

## **REPORT 2009 -2011 SOUTH EAST ASIAN REGION OF IBE**

### **Dr HV Srinivas Chair SEAREC**

A letter was addressed to all members of South East Asian Region (Bangladesh, Hong Kong, India, Indonesia, Nepal, Sri Lanka and Thailand) requesting information from their respective associations. The Indian Epilepsy Association, Epilepsy Association of Sri Lanka and Nepal Epilepsy Association have responded with reports. Sadly as there was no response from the other members, I am writing this report based on their previous reports submitted during the 8th Asian & Oceanian Epilepsy Congress, Melbourne, Australia in October 2010.

In addition I had the pleasure and opportunity to meet some of the executive committee members of the Epilepsy Association of Sri Lanka, when I was on a personal visit to Colombo on 2<sup>nd</sup> July 2011. There I was able to invite Dr. Wickramasinghe, President of EASL for the IBE satellite meeting to be held in Kochi on 7<sup>th</sup> August 2011. The Satellite Meeting in Kochi will have a session for the members of SEAREC during which the activities and experiences of each member will be presented. I am happy to note that Sri Lanka, Indonesia, Bangladesh, Nepal & India will be participating in this meeting.

### **1) Activities of Indian Epilepsy Association 2009 – 2011 (Dr. M M Mehndiratta)**

#### *Introduction:*

The Indian Epilepsy Association (IEA) was established in 1970. Present membership is 1875 members (Medical, Non -medical, People with epilepsy) and has 28 chapters spread all over the country.

*Publication:* The newsletter Epilepsy India is published quarterly. The website of IEA is [www.epilepsyindia.org](http://www.epilepsyindia.org). It is very informative and it covers a wide range of topics with photographs and information on activities of various IEA's chapters throughout the year.

Activities for Persons with Epilepsy (PWE) carried out by various chapters of IEA;

- Counselling
- Monthly Camps: Diagnosis & free drug distribution, subsidized medicines, special education & support groups.
- Essay, painting, quiz competitions and sports.
- Rural Epilepsy Programme (CORE)
- Street Plays.

*National Epilepsy Day* is celebrated by most of the chapters on 16<sup>th</sup> November every year. They celebrate by holding public awareness programmes, organising activities like sports, painting and essay writing competitions and other activities for children with epilepsy. In addition, participants are provided with opportunities to ask questions related to their problems over lunch or a cup of tea.

*Diploma In Epilepsy Care* (Bangalore University, in Collaboration with CBR Network & Indian Epilepsy Association): a one-year distance education programme which started in 2008

and is open to national & international students. It is a value –added course for teachers and nurses, public health workers, social workers etc...

The 11<sup>th</sup> joint Annual conference of IEA & IES was held on February 5<sup>th</sup> – 7<sup>th</sup> 2010 in Indore, Madhya Pradesh. The international faculty for the conference included Dr. Solomon L Moshe, President International League Against Epilepsy, Dr Patrick Kwan (Hong Kong), Dr A.N. Prasad (Canada), Dr Sunita Deglaust (USA) and Dr. Zenobia Zaiwala (UK). The second day of the programme dealt with social aspects of epilepsy and it was open to non-medical persons and people with epilepsy.

Support Groups: A number of chapters run support groups for people with epilepsy. Mumbai, Pune, Bangalore, Indore, Trivandrum and other chapters run very active programs to counsel PWE and their caregivers. IEA has also taken the initiative in defining disability for PWE whose seizures are uncontrolled.

Support Groups such as ‘Samman’ in Mumbai and ‘Sanvedana’ in Pune give members the opportunity to make friends, learn from each other how to cope with the disorder, build their personality and grow in confidence. Meetings are held fortnightly and at times professionals are invited to educate and interact with members. Members grow in confidence and ability by organizing and participating in the chapter’s activities, such as rural camps, skits, conferences, workshops, awareness programmes, picnics and parties. A particular important achievement of Sanvedana, which has completed 5 years, has been the foundation of a marriage bureau for people with epilepsy.

Rural Camps for adequate management of epilepsy and enhancement of public awareness are organised by various chapters of IEA. Mumbai and Trivandrum chapters hold these camps on a regular basis.

The Indore chapter conducted BMD screening tests to detect osteoporosis & osteopenia in patients with long term AED intake and random therapeutic drug monitoring in Epilepsy Camps for the most common drugs (CBZ, VPA, PHT, PHB, Lamotrigine). In addition, they have been organising Epilepsy education program for patients to increase their knowledge on social aspects like sports, jobs and psychosocial activities. They have been conducting these programmes for the past 10 years.

## **2) Epilepsy Association of Sri Lanka -( Dr. H T Wickramasinghe)**

The Epilepsy Association of Sri Lanka (EASL) was founded in February 1989. The inaugural meeting consisted of 11 participants. Five members were elected for the executive committee with Professor Nimal Senanayake as the President. Mr. Hemal Pieris acted as the chairman. Within a few years, the membership further increased to 278 members of which 105 members obtained life membership. There are a few members whose efforts need special appreciation: Nimal Senanayake and Mr. Hemal Pieris.

The EASL used to hold regular activities and lectures delivered by many national and international guest speakers. A Special Epilepsy clinic was set up for members at Sri Jayawardanepura Hospital with facilities for free access for investigations and treatment. “EPI news”, a newsletter of the association was regularly distributed among the members free of charge. However for unknown reasons, medical professionals started to show reluctance in taking part of the association’s committee and as a result recruitment of new members became difficult. At the same time, interest was lost amongst regular members. For the last few years, the Epilepsy Association of Sri Lanka was dormant with virtually no activities.

This year they decided to rejuvenate the association. They needed to evolve strategies to attract new members. Therefore they decided to publish articles related to various aspects of epilepsy in the most popular newspapers in the country. At the end of each article, an invitation is made to join EASL. A dedicated telephone line was also established for the public to contact EASL for advice. Furthermore, an application form for membership has been made available in epilepsy and neurology clinics in all major hospitals in the country. Printed material and posters regarding the vision and mission of EASL is now displayed in all epilepsy clinics. The Epilepsy Association of Sri Lanka is very hopeful that by next year, they will be able to fulfil all their aspirations.

### **3) Nepal Epilepsy Association (NEA), (Kabindra Man Pradhan, General Secretary)**

#### *Activities:*

- Epilepsy clinics in Kathmandu and Dolakha (remote mountain village);
- Epilepsy and Neurological disease related camps held in Bhattedada, Lalitpur District, Matche Gaon, Kathmandu, Bhaktapur, Pashupatinagar and Ilam;
- Provision of free AED;
- Provision of scholarships to poor students in Orphanages, Hospitals and Health centres;
- Mobile clinics are also in place;

#### Plan of future activities (Nepal) and budget for year 2011

This year NEA has decided to conduct more epilepsy camps throughout Nepal, and to open two epilepsy centres in Pokhara and Biratnagar. Furthermore, NEA has decided to make a short telefilm on epilepsy in the order to benefit patients with epilepsy. NEA has also decided to increase the number of scholarship given to students.

NEA will be working with its counterpart Family Academy Korea in order to support patients with epilepsy. FA Korea has donated 50,000 tablets of Phenytoin for 2011.

### **4) Epilepsy Association of Thailand (Dr. Araya Charuvanij).**

The EAT has 14 executive committee members including physicians, pharmacists, technicians and parents of children with epilepsy. At present there are 996 registered members. Among them, 618 are patients and care givers, 256 are physicians and the remaining members are from primary schools. The incidence of epilepsy in Thai people is about 5.9 - 7.2 per 1000 (about 383,500 -468,000 PWE). The majority of patients are treated and followed by general practitioners due to the limited number of neurology specialists.

The regular activities include publication of epilepsy bulletins, Epilepsy awareness programmes and an Annual meeting for members.

Plans of activities for 2011: To continue with the above mentioned activities.

### **5) (a) Enlighten action for epilepsy –Hong Kong**

Activities and Programmes:

- Bilingual Community Epilepsy Awareness Programmes;
- Bilingual Community Epilepsy Education;
- Training programmes;
- Bilingual Epilepsy Support Programmes;
- Bilingual Epilepsy Community Welfare Programmes;
- Other activities include: Family Day, Children’s Day, The Sunflower Schools Epilepsy Awareness Programmes and Information and Educational Booth.

### **(b) Epilepsy Association Hong Kong (Ms Ying Yi LI, N G Wai Hung )**

Activities and Programmes:

- Establishment of a local network of Mutual Support Groups;
- Periodical visits to patients and their families to recognize their difficulties and provide support;
- Quarterly newsletters;
- Training campaigns;
- Medical talks and seminars;

In 2010, the association has started a Symposium entitled ‘New Name for Epilepsy Ceremony’ combined with “Positive Change, Co-creating Harmony”. A new Chinese name was officially launched in June 2010.

### **6) Bangladesh Epilepsy Association (Dr Mannan)**

The Association was founded in 1992 and affiliated to IBE in 2005. They have 37 members of which 20 are doctors. The remaining members are patients and care givers.

Activities and Programmes:

- Free weekend clinics;
- Counselling;
- Quarterly awareness programmes for care givers and general public;
- An epilepsy management training programme for doctors;
- An annual programme both for medical and non medical participants;
- A short documentary film on Epilepsy is currently in development;

### **7) Indonesian Epilepsy Association (Dr. Achdiat Agoes, Secretary)**

Meetings to get in touch with all members in Middle and East Java Chapter;  
Pilot project in Malang, East Java;

Dr HV Srinivas  
Chair SEAREC –IBE

## IBE Satellite Meeting in Kochi



**Back row left to right:** Mr Kabindra Man Pradhan, Nepal; Dr HT Wikhramasinghe, Sri Lanka; Dr Achdiat Agoes Djamil, Indonesia; Dr. M. Mannan, Bangladesh & IBE Vice-Chair South East Asia;

**Front row left to right:** Dr HV Srinivas, IBE Chair South East Asia; Mr. Mike Glynn, IBE President; Dr. Vinod Saxena, IBE Vice President South East Asia; Dr. MM Mehndiratta, India & IBE Secretary South East Asia;