of Human Services, Department of Families, Housing, Community Services and Indigenous Affairs.

Members reported a 10% increase in the number of people accessing epilepsy services and:

- More than 15,000 people sought counselling and guidance, with an additional 4,500 clients being case managed locally;
- 6,000 sought professional development in epilepsy management;
- more than 400 hospital based epilepsy clinics were conducted.

China

June 28th 2009 was the third "International Epilepsy Caring Day" (IECD):

- The theme of the 3rd IECD was: "Caring patients, Guiding treatment";
- the IECD leaflet was disseminated widely;
- they had a high ranking "press release" announcing their conference in the Ministry of Health (MOH). China's Honorary President, Madam He Luli, the former vice-chair of National People's Congress, and a number of leaders of the MOH attended. More than 20 important mass media representatives participated in the conference and reported the activities of the 3rd IECD on Television, in broadcasts and in news papers.

The main activities of the 3rd IECD included:

- Publicity on overcoming stigma encountered by people with epilepsy and promoting regular treatment;
- publication of the "Green Book on Prevention and Control of Epilepsy in China";
- renaming the term of "epilepsy" (in Chinese character) to avoid discrimination/stigma through mass media. Many people joined this activity and a new term is under consideration;
- free of charge consultations with patients, public education to patients and family members in around 30 cities in China.

China recommends that the "IECD" be extended to other countries and regions because it is a very worthwhile day that enhances epilepsy awareness.

Mongolia

The Mongolian Epilepsy Association has conducted their "Quality of Life Program - Improving Public Knowledge for Epilepsy in Mongolia" in Uvurkhangai, Orkhon (Erdenet city) and Selenge (Zuun kharaa city) province between July 2009 – October 2009. The goals and objectives of the program are: To improve the public health education on epilepsy among population.

Activities involved providing their; "Quality of life program" in three provinces of Mongolia. During the training they improved medical and social assistance to people with epilepsy and reduced social stigma.

They conducted research and health education among neurologists in provincial hospitals, with family doctors, nurses, people with epilepsy and their family members on epilepsy care. They also identified the needs of people with epilepsy on a capital city in this area.

They improved quality of life for people with epilepsy including awareness, education, diagnosis, treatment, care, services and prevention and management options in patients with epilepsies. In the future, they will produce and publish handouts on epilepsy care and the prevention of epilepsy for doctors as well as for patients with epilepsy their families.

Financial Report:

<u>No</u>	<u>Name of Activity</u>	<u>Provinces</u>	<u>Period</u>	<u>Expenditure (USD)</u>
1	Improving the Public Health Education on Epilepsy	Uburkhangai Province (located 430 km from the capital city)	29th -30th July. 2009	
		Orkhon Province (located 410 km away from the capital city)	10 th -11 th Aug. 2009	
		Zuun kharaa city (located 160 km away from the capital city)	18 th 19 th Sept. 2009	
2	Payment of teachers, tea break, printing the manual on Epilepsy for PWE and doctors, Certificate of attendance, food & lodging, Rental car, Fuel etc			\$1,019

Philippines

In the Philippines, through Presidential Proclamation 230 (P.P. 230), the first week of every September has been declared *National Epilepsy Awareness Week*. Every other year, the Epilepsy Awareness & Advocacy Inc. (EAAI) together with the Philippine League Against Epilepsy (PLAE) has the *National Epilepsy Camp*.

In alternating years, the EAAI holds the *Epilepsy Lay Symposium* while the PLAE holds their *Epilepsy Congress* simultaneously. Dr Shunglon-Lai was speaker to both the 2007 and 2009 Epilepsy Lay Symposia. His presentation was entitled: "International Bureau for Epilepsy: what it does for persons with epilepsy", Dr. Marshall Mosong was speaker at the 2007 Epilepsy Lay Symposium. The different chapters still have their own activities, depending on the needs of their area, ongoing throughout the year.

Jeannie Khonghun, President, EAAI gave talks on Stigma and Discrimination which is their current issue, and she also presented this to the Philippine General Hospital.

Singapore

Grace Tan reports that:

- The Helping Other People with Epilepsy Programme (HOPE) is progressing;
- they provide ongoing talks to teachers to the National Institute of Education (NIE);
- they are working with Ministry of Education to promote awareness of epilepsy amongst the teachers in primary & secondary schools and junior colleges
- they are working with Law Enforcement Officers to provide epilepsy awareness and AEDs
- PWEs and CWEs and their caregivers continue to be provided with counselling, employment skill sets, social gatherings, AEDs management etc.;
- employers are encouraged to provide employment for PWEs.

New Zealand

Epilepsy New Zealand has entered into an alliance with the New Zealand chapter of the ILAE. This closer working relationship sees the current ILAE President Dr Peter Bergin take a seat on the Epilepsy New Zealand Board. One of the immediate joint projects people with epilepsy will benefit from this alliance is Neurologists having the Epilepsy New Zealand Field Officer working closely with them in providing social support and the provision of information to these patients, family and other associated parties.

Epilepsy New Zealand, through contacts with the New Zealand Government Health agencies has commenced a research program into epilepsy and its care in the Pacific Islands. At this stage Epilepsy New Zealand is trying to establish contact with leading health professionals in these islands to ascertain what level of care is available.

Many of the islands epilepsy population have relatives in New Zealand and often Epilepsy New Zealand is asked to provide information to island addresses by these relatives. Their website www.epilepsy.org.nz is accessible to the islands and is attracting good inquiry from them, but Epilepsy New Zealand feels that they could extend their services and have more face to face contact with people with epilepsy in those countries.

Korea

Since June 2008, the Korean Epilepsy Association and the Korean Epilepsy Society have been carrying out an "Epilepsy Renaming Project". Finally, in June 2009, "*Noejunjeung*" was adopted among many candidates as the new term to replace the existing name, "*Ganjil*", which contains a great deal of stigma.

The new word "Noejunjeung" literally means "Cerebro-Electric Diseases", indicating, in very neutral and scientific tone, that epilepsy is due to the electrical dysfunction of the brain. The new term is to be approved by the Korean Academy of Sciences in order to be officially used, hopefully before June 2010. The new name will alleviate greatly the stigma and discrimination on Epilepsy in Korea.

Taiwan

No report

Japan

No report

Malaysia

No report

2010 BUDGET

We are advised that funds are available for 2010 are:

BUDGET - WESTERN PACIFIC

General Funds 2009	US\$10,000
General Funds 2010	US\$5,000
LESS EXPENSES	US\$2,048
FINAL BALANCE	US\$12,952

2010 PLAN

Epilepsy & Society Programme

The Special Program for People with Epilepsy which will be held at the 8th Asian & Oceanian Epilepsy Congress in Melbourne, Thursday 21st October 2010 will be the main activity for the Western Pacific Regional Executive Committee. The Special Programme provides a great opportunity for people to meet and to discuss common problems and will be of great interest to both individuals living with epilepsy and for staff from community organisations supporting people living with epilepsy.

<http://www.epilepsymelbourne2010.org/ibeprog/ibeprog.html>

A well regarded group of presenters includes widely published sociologist Graham Scambler from University of Central London, who will present on “stigma and quality of life”, and Olympic cyclist Marion Clignet, who will speak about “exercise, diet and AED’s”. Other keynote addresses will focus on “epilepsy and depression”, “epilepsy and sexuality”, “epilepsy and employment”, “SUDEP” and “advocacy and epilepsy”.

There will be a session devoted to reports from the region on “improving outcomes for people living with epilepsy”, and a series of group discussions will explore “memory and epilepsy”, “epilepsy, sport and exercise”, “practical ways to manage depression”. In addition there will be a feature on epilepsy and the arts.

A book launch, Social Epileptology, edited by Dr Jaya Pinikahana and Dr Christine Walker, will precede the presentation of Outstanding Persons Awards from our ten member countries where each recipient will share their personal experiences and will be recognized for their achievements in facing issues related to their epilepsy. We need to provide travel assistance/support for the recipients to attend the Special Program for People with Epilepsy.

It is clear that we cannot provide full expenses because travel to Melbourne, Australia is more expensive than travel within Asia. We plan to provide each person with US\$600 to assist them to attend.

Budget: US\$4,800 (8 x US\$600)

Note that the Australian recipient may not need to travel if he/she is Victorian, however, an interstate airfare and accommodation will need to be provided if the recipient is from interstate. India is funding its representative. Not all 10 members might attend, in which case, unused funds can be redistributed.

Western-Pacific Regional Committee Meeting

We will hold a face to face meeting of the 10 members during the 8th Asian & Oceanian Epilepsy Congress in Melbourne, for 10 members Friday 22 October, 9.00am – 11.00am to progress the charter of the WPREC.

Budget: nil

Western-Pacific Regional Executive Committee Meeting

We will then hold a meeting during the 8th Asian & Oceanian Epilepsy Congress in Melbourne, 4 members, Friday 22 October, 11.00am – 12.00noon following the WPREC general meeting.

Budget: nil

Joint meeting of Western-Pacific and South-East Regions

A joint meeting of Western-Pacific and South-East Regions is planned in Melbourne on Friday 22nd October at 7.00pm. A Cocktail Reception will follow the brief meeting. This is to enhance the relationship between the two regions and to provide a social environment in which to get to know one another.

Budget: US\$200

Olympic cyclist, Marion Clignet & Bike Race

To address the main goal in the Western Pacific Region Terms of Reference which is to raise awareness of epilepsy in the region, we plan to invite Olympic cyclist Marion Clignet to present at the Special Program for People with Epilepsy on 21st October 2010.

It is planned to enable Marion to speak about “exercise, diet and AED's” and to conduct a workshop on. “epilepsy, sport and exercise”. Negotiations are still underway to reach an agreement to enable her to attend.

Budget Attendance: US\$2,200 (includes economy airfare, free congress registration and 3 days accommodation).

New Members

One of the aims of the Regional Committees was to enlarge the region by encouraging new membership applications, and to support existing members. New Members will be sought from the Pacific Islands because of the IBE Constitution change which now allows for new regional membership. We will seek the assistance of New Zealand to develop relationships because of their close proximity and the work they have already begun.

We are very eager to conduct a follow up meeting in Vietnam to progress establishing a Vietnam Chapter. We envisage that we will send a neighbouring member representative (probably Shunglon Lau) to progress this.

Budget: US\$1,000

Philippines Visit

Shunglon Lai and Robert Cole plan to visit Philippines to further support them and to establish a stronger relationship with a view to assisting them to plan and conduct the 9th Asian & Oceanian Epilepsy Congress in 2012.

Budget: US\$1,500

Survey of Members' Boards of Directors

We will assist the IBE with the Survey of Members' Boards of Directors to address the IBE membership criteria that all members of an association, including those with epilepsy, should be eligible to be nominated, stand for election to the association's board. The WPREC will survey members to establish the percentage of persons with epilepsy on the board of each IBE member in their region.

Budget: nil

BUDGET SUMMARY

<u>ACTIVITY</u>	<u>COST</u>
Outstanding Persons Awards	US\$4,800
Western-Pacific Regional Committee Meeting	nil
Western-Pacific Regional Executive Committee Meeting	nil
Joint meeting of Western Pacific and South-East Regions	US\$200
Marion Clignet Attendance at 8 th AOEC, Melbourne	US\$2,200
New Members (Vietnam visit)	US\$1,000
Philippines Visit	US\$1,500
Survey of Members' Boards of Directors	nil
TOTAL	US\$9,700

Robert Cole

Chair - IBE Editors Network

Chair - IBE Western Pacific Regional Executive Committee

Member - ILAE/IBE Scientific Consultative Committee 8th AOEC

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