

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

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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.
- Various books and first aid videos.
- Acknowledging our cultural diversity, information on Seizure First Aid is available in 20 languages.

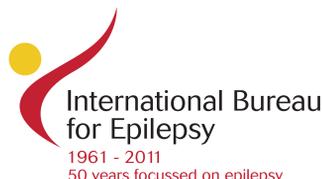
CHANGING COMMUNITY ATTITUDES

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. Editors 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



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EPILEPSY QUEENSLAND INC., AUSTRALIA



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.



CONTACT DETAILS

Helen Whitehead

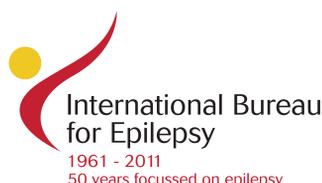
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EPILEPSY ACTION AUSTRALIA



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

CONTACT DETAILS

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- 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

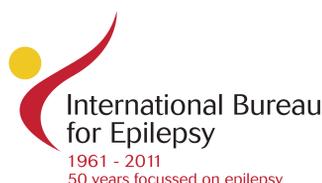
To ensure we did not compromise our national services strategy EAA initiated a research effort to produce strong, independent data. After establishing a key partnership with the George Institute for Global Health, providing seed funding and several years of collaboration, the Sydney Epilepsy Incidence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

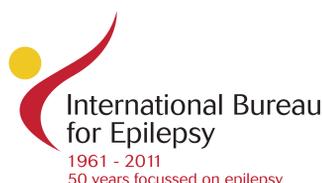
OTHER JECA INITIATIVES & ACHIEVEMENTS

- 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

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.

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

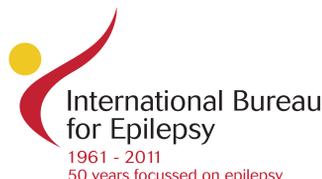
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CHINA ASSOCIATION AGAINST EPILEPSY (CAAE)



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.

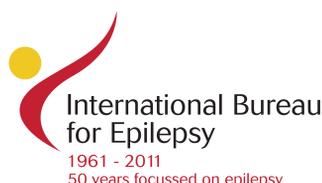
ACTIVITIES:

- 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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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.



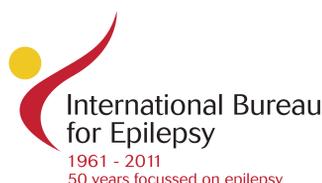
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MONGOLIAN EPILEPSY ASSOCIATION (MEA)



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

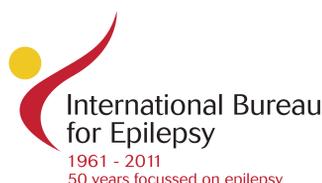
SPECIAL ACTIVITIES DURING 2009 AND 2010

- "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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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.



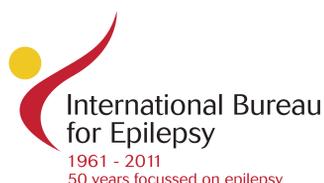
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EPILEPSY AWARENESS AND ADVOCACY, INC. PHILIPPINES



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.



MISSION 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.

OBJECTIVES 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:

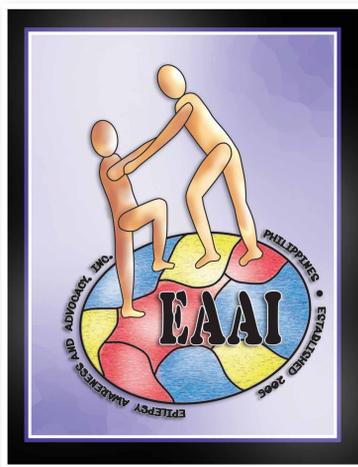
- To collaborate with the Philippine League Against Epilepsy (PLAE) in its awareness, advocacy and healthcare delivery projects.

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

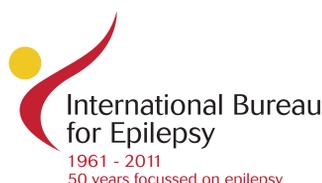
Healthcare System:

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



CONTACT DETAILS

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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

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

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

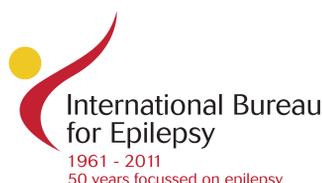
RECENT ACHIEVEMENTS

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



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SINGAPORE EPILEPSY FOUNDATION



Singapore Epilepsy Foundation is the Singapore Chapter of the International Bureau for Epilepsy. SEF is a non-profit organisation dedicated to promote public awareness and education on topics surrounding epilepsy for the welfare of people with epilepsy.

OBJECTIVES:

- To provide an organisation for the benefit and service of people with epilepsy and others interested in epilepsy and associated conditions
- To promote the study of the causes and treatment thereof and the diffusion of information concerning the same

VISION/MISSION:

To promote a good quality of life for people affected by epilepsy.

PROGRAMS/INITIATIVES

- Children and Youths: SEF is working with schools and tertiary institutions to promote greater awareness on epilepsy. The aim of this education programme is to encourage acceptance of people with epilepsy.
- Employment and Employers SEF is promoting an Epilepsy Awareness Programme to employers on the employability of people with epilepsy.
- Epilepsy Support SEF works closely with caregivers and people with epilepsy to meet their needs to address issues relating to epilepsy.
- Public Education: A number of epilepsy awareness education programmes were conducted to equip the following groups on how handling seizures:-
 - Healthcare professional of residential home and structured workshops.
 - Lifeguards, and
 - Law enforcement officers.

SEF COUNCIL:

Chairman: Mrs Grace Tan
Deputy Chairman: Dr Clifford Abayasekara
Honorary Treasurer: Ms Selina Yeo Li Ling
Secretary: Ms Teng Bee Suan
Adviser: Mr Lee Fook Hong

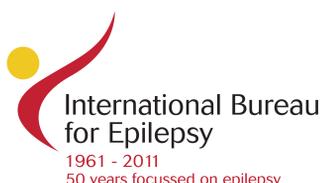
COUNCIL MEMBERS:

Dr Lim Shih Hui
Dr Einar Wilder-Smith
Ms Zainaf Bte Ya'akub
Mr Nikhil Nicholas
Mr Stephen Woo Kam Seng



CONTACT DETAILS

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MALAYSIA SOCIETY FOR EPILEPSY



The Malaysia Society of Epilepsy provides support to people with epilepsy and their care providers and is a member of the IBE Western Pacific Regional Committee. The Society is managed by a Council, which is elected amongst Ordinary and Life members and its responsibilities consist of the administration of the business affairs and property of the Society in accordance with the Rules and By-Laws and the general policy laid down by annual general meeting.

OBJECTIVES:

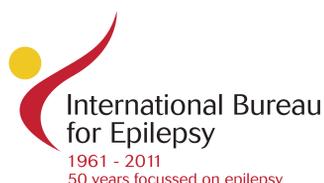
- To be of service to people with epilepsy and others interested in medical science, public health and social care related to epilepsy.
- To establish a register for people with epilepsy in Malaysia. To provide information and advice to those living with epilepsy.
- To liaise with international organizations interested in epilepsy.

The Malaysian Society of Epilepsy has developed a website <http://www.epilepsy.org.my/> with the purpose of establishing an online community for doctors/specialists, people with epilepsy, their families and the general public. The association provides educational information and resources about epilepsy and it is the society's hope that people living with epilepsy and their relatives and friends and other interested users find valuable disease management tools and other useful information to support them in their daily lives.



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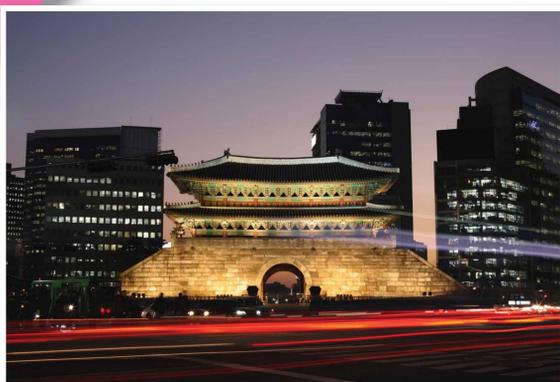
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KOREAN EPILEPSY SOCIETY



Epilepsy is considered one of the oldest diseases in the history of mankind and a social malady in the modern society. Particularly because of its unique symptoms, epilepsy has been thought as a supernatural disease different from spontaneous general diseases since long ago, and the resulting social bias against epilepsy still remains in every society.

In Korea, as in some other countries around the world, the social stigma attached to people with epilepsy leads to social ostracization leading to difficulties in all aspects of life. Considering these social conditions, the medical treatment of epilepsy must be juxtaposed with a solution to the social issues, such as the prejudice against and disadvantages faced by people with epilepsy.

On March 31st 1968, the Korean Epilepsy Association was officially founded, and Dr. Lee Ju-Geol was elected as the first chairman. On May 31st 1969, the first national epilepsy symposium was held at the National Medical Center, and the attendance of approximately 100 members made it possible to establish a great interest in epilepsy in the medical sphere at that time.

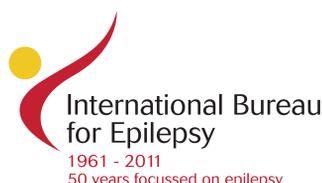
On December 14, 1974, the 1st International Epilepsy Workshop was held at Yonsei Medical School under the joint sponsorship of the Korean Epilepsy Association and the International Bureau of Epilepsy. It allowed the anti-epilepsy campaign of Korea to be internationally recognized and the Korean Epilepsy Association became an official member of the International Bureau of Epilepsy (IBE) as the representative of Korea in September 1979.

The Korean Epilepsy Society holds an annual academic meeting in June and an Educational Course in November every year.



CONTACT DETAILS

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EPILEPSY HOSPITAL BETHEL, JAPAN



The Epilepsy Hospital Bethel opened in 1992 as a private hospital specialising in epilepsy surgery and care. The centre provides a comprehensive treatment program, including diagnosis of epilepsy syndrome and seizure type, treatment programs as well as the provision of reintegration training and sheltered accommodation.

Based in Iwanuma City in North Japan, the area most badly affected by the March 2011 earthquake and tsunami, the hospital faced a huge disaster following these events. In response, the Japan Epilepsy Society (ILAE chapter in Japan) and Japan Epilepsy Association (IBE member in Japan) joined forces and rallied to help. Efforts were made to contact all of the 387 members of Japan Epilepsy Association by phone, although 44 members were not found.

An epilepsy hotline was set up to provide information and support to both persons with epilepsy and medical professionals. When the disaster struck, many of the medical professionals caring for those affected by the disaster would have had limited knowledge about epilepsy and the hotline provided an important source of information and advice.

As a first response, medical teams from Shizuoka and Nishi-Niigata national epilepsy centres travelled north to the disaster area bringing stocks of anti-epilepsy drugs (AEDs) with them. One team stayed at the biggest shelter in the area (which had previously been a school) to provide treatment and care to persons with epilepsy who arrived. Another team visited other shelters announcing they were an epilepsy specialist team, that they had AEDs and could give advice. They also left written notices to let people know that there were AEDs in the school shelter and in some hospitals. They and other epileptologists in disaster area reported back that seizure activity for a significant number of people with epilepsy was exacerbated and some people with epilepsy had convulsive status epilepticus and were transported to hospital by helicopter, because the devastation of the tsunami left a large number of people without their medication.

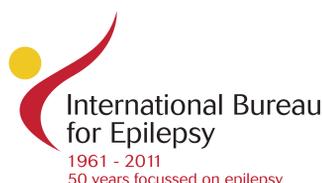
Japan Epilepsy Society and Shizuoka Epilepsy Center asked pharmaceutical companies to donate supplies of AEDs and these requests were generously met. However, transporting the medication to the disaster area remained a large problem. In the end, the supplies were transported to the hub-hospital by Japan Trucking Association, following a plea for help by Japan Epilepsy Associations. The supplies were then distributed to the three main hospitals in the area.

Four months after the tsunami, the area is slowly recovering.



CONTACT DETAILS

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EPILEPSY CARE GROUP (SINGAPORE) [ECG]



Epilepsy Care Group (Singapore) [ECG] is a non-profit, volunteer-based organization that began in 1993 as an effort to address the needs of persons with epilepsy and their caregivers in Singapore.

We are a registered society (ROS 226/95 Wel) under the Societies Act, which means that we are accountable to the Registrar of Societies and have a Constitution that mandates an Annual General Meeting at which ECG members elect an Executive Council. The work of the Executive Council is assisted by various medical and legal professionals who sit on a Board of Consultants. The ECG is also recognized as a charity (CA1204) under the Charities Act by the Commissioner of Charities. The Ministry of Health therefore has an account (HEF0043/G) in our name under the Health Endowment Fund to receive tax-exempt donations.

We are an Associate Member of the International Bureau for Epilepsy (IBE) which is a world-wide chain of organizations working to improve the social conditions that affect people with epilepsy.

The current 15th Executive Council (2009/2010) comprises the following members:

President : Dr Choong Chew Thye
Vice-President : Ms Diana Koh Hwee Hoon
Honorary Secretary : Mr Goh Keng Hwee
Asst Secretary : Mr Gavin Goh Zonghan
Honorary Treasurer : Mr Lee Soon Chua
Asst Treasurer : Mr Low Qing Xiang
Welfare Officer : Mr Jeow Shi Yuan

COUNCIL MEMBERS :

Ms Mok Wai Pun
Mr Tan Pek Ann
Ms Wendy Woon Yuet Mei
Mr Calvin Koh Chin Khoon
Mr Neo Vinn Zen

BOARD OF CONSULTANTS:

Associate Professor Goh Lee Gan
Professor Michael Chee
Dr Lim Kim Whee
Dr Adrian Wang Chee Cheng
Dr Vijayan Loganathan

OBJECTIVES:

- To educate persons with epilepsy, their caregivers and the public about epilepsy
- To provide opportunities and activities for meaningful social integration for persons with epilepsy and their caregivers
- To advance the cause and interests of persons with epilepsy in Singapore
- To provide social and emotional support for persons with epilepsy

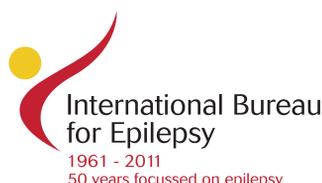
VISION/MISSION:

We seek to promote awareness concerning epilepsy and to provide epilepsy related education and counselling to persons with epilepsy, their family members and to the public.



CONTACT DETAILS

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ecgs93@singnet.com.sg



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EPILEPSY ASSOCIATION (ACT) INC., AUSTRALIA



VISION

The Epilepsy Association (ACT) Inc works to dispel the myths about epilepsy through a program of continuing education based on facts, and to eliminate misunderstanding that leads to discrimination.

MISSION STATEMENT

The Epilepsy Association (ACT) Inc supports people with epilepsy, their family, friends and the community with a comprehensive and responsive range of services. These include information and support, public education programs, counselling for clients, their family and their community, a library service consisting of books, videos and pamphlets, an advocacy service and a drop in centre for those who just need to talk or browse through the library.

OVERVIEW OF EPILEPSY (ACT) INC

Since 1982, the Association has been dedicated to improving the quality of life of people with epilepsy, their carers and family through advocacy, research, support and information. Considerable effort is put into increasing public awareness and raising community understanding of epilepsy. Our Association provides:

- Information
- Support
- Community education
- Advocacy
- Resource Development
- Information and Referral

Our annual income is from Disability ACT, Department of Disability, Housing and Community Services, but this only covers part of our expenses. We rely heavily on fundraising and the generosity of our members and the public.

OUR COMMITTEE OF MANAGEMENT

President: Alan Evans
Past president: Richard Eccles
Treasurer: Margaret Marshall
Secretary: Elizabeth O'Brien

MEMBERS:

Allison Clarke
Brian Costello
Jacinta Cummins
Tanya Funnell
Ann Murphy
Helen Portlock
Ian Thompson
Peter Walshe

ACTIVITIES AND INITIATIVES

It has been another year of hard work. We completed 53 education sessions and saw approximately 6,500 clients.

The fundraising and awareness activities included:

- ACU Bed Race
- Adam Fry Football Day
- Adam Fry Dinner
- Epilepsy Week
- Race and Taste
- World of Trivia and the
- Combined Charities Card Shop

I think a real challenge for us is to demonstrate that good preventive work can really assist alleviate the burden on our hospital system. Proper care for those with epilepsy, provision of good medication management, understanding better how to manage the condition, are all key elements of our work program, and all aspects that can help prevent people going to hospital.

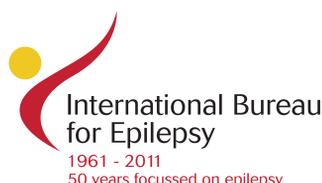
EPILEPSY AND EMPLOYMENT: A GUIDE FOR WORKERS AND EMPLOYERS

A guidebook on epilepsy and employment, geared at people with epilepsy and their employers, has been published in Australia by Epilepsy ACT. The publication was launched at the Australian Capital Territory's Legislative Assembly in May 2011, with Senator Gary Humphries acting as Master of Ceremonies and Minister Joy Burch introducing the publication. The publication has been well received by Australian politicians and by people with epilepsy and their carers. Prior to publication, the document was checked by five lawyers and was also reviewed by a focus group of persons with epilepsy.



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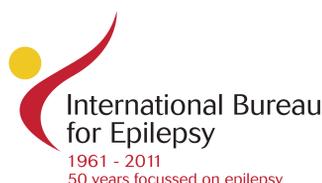
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MEMBERS IN THE WESTERN PACIFIC REGION

- 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)
Epilepsy Association (ACT) Inc. (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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