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# BANGLADESH EPILEPSY ASSOCIATION



# COUNTRY OF OPERATION Bangladesh

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1992
INITIAL AFFILIATION TO IBE

2005
TYPE OF ORGANISATION

Individual

RANGE OF OPERATION
National

#### MISSION

To ensure a better quality of life for people with epilepsy and their care givers.

#### GOALS

- To increase Awareness
- To Promote Public Health
- To Ensure Treatment
- To increase Social Acceptability
- To Ensure Education and Sports
- To Educate Caregivers about Epilepsy
- To offer Continuing Medical Education for Doctors and Health care givers
- To organise Social Responsibility

#### STATISTICS

At present we have 37 Members in our organisation. Among them 20 are doctors, 10 health professionals working with epilepsy, 5 caregivers and 2 people with epilepsy.

# REGULAR ANNUAL ACTIVITIES

- Weekly free medical clinic for epilepsy patients to ensure proper and regular treatment and counseling
- Quarterly awareness program for the general public and caregivers
- Half yearly training program for caregivers and health professionals
   Yearly training program for physicians from all over the country
- Yearly training program for physicians from all over the country
- Biennial International Epilepsy Teaching course for physicians jointly with the Asian Epilepsy Academy

# SPECIAL ACTIVITIES DURING 2009-2010

- Public awareness program about epilepsy
- Basic epilepsy management training program for young graduated doctors
- "Meet Epilepsy"- to share the experience of persons with epilepsy

# "CARING FOR EPILEPSY" – AN AWARENESS DEVELOPING DOCUMENTARY FOR LOCAL MEDIA

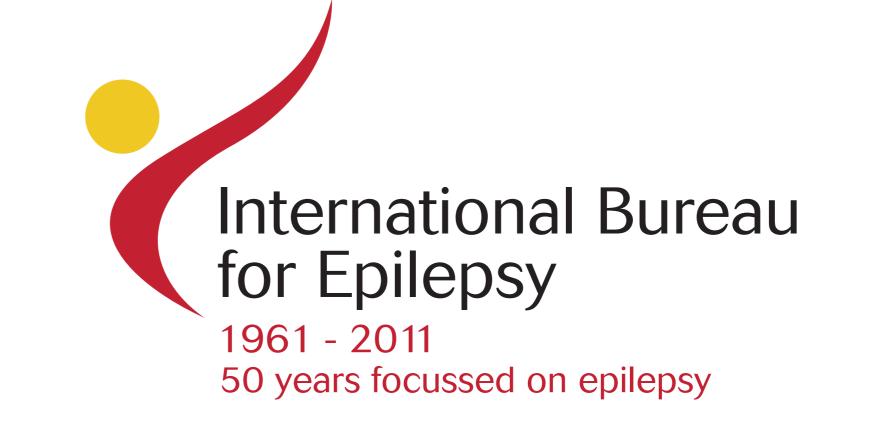


With the financial support of IBE, under the Promising Strategies Program, Bangladesh Epilepsy Association is making a short documentary film which will be shown in all electronic media in Bangladesh to develop and increase knowledge and awareness about epilepsy.

# CONTACT DETAILS

Dr Muzharul Mannan, Secretary General, Bangladesh Epilepsy Association 3/1 Lake Circus Kalabagan, Dhaka-1205, Bangladesh Tel: (8802) 8114846, Fax: (8802) 8151224 E-mail: epilepsy\_bd@yahoo.com or parthobd@hotmail.com







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# THE HONG KONG EPILEPSY ASSOCIATION (HKEA)





#### COUNTRY OF OPERATION Hong Kong (China)

TYPE OF IBE MEMBER Full member (Hong Kong)

FOUNDING DATE 1997

TYPE OF ORGANISATION Individual membership

RANGE OF OPERATION

Local

Hong Kong Epilepsy Association (HKEA) is a non-profit-making organisation founded in 1997. We started as a self-help group comprising persons with epilepsy and their families.

#### **GOALS**

HKEA works to

- Promote a sense of self-help and mutual aid among the patients.
- Educate the public with appropriate information on epilepsy, in order to minimize discrimination and stigma against persons with epilepsy.
- Raise public concern on the rights of persons with epilepsy.
- Advocate for equal opportunities on the basis of harmony in society.

### MISSION AND SERVICE

To achieve our goals, we have

- Established a local network of Mutual Support Groups.
- Arranged periodic visits to persons with epilepsy and their families, in order to find out about the difficulties they face and to provide support.
- Published a quarterly newsletter to disseminate the latest news and information about epilepsy.
- Organised training events together with recreational activities.
- Organised medical talks and seminars.

Since 2002, we have been approved for funding from the Social Welfare Department of the Government of HKSAR for our social activities. It definitely is an encouragement but also a recognition of all of the members in HKEA. With this subsidization, we have employed staff to help us in co-ordination of our programs and to widen our service.

In 2010, we started the project 'New Name for Epilepsy' and "Positive Change, Co-creating Harmony" Symposium' intending to minimize discrimination of persons with epilepsy caused by the Chinese name for epilepsy.



On June 27th 2010, a new Chinese name was officially launched in a special ceremony.





# **CONTACT DETAILS**

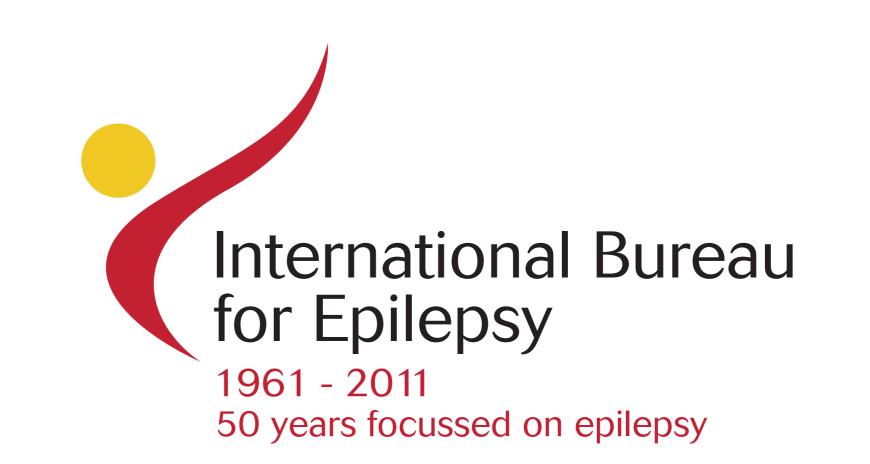
Mr Ted Chiu

The Hong Kong Epilepsy Association

12th Floor, Kuo Wah Building340-342 Hennessy Road, Hong Kong E-mail address: hkea@hkepilepsy.org or hkea\_hkea@yahoo.com.hk

Website: http://www.hkepilepsy.org http://www.hkepilepsy.com







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# ENLIGHTEN - ACTION FOR EPILEPSY



# COUNTRY OF OPERATION Hong Kong

TYPE OF IBE MEMBER
Associate (2002)

# FOUNDING DATE

7 August 2002

# TYPE OF ORGANISATION Individual Membership and Family Membership

RANGE OF OPERATION
National

#### **GOALS:**

- To offer free of charge bi-lingual (Cantonese English) personalised services to people with epilepsy, their families, carers, friends and colleagues.
- To provide accurate, up-to-date bilingual advice and information to all who are affected by epilepsy.
- To increase public understanding of epilepsy and its impact on the quality of life through the education and training.

#### **OUR SERVICES:**

Our key combined services are provided to all sectors of the Hong Kong community and they are, but not limited to:

#### (A) Bilingual Epilepsy Support and Community Welfare Programmes

Enlighten provides epilepsy support services to people with epilepsy, their families and carers, schools or work places by:

- Providing up-to-date information, knowledge and skills regarding epilepsy
- Offering practical help and professional advice on issues concerning epilepsy
- Giving emotional support and psycho-social therapy
- Supporting members through the complex and difficult process of initiating anti-epileptic drug changes and/or withdrawing medication
- Advising on other rehabilitative approaches to epilepsy
- Assisting members to overcome stigma

# (B) Bilingual Community Epilepsy Education and Training Programmes

- Enlighten offers a wide range of bi-lingual complimentary Education and Training to the Hong Kong community on issues related to epilepsy.
- Enlighten is committed to providing training for different sectors and we ensure that the specific needs of those we are training are met.

# (C) Bilingual Community Epilepsy Awareness Programmes

• Enlighten raises epilepsy awareness through strategic awareness campaigns throughout the region.

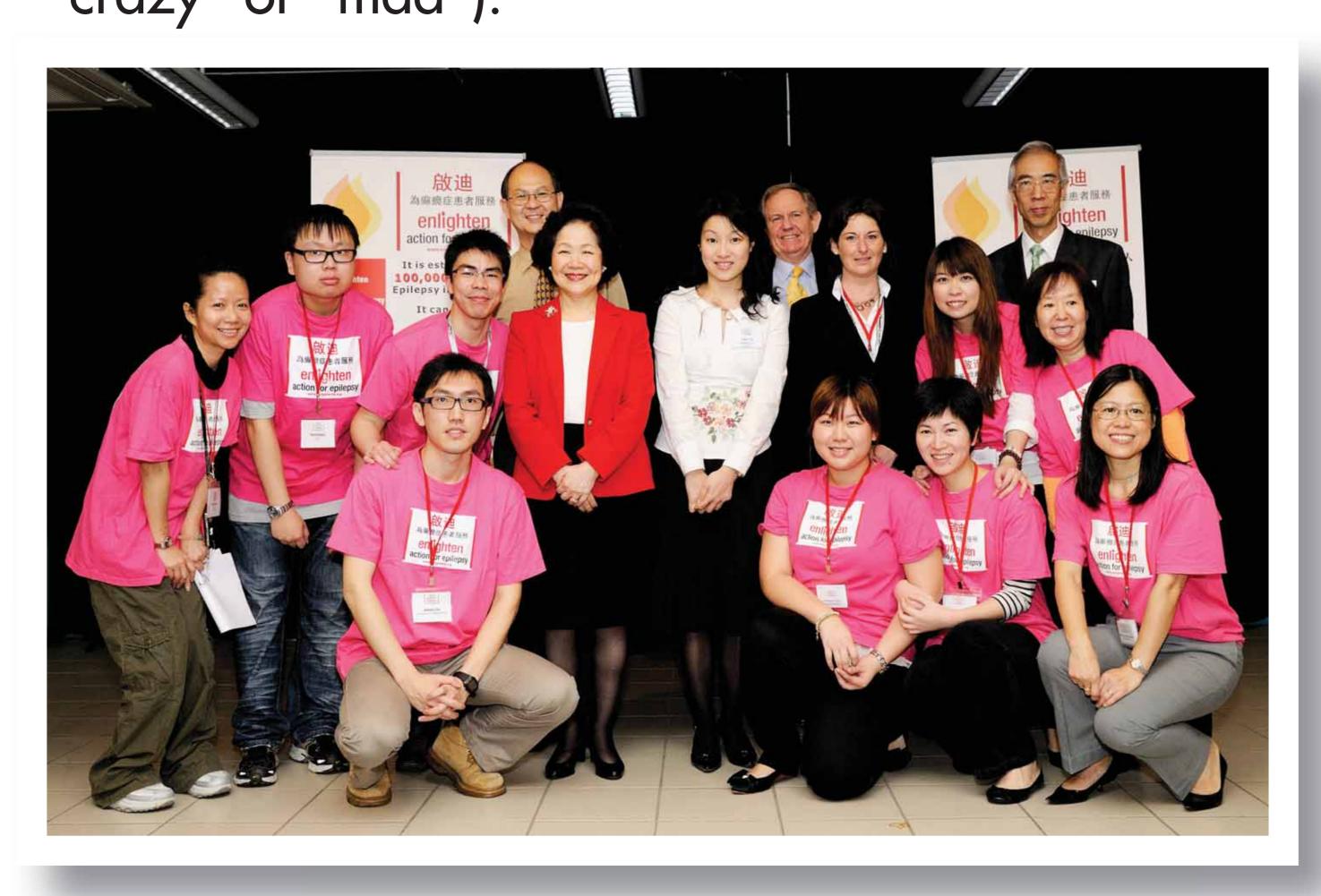
# ADVOCACY:

Enlighten advocates for the rights and benefits of the people affected by epilepsy in the light of Government legislature and ordinance striving for equal opportunities for medical treatment, social rehabilitation, education, employment, housing, transport, leisure and other community resources.

# SOME FACTS ABOUT EPILEPSY IN HONG KONG

It is estimated that over \*100,000 people have epilepsy in Hong Kong. It is estimated that it occurs in 1:69 people and affects 1:23 families. There is a strong tradition, with thousands of years of myths and misconceptions about epilepsy in Hong Kong.

Some believe that the person affected is contagious; some believe that the person is crazy due to the fact that the word for epilepsy in Chinese is "Dean Gan Tsing" (in translation, "Dean" means "crazy" or "mad").



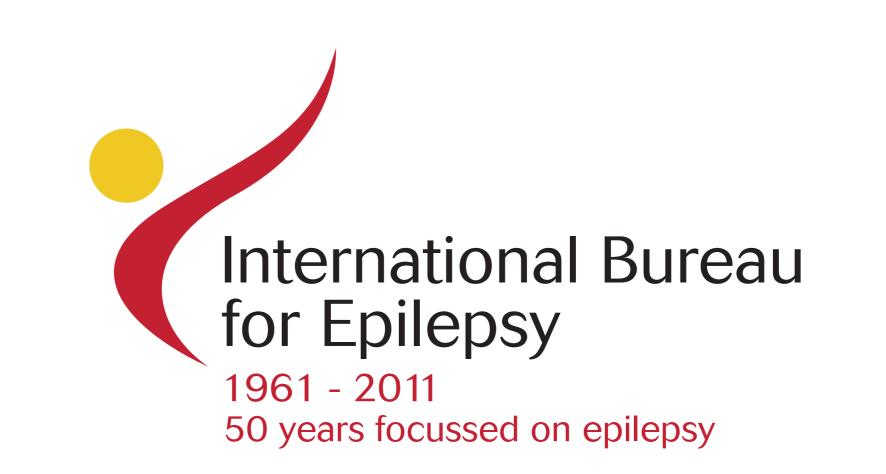
Some believe that the person is affected because his/her mother has eaten lamb during pregnancy.

\*100,000 – this figure was presented to Enlighten-Action for Epilepsy by a Hong Kong Neurosurgeon in 2005. He stated that he believes the number is much higher than recorded as many people are either misdiagnosed or do not come forward for treatment for fear of being discriminated against.

# CONTACT DETAILS

Address: 12/F Kuo Hwa Building, 340-342 Henessy Road, Hong Kong. E-mail: admin@enlightenhk.org
Website: http://www.enlightenhk.org/

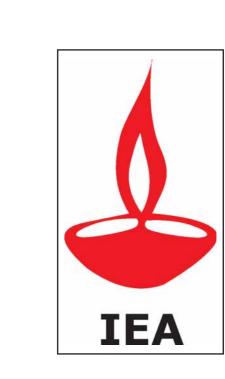






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# INDIAN EPILEPSY ASSOCIATION





The Indian Epilepsy Association (IEA) was established in 1970 with the following principal objectives:

- To promote better treatment and care, welfare and rehabilitation of persons suffering from epilepsies.
- The collection, compilation, advertisement and dissemination of knowledge concerning epilepsy.
- To disseminate knowledge and understanding of the disease amongst the lay public, persons with epilepsy and their relations and to make known to the public the various difficulties facing persons with

epilepsy, so as to facilitate their adjustment into Society.

- To promote, guide, co-ordinate, organise, finance and conduct research in all aspects of epilepsy.
- To provide training facilities for medical, scientific and other technical staff working in the Society.

#### **CURRENT MEMBERSHIP**

1,875 (medical, non-medical, and persons with epilepsy)

#### **PUBLICATION:**

Epilepsy India, the newsletter of Epilepsy India, is published quarterly. It is circulated to all members of Indian Epilepsy Association, to IBE central office and to the secretariats of other member associations of IBE.

#### Activities for Persons with Epilepsy carried out by various chapters of IEA

- Counseling
- Monthly camps: Diagnosis and free drug distribution
- Essay, painting and Quiz competitions
- Subsidized medicines, counseling, special education and support group
- Sports
- Rural Epilepsy programme (CORE)

National Epilepsy Day: is celebrated by most of the chapters with public awareness program, sports for children with epilepsy, painting and essay writing competitions etc.

# DIPLOMA IN EPILEPSY CARE:

- Open to National and International students
- A value-added course for Teachers and Nurses
- For further information contact: ieablr@vsnl.net or visit www.epilepsyindia.org

# ANNUAL CONFERENCES:

Joint annual conference of Indian Epilepsy Association and Indian Epilepsy Society is organised every year. Medical as well as Social aspects are covered. The 12th Joint meeting of IEA and IES will be held in Ludhiana, Punjab 25th-27th February 2011.

# GUIDELINES FOR THE MANAGEMENT OF EPILEPSY IN INDIA:

Experts in the field of epilepsy from different parts of the country held a meeting to draft Guidelines for the Management of Epilepsy in India. These guidelines have been very well received. The complete booklet of guidelines has also been uploaded to the IEA and ILAE websites.

# **SUPPORT GROUPS:**

A number of chapters run support groups for people with epilepsy. Mumbai, Pune, Bangalore, Indore, Trivandrum etc chapters run very active programs to counsel people with epilepsy and their caregivers. IEA has taken initiative in defining disability in persons with epilepsy whose seizures are uncontrolled. The current President Dr. Pravina Shah efforts are laudable in this respect.

# E-VISION

• To increase the affordability of epilepsy medication on a large scale.

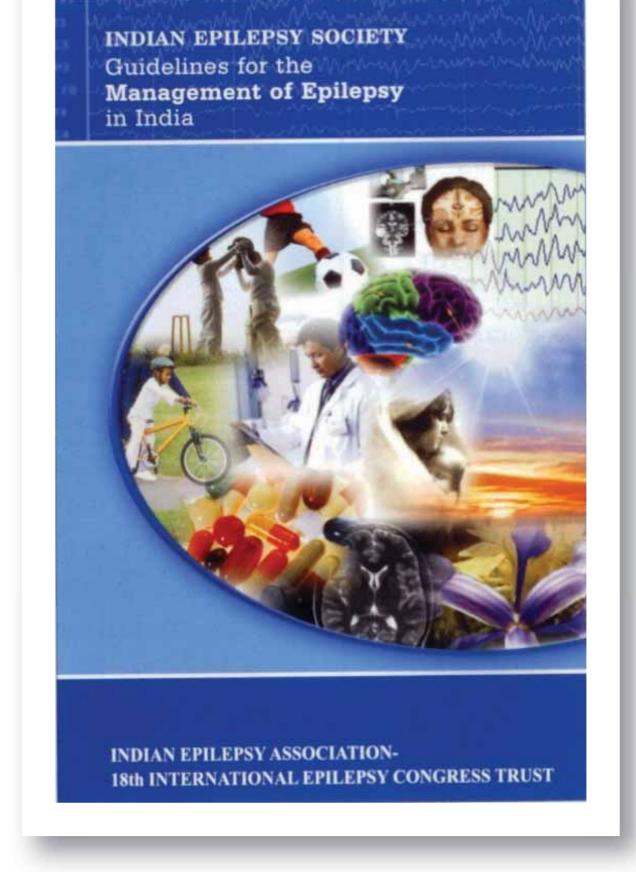
 To reduce the stigma of epilepsy so that each person who deserves a job is able to get one and people of marriageable age are able to get married.

 To increase independence and self sufficiency of all people with epilepsy

To raise the quality of life of people with epilepsy and their families.

# RURAL EPILEPSY CAMPS

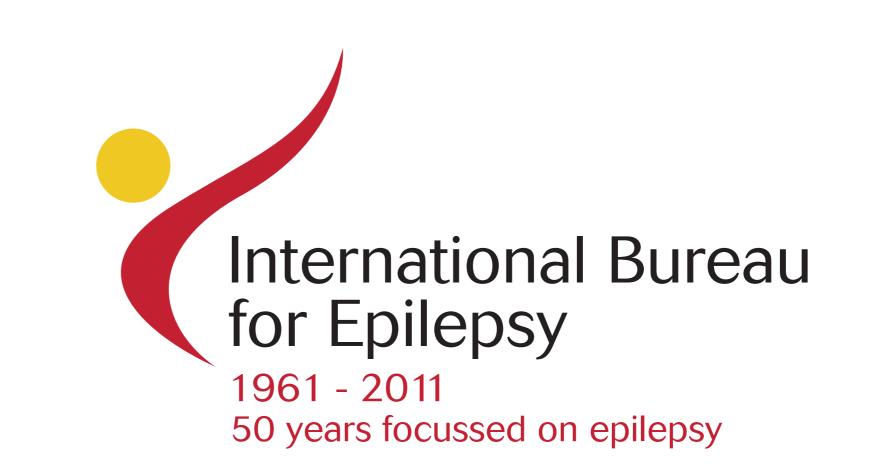
Camps in rural areas of different states are held by the state chapters of IEA. Mumbai and Trivandrum chapters hold these camps on a regular basis. The camps help to provide adequate management of epilepsy and enhancement of public awareness The Indian Epilepsy Association, hopes to make a difference to the lives of people with epilepsy.



# CONTACT DETAILS

Dr. M.M. Mehndiratta, Secretary General Indian Epilepsy Association, Professor of Neurology, Department of Neurology, #502, Academic Block, G.B. Pant Hospital, New Delhi 110 002, Ph: 091-11-23234350 E-mail: mmehndi@hotmail.com • Website www.epilepsyindia.org







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# PERPEI, INDONESIA



- Population (July 2009 est.): 240.3 million.
- Annual population growth rate (2009 est.): 1.136%.
- Ethnic groups (2000 census): Javanese 40.6%, Sundanese 15%, Madurese 3.3%, Minangkabau 2.7%, others 38.4%.
- Languages: Indonesian (official), local languages, the most prevalent of which is Javanese.
- Health: Infant mortality rate (2009 est.): 29.97/1,000.
- Life expectancy at birth (2009 est.): 70.76 years.
- Terrain: More than 17,500 islands; 6,000 are inhabited; 1,000 of which are permanently settled. Large islands consist of coastal plains with mountainous interiors.

Spread across a chain of thousands of islands between Asia and Australia, Indonesia has the world's largest Muslim population. Ethnically it is highly diverse, with more than 300 local languages. The people range from rural hunter-gatherers to a modern urban elite.

Indonesia's approximately 240.3 million people make it the world's fourth-most populous nation. The island of Java is the most populous island in the world (124 million, 2005 est.) and one of the most densely populated areas in the world.

Indonesia includes numerous related but distinct cultural and linguistic groups, many of which are ethnically Malay. Since independence, Bahasa Indonesia (the national language, a form of Malay) has spread throughout the archipelago and has become the language of most written communication, education, government, business, and media.

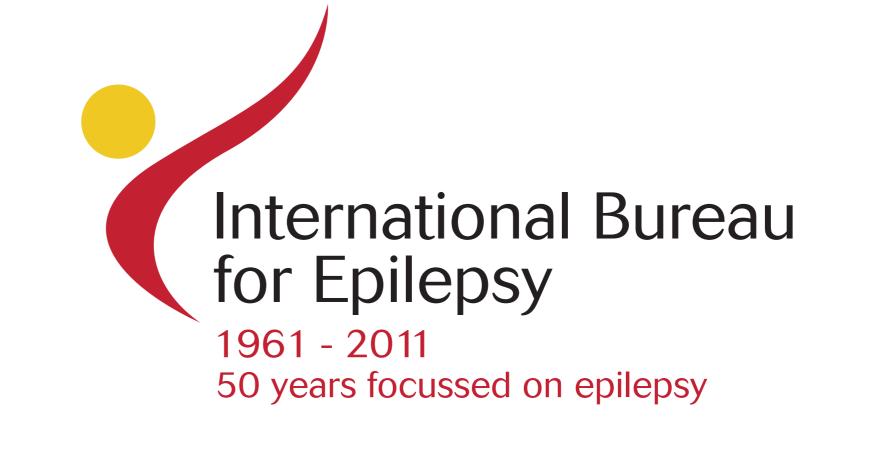
Indonesia has seen great turmoil in recent years, having faced the Asian financial crisis, the fall of President Suharto after 32 years in office, the first free elections since the 1960s, the loss of East Timor, independence demands from restive provinces, bloody ethnic and religious conflict and a devastating tsunami.



# CONTACT DETAILS

PERPEI, Bagian Neurologi FKUI Jl. Salemba 6, Jakarta Pusat 10430, Indonesia T: +62 2133 5044 perpei2004@yahoo.com Contact: Dr Silvia Lumempouw







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# YAYASAN EPILEPSI INDONESIA



Indonesia comprises 17,508 islands and thirty three provinces. With over 238 million people, it is the world's fourth most populous country, and has the world's largest population of Muslims. Indonesia is a republic, with an elected legislature and president. The country shares land borders with Papua New Guinea, East Timor, and Malaysia. Other neighboring countries include Singapore, Philippines, Australia, and the Indian territory of the Andaman and Nicobar Islands.

Indonesia is a founding member of ASEAN and a member of the G-20 major economies. The Indonesian economy is the world's eighteenth largest economy by nominal GDP and fifteenth largest by purchasing power parity.

The Indonesian archipelago has been an important trade region since at least the 7th century, when Srivijaya and then later Majapahit traded with China and India. Local rulers gradually absorbed foreign cultural, religious and political models from the early centuries CE, and Hindu and Buddhist kingdoms flourished.

Indonesian history has been influenced by foreign powers drawn to its natural resources. Muslim traders brought Islam, and European powers brought Christianity and fought one another to monopolize trade in the Spice Islands of Maluku during the Age of Discovery. Following three and a half centuries of Dutch colonialism, Indonesia secured its independence after World War II. Indonesia's history has since been turbulent, with challenges posed by natural disasters, corruption, separatism, a democratization process, and periods of rapid economic change.

Across its many islands, Indonesia consists of distinct ethnic, linguistic, and religious groups. The Javanese are the largest ethnic group. Indonesia has developed a shared identity defined by a national language, ethnic diversity, religious pluralism within a majority Muslim population, and a history of colonialism including rebellion against it. Indonesia's national motto, "Bhinneka Tunggal Ika" ("Unity in Diversity" literally, "many, yet one"), articulates the diversity that shapes the country.

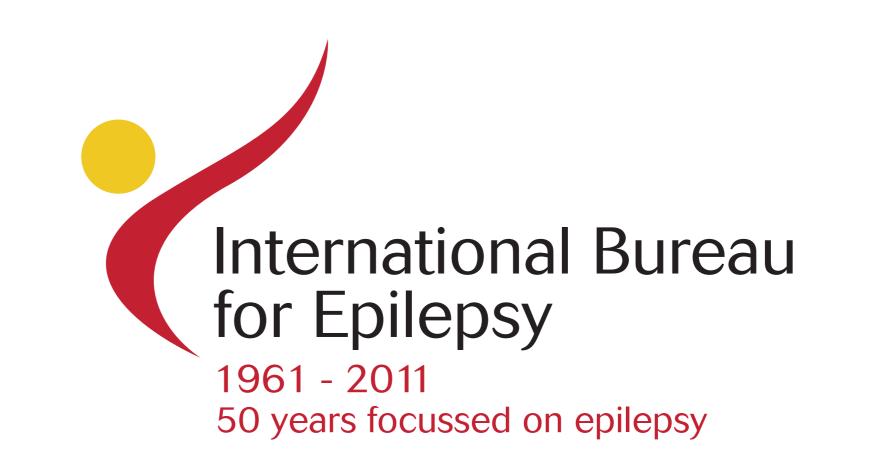


Despite its large population and densely populated regions, Indonesia has vast areas of wilderness that support the world's second highest level of biodiversity. The country is richly endowed with natural resources, yet poverty remains widespread in contemporary Indonesia.

# CONTACT DETAILS

Yayasan Epilepsi Indonesia, Jl. Hang Jebat II/2, Kebayoran Baru, Jakarta Selatan 12120, Indonesia. T: +62 217251710 Contact: Ms Mahar Mardjono.



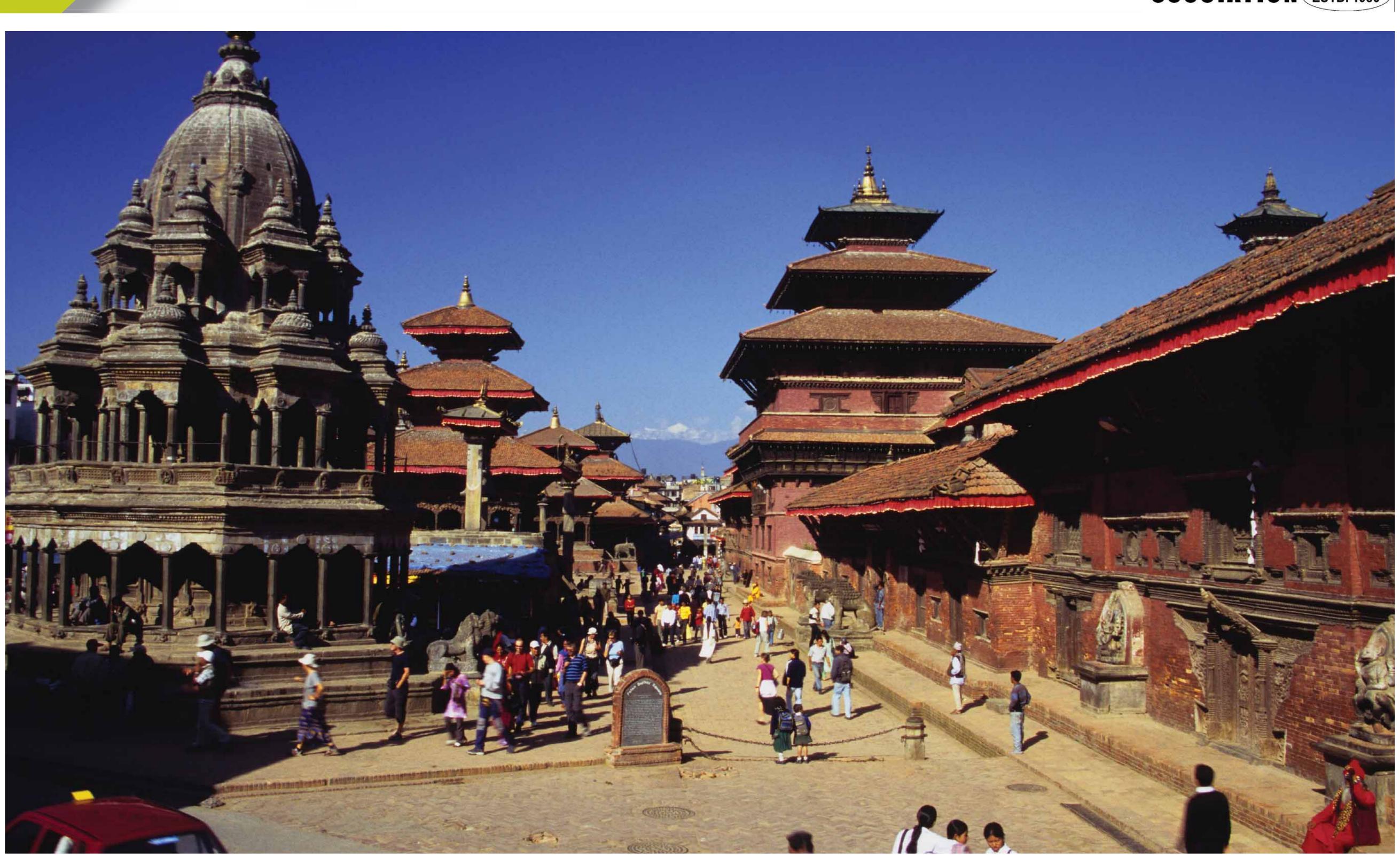




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# NEPAL EPILEPSY ASSOCIATION

NEPAL NEAL STD. 1986



#### COUNTRY OF OPERATION

Nepal

#### TYPE OF IBE MEMBER

Full Member

# DATE ORGANISATION WAS CREATED 1006

1986

# DATE ORGANISATON FIRST AFILIATED TO IBE

2007

# TYPE OF ORGANISATION

Individual and Organisational Membership

# RANGE OF OPERATION

National

# MISSION

To care for the persons living with epilepsy and to raise awareness about epilepsy in Nepal.

# GOALS

- To provide medical education for public awareness of epilepsy.
- To run epilepsy centers throughout the country.
- To launch epilepsy camps and free medicine throughout the country.

# NEPAL EPILEPSY + ASSOCIATION



# STATISTICS

There are more than 1000 persons with epilepsy who are the general members of the associations. But these general members do not have voting rights. Life members and Executive members have voting rights. More than 7,000 persons with epilepsy have been treated in different epilepsy camps throughout Nepal.

# REGULAR ANNUAL ACTIVITIES

- Runs weekly an epilepsy clinic in the center of Kathmandu.
- Runs Monthly clinic in Dolakha and Pokhara.
- Runs at least one epilepsy camp with free medicine distribution every two months throughout Nepal.
- EEG service in the remote area.
- Awareness program during epilepsy camp.

# SPECIAL ACTIVITIES DURING 2010-2011

Epilepsy camps in various remote area of Nepal with Korean counter-part. Awareness via electronic media as a program for promising strategy 2011

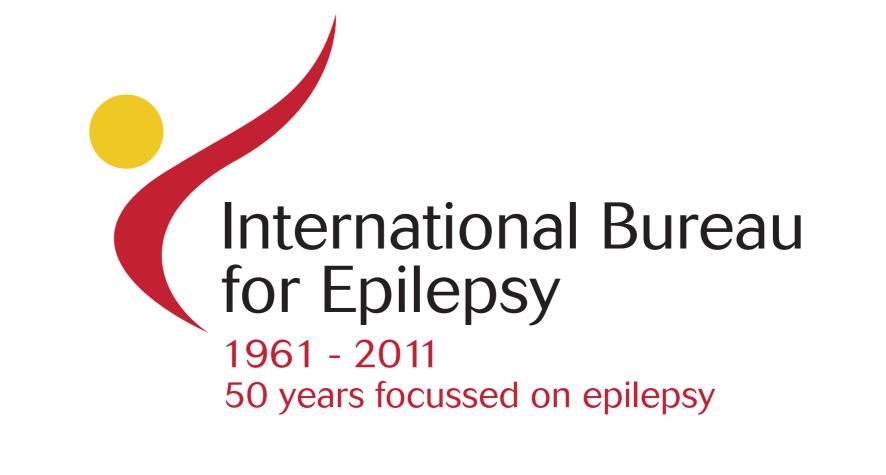
# CONTACT DETAILS

Kishor Shrestha

736/49 Narayan Gopal Sadak, Lazimpat, Nepal

E-mail: nepeas@yahoo.com Web site: www. nepilepsy.org.np







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# EPILEPSY ASSOCIATION OF SRI LANKA



The Epilepsy Association of Sri Lanka was revived last year, after lying "dormant" for several years. A new Executive was appointed last year, and the audited accounts were brought up to date.



# CONTACT DETAILS Epilepsy Association of Sri Lanka, 119/1 Kynsey Road,

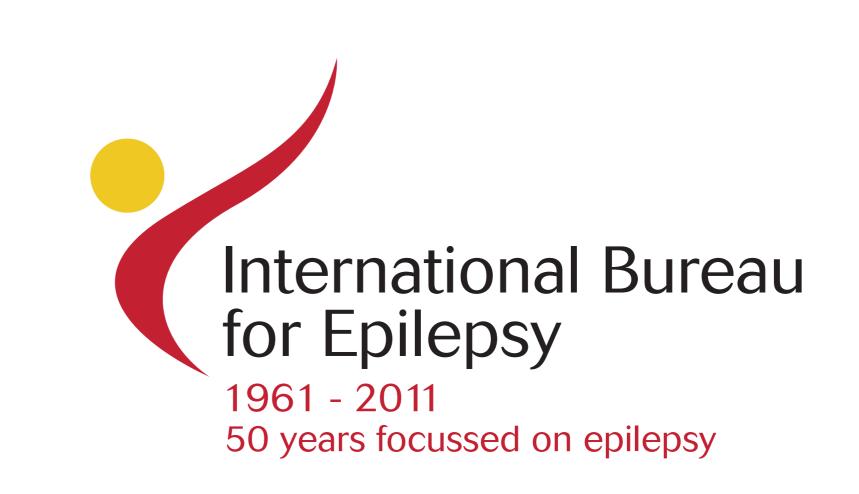
Colombo 08, Sri Lanka

# OBJECTIVES

- To attract a handful of active [younger] members who can together with the doctor members make our association more "active". The association understands the fundamental principle that member associations should be a balanced partnership between doctors and laymen;
- To work out a strategy to attract new committed members;
- To continue the work intended to help those with Epilepsy and allied needs,— e.g. training in "life-skills", employment needs etc...

The board of Epilepsy Association of Sri Lanka met with the IBE Chair of the South East Asia region. The meeting was very successful and it helped strengthen the bond between IBE and the Epilepsy Association of Sri Lanka.







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# EPILEPSY ASSOCIATION OF THAILAND (EAT)



# COUNTRY OF OPERATION Thailand

TYPE OF IBE MEMBER
Full member

FOUNDING DATE
July 2002

INITIAL AFFILIATION TO IBE

2005
TYPE OF ORGANISATION

Individual and organisational membership

RANGE OF OPERATION
National

#### MISSION

To improve the quality of life of people with epilepsy and to promote public understanding about epilepsy through the propagation of epilepsy knowledge.

#### GOALS

- To provide a broader understanding/knowledge of the nature of epilepsy for people with epilepsy.
- To improve the quality of life of people with epilepsy.
- To promote the exchange of information among people with epilepsy, their relatives and care givers.
- To bring together, from all sources, information about social and medical care for people with epilepsy and to disseminate such information throughout the country.
- To represent people with epilepsy in relation to national and international organisations concerned with human welfare.

# STATISTICS

The incidence of epilepsy in Thai people is about 5.9 to 7.2 per 1,000. Since the population of Thailand is about 65 million, the estimated number of people with epilepsy is about 383,500 -468,000. The majority of patients are treated and cared for by general practitioners owing to the limited number of neurology specialists, who are based mostly in the university or the regional hospitals and in a few general hospitals.

The EAT has 14 executive committee members including physicians, pharmacists, technicians and parents of the affected children. At present there are 996 registered members. Among them, 618 are people with epilepsy and care givers, 256 are physicians and the rest are primary schools.

# REGULAR ANNUAL ACTIVITIES

- Three issues of an epilepsy bulletin are published and sent to members each year.
- An annual meeting for people with epilepsy, care givers and doctors are held on the third Sunday of January every year.
- A Painting Competition has been held each year since the establishment of the association.
- Presenting epilepsy information to school children and teachers: 1-3 schools per year.

# SPECIAL ACTIVITIES DURING 2009 – 2010

Epilepsy Camping Day: Twenty-five pairs of epilepsy patients and their care giver attended the first epilepsy camp at Suan-Sam-Pran garden on 8th November, 2009. We had outdoor and in-door games and also an epilepsy quiz game for them. The patients and their care-givers got to know each other better and shared their own experiences on how to survive and live well with epilepsy.



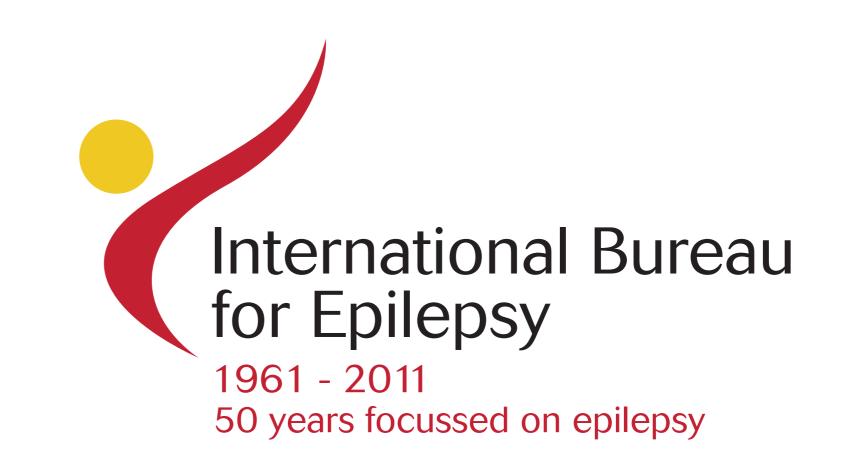
# CONTACT DETAILS

Dr. Araya Charuvanij

Address: 74/29 Raminthra 8, Raminthra Road, Bangkhaen, Bangkok 10220, Thailand.

E-mail: arayacharuvanij@yahoo.com







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# MEMBERS IN THE SOUTH EAST ASIA REGION

BANGLADESH Bangladesh Epilepsy Association

HONG KONG The Hong Kong Epilepsy Association

Associate Member: Enlighten Hong Kong Ltd

INDIA Indian Epilepsy Association

INDONESIA PERPEI

Associate Member: Yayasan Epilepsi Indonesia

NEPAL Nepal Epilepsy Association

SRI LANKA Epilepsy Association of Sri Lanka

THAILAND Epilepsy Association of Thailand



