

International Bureau for Epilepsy

Promoting and supporting the work of 122 member associations in 92 countries around the world

EPILEPSY AUSTRALIA



COUNTRY OF OPERATION

Australia

TYPE OF IBE MEMBER

Epilepsy Australia proudly became an Associate Member of IBE in 2008

WHO WE ARE

Epilepsy Australia is the national coalition of Australian Epilepsy Associations operating as a federated model that matches the governance of Australia

EPILEPSY AUSTRALIA'S MEMBER ASSOCIATIONS:

- Epilepsy ACT
- The Epilepsy Centre of South Australia & the Northern Territory
- Epilepsy Tasmania
- Epilepsy Foundation of Victoria
- Epilepsy Queensland
- Epilepsy Association of Western Australia

RANGE OF OPERATION

Epilepsy Australia thinks nationally and delivers locally. Member associations are community-based organizations providing services to local, regional and remote communities across Australia.

As the largest consumer-led epilepsy organization, Epilepsy Australia actively delivers counselling, support and information to all who access our services and is committed to supporting the Australian community in making enlightened and fully informed responses to epilepsy.

EPILEPSY AUSTRALIA'S MISSION IS TO

- Produce comprehensive information on epilepsy and seizures, and deliver accredited education and training programs
- Raise awareness and understanding of epilepsy and seizures within the wider community
- Promote and facilitate research into the medical and social aspects of epilepsy, and
- Advocate for people living with epilepsy where a national outcome is sought.

SUPPORTING OUR COMMUNITIES

Epilepsy Australia has 31 full time dedicated service staff locally delivering specialist epilepsy services across the country. This multidisciplinary team comprises registered nurses, counsellors, psychologists, teachers, disability support workers, social researchers, and a specialist epilepsy librarian.

Specialist services include:

- National helpline service – 1300 852 853
- Counselling & personal support
- Client focussed workshops and seminars
- Professional development & workplace education
- Hospital based clinics
- Community awareness programs
- Advocacy & referral services
- Support groups
- Recreational programs & weekend retreats

CONTACT DETAILS

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PROMOTING BEST PRACTICE

- National Seizure First Aid guidelines.
- Skills in Epilepsy Care & Management. Developed by Epilepsy Australia, in partnership with Victoria University of Technology, this nationally accredited course is the first of its kind in Australia and is delivered by member associations.
- Community & Professional Education Programs delivered nationally by qualified epilepsy trainers.

INFORMING OUR COMMUNITIES

Epilepsy Australia is committed to publishing information of the highest standard. Our publications include:

- Sudden Unexpected Death in Epilepsy: a global conversation.
- The Epilepsy Report.
- Information Kit for Australian Indigenous communities.
- Epifile: an epilepsy management manual.
- Seizures & Epilepsy: answering frequently asked questions.z
- Various books and first aid videos.
- Acknowledging our cultural diversity, information on Seizure First Aid is available in 20 languages.

CHANGING COMMUNITY ATTITUDES

Epilepsy Australia's **Trivia Challenge** is an educational event conducted throughout Australian schools each year. Designed to develop an understanding of epilepsy and enhance general knowledge by using a specially developed trivia questionnaire based on the curriculum, **Trivia Challenge** informs thousands of young Australians each year on basic epilepsy information and first aid for seizures. Over 40,000 school children participate in this event each year.

INFORMING POLICY MAKERS

Epilepsy Australia sponsors and facilitates applied social research into epilepsy that aims to inform government and policy makers of the impact of living with epilepsy.

- Social Epileptology: Understanding social aspects of epilepsy. Eds. Jaya Pinikahana & Christine Walker
- Epilepsy in Australian Policy: Dr Christine Walker
- Researching the personal impact of epilepsy: Dr Christine Walker
- The impact of Epilepsy on the Psychosocial Functioning of Young People: Allison Clarke

8TH ASIAN OCEANIAN
EPILEPSY
CONGRESS

21–24 October 2010
Melbourne, Australia



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EPILEPSY QUEENSLAND INC



COUNTRY OF OPERATION

Australia

TYPE OF IBE MEMBER

Associate
Also a member of JECA which is a full member

FOUNDING DATE

19 February 1969 (formal establishment)

INITIAL AFFILIATION TO IBE

2009 first year of affiliation as Associate Member

TYPE OF ORGANISATION

Individual membership
Providing services to anyone (membership not a necessity)

RANGE OF OPERATION

State of Queensland

THE GOAL OF OUR ORGANISATION

Epilepsy Queensland enhances quality of life for people with epilepsy and their families.
Epilepsy Queensland is bringing epilepsy out of the shadows.

OUR GOALS:

- To create a supportive environment for people with epilepsy and their families.
- To empower people with epilepsy and their families.
- To contribute to the scientific understanding of epilepsy through research, education and its application.
- To ensure health, welfare and other services respond appropriately to the needs of people with epilepsy and their families.
- To ensure appropriate policies for people with epilepsy are included in public policies in all sectors.
- To ensure the long-term sustainability of Epilepsy Queensland Inc.

OVERVIEW OF SERVICES

- Information about epilepsy through brochures, information sheets, seminars, newsletters, fact sheets, books and the internet
- Support and counselling
- Education and in service training for people working in the health, disability or education sectors.
- Advocacy
- Psychosocial research
- Community awareness program
- Personal development and respite through activities and retreats (for example, camps for children/families, retreats/pamper days for mothers)
- Special programs for:
 - Children
 - Teenagers
 - Families with a child who has epilepsy and high support needs

PARTICULAR SPECIALISM

Children with epilepsy

The Little Poss Program (Poss is a possum with epilepsy) which comprises 2 books, a show that visits school, a club which has a regular newsletter for children, activities (such as birthday parties), merchandise, activity packs etc.

ON-LINE PROGRAMS

- Forum called "Talk Epilepsy" where people can chat and offer/gain mutual support.
- Site called "Learn Epilepsy" with self-paced learning modules about different aspects of epilepsy.
- Annual Awards Ceremony: for example for best role model, or best tertiary student project on epilepsy.



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EPILEPSY ACTION AUSTRALIA



COUNTRY OF OPERATION

Australia

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

1952

INITIAL AFFILIATION TO IBE

1980'S

TYPE OF ORGANISATION

Individual membership

RANGE OF OPERATION

National

VISION AND MISSION

Vision: Confident living, despite seizures

Mission: Epilepsy Action Australia undertakes research and advocacy, and delivers innovative, high quality service across Australia to optimise life outcomes for people with epilepsy. An estimated 600,000 people in Australia will be diagnosed with epilepsy in their lifetime. Epilepsy Action Australia (EAA) is committed to delivering equitable and consistent services to all people in Australia, working to deliver higher, national levels of support - particularly health education and interventions to facilitate self-management.

Delivering services nationwide for more than a decade, EAA is the largest provider of specialist epilepsy services in the community.

OUR SERVICES INCLUDE:

- Information, support and education
- Individual case management
- Seizure management planning
- Emergency medication and general awareness training
- Seizure first aid
- Memory workshops
- Residential camps for families
- Epilepsy nurse support to hospital clinics

EAA has developed high level expertise and a rich base of epilepsy information, particularly vested in our Epilepsy Nurse Educators. We deliver services via phone, videoconference and internet and have a physical presence in most states and territories.

Living with epilepsy can be isolating and the diagnosis is often associated with anxiety and depression. To respond to the emotional and psychosocial needs of people with epilepsy, EAA provides Adventure Therapy Camps that allow people with epilepsy to experience the dignity of risk in a supported environment.

OUR NATIONAL STRATEGY INVOLVES:

- using technological solutions to enhance service delivery
- developing a national service centre as a base for coordinating services

- forming partnerships to build and enhance services
- consolidating links between health professionals and community service providers to ensure a continuum of care
- launching public education and awareness programs to change attitudes to epilepsy

To ensure we did not compromise our national services strategy EAA initiated a research effort to produce strong, independent data. After establishing a key partnership with the George Institute for Global Health, providing seed funding and several years of collaboration, the Sydney Epilepsy Incidence Study to Measure Illness Consequences (SEISMIC) study was born.

SEISMIC, the first major Australian incidence study of epilepsy is funded with grants from Australian Federal Government. SEISMIC will examine the incidence, psychosocial impact and household economic burden of epilepsy in a large and representative population.

SEISMIC will study a population based patient cohort over a 4 year period, gathering information on the process of care from first seizure presentation through to diagnosis of epilepsy, treatment and follow-up. The study will:

- Provide information on the burden of epilepsy to the Australian Health System
- Assess the psychological impact across the population
- Provide the sector and government with data on the impact of epilepsy on quality of life

SEISMIC will evaluate the current performance of the health and social systems in addressing the needs of those living with epilepsy and will highlight opportunities to improve programs and services, particularly around preventative health and social inclusion.

SEISMIC will be pivotal in informing a national services strategy.



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JOINT EPILEPSY COUNCIL OF AUSTRALIA (JECA)



COUNTRY OF OPERATION

Australia

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

2003

The Joint Epilepsy Council of Australia (JECA) was formed in 2003 and is Australia's Full Member of IBE. JECA provides a framework for national and international representation to the benefit of all Australians living with epilepsy.

Member associations are community member-based epilepsy organizations providing services to local, regional and remote communities across Australia.

PRINCIPLE ACTIVITIES OF THE COUNCIL INCLUDE:

- representation to the Australian Government on behalf of PWE
- the provision of public position statements on major issues facing epilepsy
- facilitating epilepsy conferences in Australia
- providing an Australian forum for the interchange of ideas and improving practices and processes.

OUR VISION

By 2012, Australia will have:

- an improved understanding of the impact epilepsy on Australia, its people and its economy
- an appropriate proportion of our research effort targeted to the better diagnosis and treatment of epilepsy
- communities that are increasingly aware of epilepsy, so that people with epilepsy can live without stigma and be active community participants
- workplaces that are informed, free of stigma, and support those with epilepsy to remain in employment
- health services that reflect world's best practice in promoting the right care by the right health professional
- support provided to people with epilepsy and their carers to assist in managing their condition and actively participating in the community.

A FAIR GO FOR PEOPLE LIVING WITH EPILEPSY IN AUSTRALIA, 2009

This comprehensive Report, prepared to inform the Parliamentary Friends of Epilepsy, puts forward the case for epilepsy to be considered a public health issue and indicates minimum level of activity required by government to afford people with epilepsy the same level of care as those with other chronic conditions.

LIFE WITH EPILEPSY REPORT, 2007

In 2006 JECA conducted the first nationwide survey on the impact of living with epilepsy. The Life With Epilepsy report, published in 2007 provides a valuable insight into the impact of living with epilepsy and strengthened our discussions with Government, while identifying areas in need of further applied research.

PARLIAMENTARY FRIENDS OF EPILEPSY (PFE)

Formed in 2008 the PFE remain committed to highlighting the social and economic costs of living with epilepsy to the Australian Parliament. Regular meetings have ensured the Friends hear first hand the impact, both socially and medically, epilepsy has on people's lives.

The Inquiry into the Impact of Epilepsy in Australia Today, conducted by the PFE in 2009, gave all stakeholders the opportunity to inform politicians and policy makers of the many challenges faced by PWE. The Friends Report and Recommendations, drawn from 350 written submissions and formal presentations from key stakeholders, was tabled in both Houses of Parliament in March 2010.

ADVOCACY

Advocacy at a national level is central to JECA's mission and includes ongoing representation to politicians, senior government officials and advisors, and formal submissions to relevant government inquiries where the case for epilepsy is put forward for inclusion in policy deliberations.

OTHER JECA INITIATIVES & ACHIEVEMENTS

- Study tour of UK epilepsy organizations 2009
- Epilepsy debate in Parliament 2007
- A National Strategy for Epilepsy in Australia: 2007-2008 Pre-Budget Submission.



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THE EPILEPSY CENTRE – EPILEPSY ASSOCIATION OF SOUTH AUSTRALIA AND THE NORTHERN TERRITORY INC.

THE EPILEPSY CENTRE

We were founded in 1976 by concerned parents to provide support and information to people living with epilepsy. We have now grown to become an organisation that covers nearly 2.5 million square kilometres. The Epilepsy Centre is part of the national coalition of Australian Epilepsy Associations to advance the cause of all Australians living with epilepsy.

MISSION:

The Epilepsy Centre's Mission is to improve in all respects the welfare of people with epilepsy and their families in South Australia and the Northern Territory.

GOALS:

- Increase awareness and educate the community about epilepsy
- Assist clients to overcome personal barriers
- Guide people with epilepsy to recognise their issues and assist them in identifying solutions
- Provide accessible Support Groups
- Increase service delivery

MEMBERSHIP

There are conservatively 400,000 people in Australia with Epilepsy and many thousands more affected through familial and community association. The association has 328 members, comprising people with epilepsy and their families.

OTHER TYPES OF SUPPORTERS

Approximately 10,000 supporters, including members, the public, school communities, employer groups, medical professionals and institutions.

AN OVERVIEW OF SERVICES

- Counselling
- Advocacy
- Seizure Clinics
- Care Planning
- Seizure First Aid
- Update emergency medications training
- Support with quality use of medicines
- Epilepsy education to individuals, families and organisations
- Epilepsy resource material such as books, DVDs, Videos and pamphlets
- Children's Camps
- Carer Retreats
- Support Groups

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COUNTRY OF OPERATION

Australia

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

1976

TYPE OF ORGANISATION

Individual and organisational membership

RANGE OF OPERATION

South Australia and the Northern Territory

SEIZURE CLINICS:

The Epilepsy Centre conducts Seizure Clinics in some South Australian and Northern Territory hospitals. They help to dramatically improve understanding and management of epilepsy therefore decreasing morbidity and mortality. Improved accessibility and continuity of care is a key to the successful management of epilepsy.

They provide for comprehensive assessment and management of epilepsy. This is usually done on a shared-care basis with local medical professionals. Clinics encompass First Seizure and Complex Epilepsy Clinics.

HIGHLIGHTS THROUGHOUT 2009-10 INCLUDE:

Seizure Clinics

The Epilepsy Centre has established regular Seizure Clinics in some major South Australian and Northern Territory hospitals. Our goal is to expand this and other services further into the rural and remote areas of our region.

Epilepsy Awareness Visits

Our Epilepsy Educator visits metropolitan, regional and remote areas of South Australia and the Northern Territory to promote epilepsy and provide much needed training sessions to families, schools and health professionals.

Development of Services in the Northern Territory

The Epilepsy Centre established an office in Nightcliff, providing support to General Practitioners, Clinics, Aged Care Facilities, disability organisations, schools, government departments and Aboriginal Health Centres.

E-Camp

Children and youth with epilepsy and their siblings mix with other children living with epilepsy and discover things most of them never have the opportunity to experience!

Carer's Retreat

The Epilepsy Centre conducts Carers Retreats. This provides a rare opportunity for participants to relax, build networks and gain information and support from others in similar circumstances.



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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 organize Social Responsibility

STATISTICS

At present we have 37 Members in our organization. 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
- 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.



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CHINA ASSOCIATION AGAINST EPILEPSY (CAAE)



COUNTRY OF OPERATION

China

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

June 24 2005

INITIAL AFFILIATION TO IBE

July 2005

TYPE OF ORGANISATION

Organisational membership

RANGE OF OPERATION

National

GOAL OF THE ORGANISATION:

The establishment of CAAE is of great significance for promoting medical and social services for the 9 million people with epilepsy in the country:

- rectifying the social discrimination and prejudice faced by people with epilepsy and safeguarding their lawful rights and interests;
- improving medical treatment, scientific research and education in epilepsy,
- enhancing international cooperation and participating in relevant international organizations on behalf of the Chinese epilepsy community.

MEMBERSHIP:

Almost 2,200 experts, scholars and relevant professionals in the field of epilepsy from 27 provinces and cities have applied for the membership of the association to date, while the number of group members has amounted to 120.

TERMS OF REFERENCE:

- 1 Public education and promotional activities;
- 2 Consultative services for persons with epilepsy and their family members;
- 3 To promote, coordinate and improve medical services and research in epilepsy;
- 4 Training of grass roots level health workers to manage the care of persons with epilepsy;
- 5 To hold public awareness, Q&A, and other public welfare activities;
- 6 To promote academic exchange and collaboration on epileptology;
- 7 To provide bases for new AEDs clinical trials;
- 8 To protect the legal rights of persons with epilepsy, provide consultation to government on epilepsy control;
- 9 To establish (when possible) entities for epilepsy medical services, research projects, etc.

PATIENTS SELF-HELP CLUSTER (PSHC):

The structure of PSHC's organization: Hospital-centered groups in a number of provinces, municipalities, and autonomous regions of the PR China.

The objectives of PSHC include:

- 1 To increase awareness in persons with epilepsy and their families of the condition, to help them move "out of shadow" to enjoy a normal social life;
- 2 To eliminate the discrimination and stigma faced by persons with epilepsy and to promote good social care;
- 3 To protect and improve the quality of life and rights of persons with epilepsy;
- 4 To help persons with epilepsy to obtain proper and regular medical treatment and rehabilitation;
- 5 To support and advise persons with epilepsy on issues relating to marriage, pregnancy, education, employment, etc.

ACTIVITIES:

- 1 Proposed International Epilepsy Caring Day (IECD), which has been supported in Singapore, Malaysia, Korea, India, etc. IECD also has been supported by WHO
- 2 Organized health education initiatives to introduce knowledge of epilepsy and provide medical consultation in 22 provinces and 30 cities. About 7,000 people with epilepsy attended the activity
- 3 Expanded the Demonstration Project of Epilepsy Management to about 80 rural provinces in China. Persons with epilepsy living in poverty can obtain free anti-epileptic drugs to control their seizure
- 4 Conducted the Promising Strategies Project 2010 (financially supported by IBE) Self-help Art Studio for People with Epilepsy, at Seahorse Club in Shanghai. The self-help art studio can provide persons with epilepsy a certain place to learn and share their creative art with each other, and they will be inspired by their own ability.



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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 & 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.

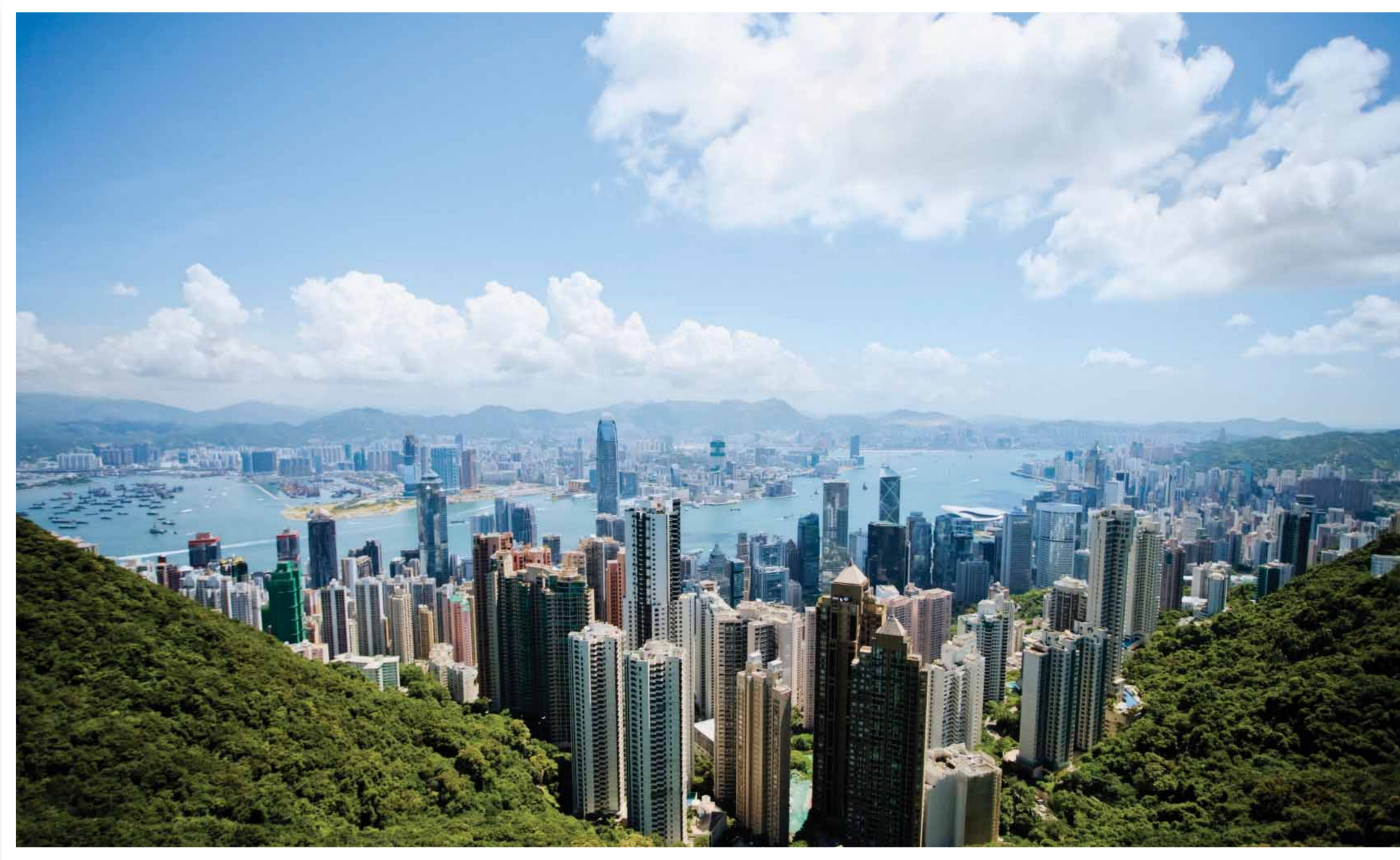
SOME FACTS ABOUT EPILEPSY IN HONG KONG

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.*



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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 organization 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 & 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.
- Organized training events together with recreational activities.
- Organized 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.

This year in 2010, we have 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.



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International Bureau for Epilepsy

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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, organize, 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 & free drug distribution
- Essay, painting & Quiz competitions
- Subsidized medicines, counseling, special education & 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 & 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 organized every year. Medical as well as Social aspects are covered. The 12th Joint meeting of IEA & 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

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Website www.epilepsyindia.org



received. The complete booklet of guidelines has also been uploaded to the IEA and ILAE websites.

SUPPORT GROUPS:

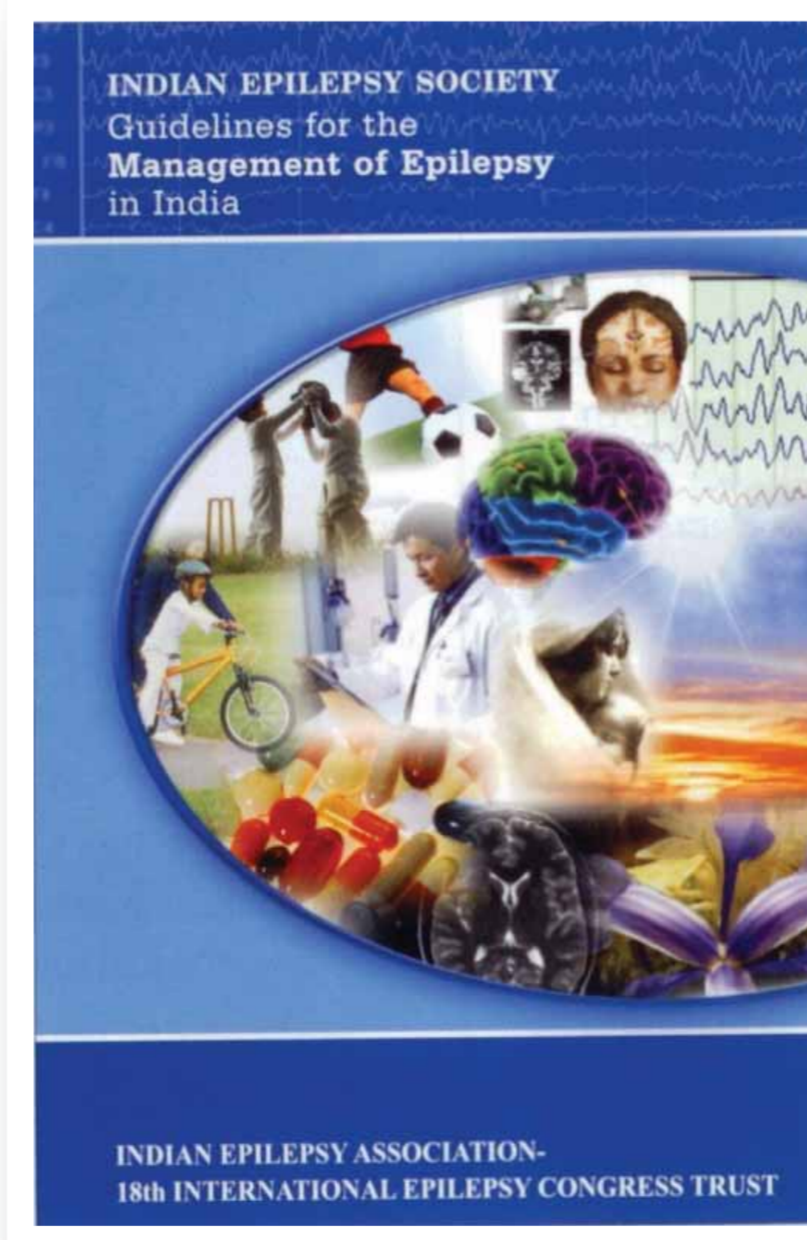
A number of chapters run support groups for people with epilepsy. Mumbai, Pune, Bangalore, Indore, Trivandrum etc chapters run very active programs to counsel people with epilepsy and their caregivers. IEA has taken initiative in defining disability in persons with epilepsy whose seizures are uncontrolled.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



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JAPANESE EPILEPSY ASSOCIATION



COUNTRY OF OPERATION

Japan

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

October 24, 1976

INITIAL AFFILIATION TO IBE

1976

TYPE OF ORGANISATION

Individual and Organisational membership

RANGE OF OPERATION

National

MISSION:

To promote QOL of People of Epilepsy

GOALS:

- To provide information on epilepsy for people with epilepsy and their families
- To improve social awareness of epilepsy
- To organize and support local self-help groups for both persons with epilepsy and their families.
- To survey and investigate the needs of persons with and their families
- To promote social welfare, education and employment for people with epilepsy

OVERVIEW:

- It is estimated that 1.000.000 have epilepsy in Japan. JEA has 5,000 members consisting of persons with epilepsy (1,236), their families (2,963), medical doctors (490), other professionals (295) and organisational members (109).
- The annual budget of the association is about US\$780,000 of which approximately half consists of individual membership fees.
- JEA publishes a monthly magazine whose special articles are not only medical issue but also cover all aspects of epilepsy.
- There are 47 local branches (One branch in one prefecture) that arrange their own special programs and self-help groups.

ANNUAL ACTIVITIES

- We continue our nationwide seminar for non-medical professionals and care givers 2 times a year (audience: ca 800-900 persons)
- We petition parliament and the government to improve legislation and conditions for persons with epilepsy
- We publish entry-level videos and books: One publication a year.



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MONGOLIAN EPILEPSY ASSOCIATION (MEA)



COUNTRY OF OPERATION

Mongolia

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

March 25, 2004

INITIAL AFFILIATION TO IBE

December 1, 2003

TYPE OF ORGANISATION

Individual and organizational membership

RANGE OF OPERATION

National

MISSION:

The mission of Association is to run a wide scope of activities aimed towards securing the social and health protection of people with epilepsy in compliance with the principles of IBE and improve the quality of life of people with epilepsy.

GOALS:

- Assist people with epilepsy on education and training
- Increase public awareness of epilepsy through the provision to the public of a wide range of information on epilepsy prevention and care
- Work closely with epilepsy associations in other countries.

REGULAR ANNUAL ACTIVITIES:

- Continuing medical education and health programs: 1 to 2 times per year
- Preparing brochures for the general public with general information on epilepsy and its prevention and care.
- Training program for doctors and nurses on epilepsy
- Raising awareness on epilepsy in the general public through educational programs

SPECIAL ACTIVITIES DURING 2009 AND 2010

- "Quality of life" – the Charity activity (program) for improving health education on epilepsy amongst the population in Mongolia.
- Promising Strategies Program of the IBE - Improving public knowledge of epilepsy in Mongolia



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NEPAL EPILEPSY ASSOCIATION



COUNTRY OF OPERATION

Nepal

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1986

INITIAL AFFILIATION TO IBE

2007

TYPE OF ORGANISATION

Individual & Organisational Membership

RANGE OF OPERATION

National

MISSION

To care for people living with epilepsy & to raise awareness about epilepsy in Nepal

GOALS

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

STATISTICS

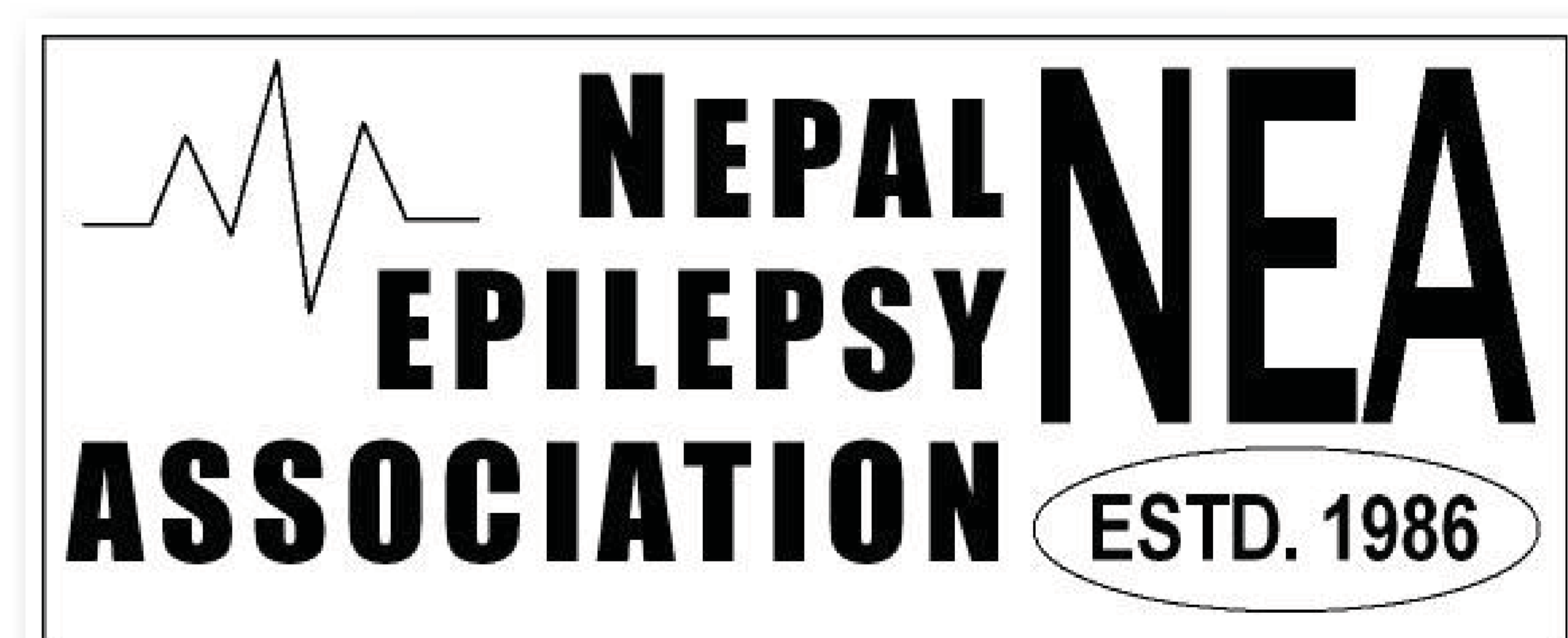
There are more than 1,000 people with epilepsy who are the general members of the associations.

REGULAR ANNUAL ACTIVITIES

- Runs a weekly epilepsy clinic in the center of Kathmandu.
- Runs a monthly clinic in Dolakha & Pokhara.
- Runs at least one epilepsy camp, with free medicine distribution, every two months throughout Nepal.
- EEG services in the remote areas.
- Awareness programme during epilepsy camps.

SPECIAL ACTIVITIES DURING 2009 & 2010

Epilepsy camps in various remote areas with Korean counter parts



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EPILEPSY NEW ZEALAND



COUNTRY OF OPERATION

New Zealand

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1956

TYPE OF ORGANISATION

Client and Individual Membership

RANGE OF OPERATION

National, provincial and regional

The Epilepsy Association of New Zealand (ENZ) has been in existence since 1956.

ENZ is the only not-for-profit organisation which provides a service dedicated to supporting people with epilepsy in New Zealand.

ENZ VISION STATEMENT:

To enhance the quality of life of people with epilepsy and their families, and to increase public awareness.

ENZ MISSION STATEMENT:

Epilepsy Association of New Zealand believes that people with epilepsy should be:

- Accepted and treated as individuals;
- Accorded education and training opportunities suiting their needs and abilities;
- Accorded employment opportunities in terms of their skills, experience and qualifications;
- Accorded ready access to quality medical care;
- Able to decide on medical treatment on a fully informed basis;
- Able to be open about their epilepsy without attracting prejudice or discrimination.

ENZ OPERATIONS:

- ENZ has 17 Branches located throughout New Zealand
- Each Branch employs administration staff – 27 in total
- Each Branch has at least one employed Field officer – 28 in total
- Field Officers role is to:
 - Work alongside people with epilepsy and their families, providing information and representation
 - Promoting an understanding of epilepsy in the community and speaking out for people living with epilepsy
 - To educate people about epilepsy and empower those with epilepsy

ENZ holds a government contract through the New Zealand Ministry of Health. Funding is provided to a level of approximately 10% of total operating income. The balance of revenue is self funded.

ENZ maintains a National Support Centre which provides support to the service delivery field staff, branch administration and volunteer committee's.

ENZ is the official employer of all staff and all staff and volunteers who hold a position within the organisation, paid or unpaid, report to the General Manager.

ENZ National Support Centre is also responsible for funding, finance, operational and legal areas of the organisation. Production of all material and branding is controlled by the National Support Centre and developed in conjunction with medical and field advisory panels.

ENZ delivers an awareness program throughout the entire year, with a special program delivered during an awareness week which is dedicated to the first week of September each year.

ENZ is a member of the Neurological Alliance of New Zealand; the Alliance consists of agencies which represent people with various Neurological conditions. The role of the Alliance is to ensure it is heard, as a larger and combined voice, to Government on issues that affects the people with conditions, which the member of the Alliance represents.

ENZ has formed an alliance between the New Zealand Chapter of the ILAE and the New Zealand Epilepsy Assist Dog Trust to ensure a closer working relationship is achieved to the benefit of people with epilepsy.



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EPILEPSY AWARENESS AND ADVOCACY, INC. PHILIPPINES



REACH OUT, TOUCH LIVES; MAKE A DIFFERENCE!

In the Philippines, there are an estimated 800,000 people with epilepsy. The majority are children and adults in the most productive years of their life. There are many more persons who may have epilepsy but due to the stigma related to the illness, they may be reluctant to go public or even go to a doctor to be examined.

FRIENDS OF PLAE TO EPILEPSY AWARENESS AND ADVOCACY, INC.

Established in April 2002 as the Epilepsy Support Group of the Philippine League Against Epilepsy (PLAE), the Friends of PLAE began as a group of concerned families, patients and professionals who felt the need to know more about epilepsy and to provide psychological support to each other. Monthly meetings were held for over 3 years. Then a "Starting Self-help Groups" workshop in September 2003 led to the organization of epilepsy support groups in several regions in the country. Another meeting was held on March 2004. Representatives from all over the country gathered together to learn about the problems in their respective areas and to map out a concerted plan of action which focuses on knowledge, advocacy and psychological support.

Friends of PLAE officially became the Epilepsy Awareness Advocacy Inc. (EAAI) in March 2004. In August 2005, EAAI was accepted as the Full Member of IBE in the Philippines. EAAI is the umbrella organization for the different epilepsy support groups in the country. There are 17 chapters to date.

VISION STATEMENT:

EAAI is a community of advocates working together so that persons with epilepsy can achieve their full potential and be accepted and respected members of society.



MISSION OF EAAI:

PWE:

- To provide a venue and opportunities for sharing of experiences.
- To inspire others to achieve their full potential and be accepted and respected by society.

General Public:

To disseminate information through tri-media about epilepsy care and to create links with interested groups for support.

With PLAE:

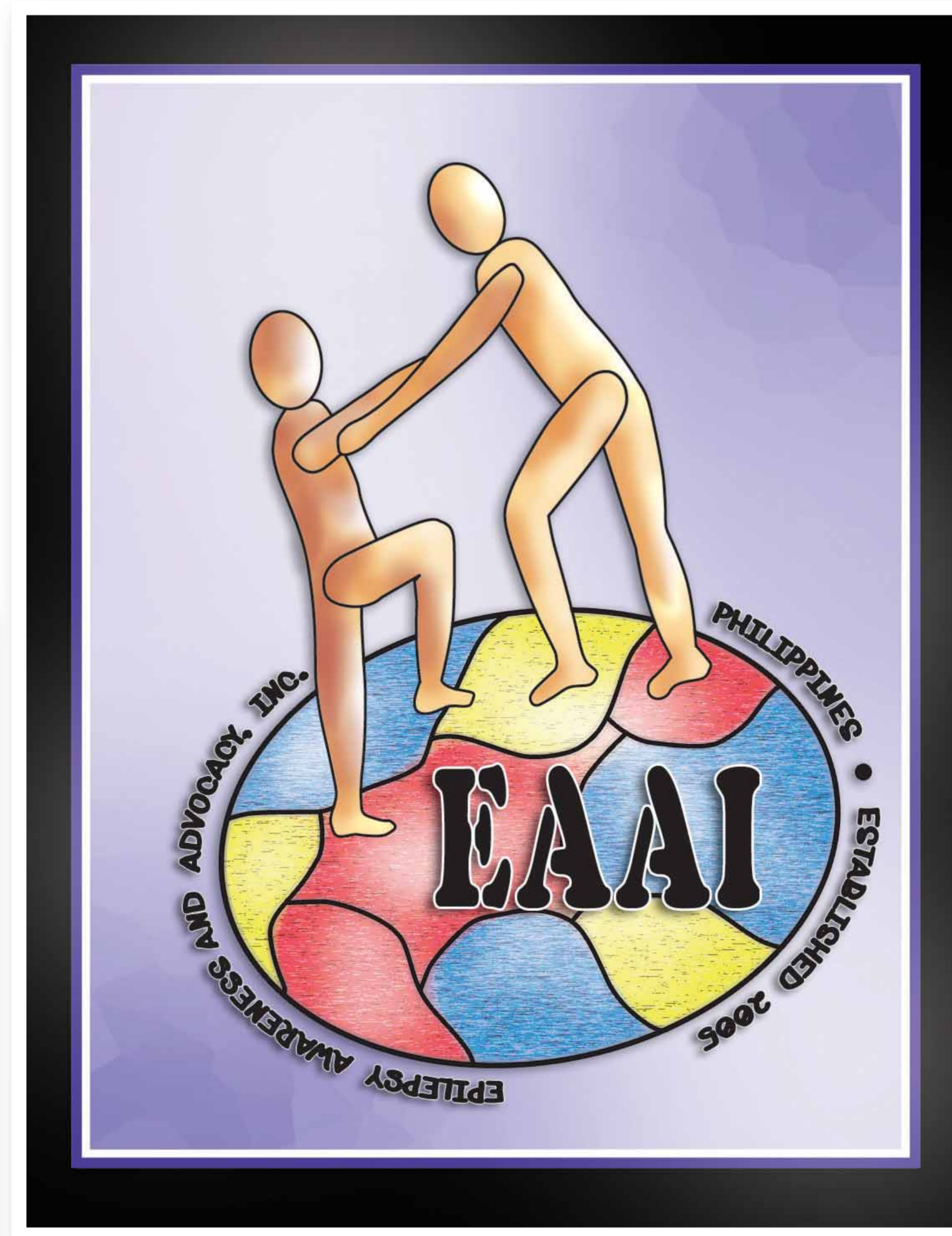
To collaborate with the Philippine League Against Epilepsy (PLAE) in its awareness, advocacy and healthcare delivery projects.

Families:

- To educate families regarding the needs of persons with epilepsy and the care that should be given to them.
- To provide families with moral support, inspiration, and opportunities to share their experiences

Healthcare System:

To promote accessible and affordable health care delivery systems for persons with epilepsy.



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TAIWAN EPILEPSY ASSOCIATION (TEA)



COUNTRY OF OPERATION

Taiwan

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

January 21, 1995

INITIAL AFFILIATION TO IBE

1997

TYPE OF ORGANISATION

Individual & organizational membership

RANGE OF OPERATION

National

SPECIAL ACTIVITIES

Taiwan Epilepsy Ambassadors Program (since 2007): People with epilepsy, care givers or advocates who have volunteered to share their stories of living beyond their epilepsy, in order to help empower others to do the same.

Outstanding people with epilepsy (since 2002): held biennially, this event has been held five times to date

RECENT ACHIEVEMENTS

- Introduction of driving licence legislation for persons with epilepsy in Taiwan
- Equal opportunity of employment for persons with epilepsy in Taiwan

OUR MISSION:

To promote public health and improve quality of life of people with epilepsy through promoting medical and social education.

OUR GOALS:

- To provide medical education for public awareness of epilepsy
- To arrange healthy activities for both members and the general public
- To propagate medical knowledge of epilepsy through various medical publications
- To establish information centres offering medical consultation for the public
- To offer continuing medical education for each member

MEMBERSHIPS:

Two different memberships in TEA:

- Individual member (544)
- Organizational member (241)

REGULARLY PUBLICATION:

- TEA monthly newsletter
- TEA quarterly Epilepsy News

Ten thousand TEA publications are sent to members, schools and other interested individuals each month – this is 10 times the number of members in the association.

REGULAR ACTIVITIES

Outdoor leisure activity: 2 to 3 times each year

Continuing medical education and healthy program for members and the general public: 1 to 2 times each year

Art competitions: have been held for 15 consecutive years

Student bursaries to outstanding young people with epilepsy: for 6 consecutive years



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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 organizational 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 organizations 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 out-door 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.



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MEMBERS IN THE SOUTH EAST ASIA REGION

Bangladesh:	Bangladesh Epilepsy Association
Hong Kong:	Hong Kong Epilepsy Association Enlighten Hong Kong (Associate Member)
India:	India Epilepsy Association
Indonesia:	PERPEI Yayasan Epilepsi Indonesia (Associate Member)
Nepal:	Nepal Epilepsy Association
Sri Lanka:	Epilepsy Association of Sri Lanka
Thailand:	Epilepsy Association of Thailand

MEMBERS IN THE WESTERN PACIFIC REGION

Australia:	Joint Epilepsy Council of Australia - JECA Epilepsy Association of South Australia & the Northern Territory Inc (Associate Member) Epilepsy Action, Australia (Associate Member) Epilepsy Australia Ltd (Associate Member) Epilepsy Queensland (Associate Member)
China:	China Association Against Epilepsy
Japan:	Japan Epilepsy Association Inc. Epilepsy Hospital Bethel (Associate Member)
Korea:	Korean Epilepsy Association
Malaysia:	Malaysia Society of Epilepsy
Mongolia:	Mongolian Epilepsy Association HSUM
New Zealand:	Epilepsy New Zealand
Philippines:	Epilepsy Awareness & Advocacy Inc
Singapore:	Singapore Epilepsy Foundation Epilepsy Care Group Singapore (Associate Member)
Taiwan:	Taiwan Epilepsy Association

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