



# INTERNATIONAL BUREAU FOR EPILEPSY

11 Priory Hall, Stillorgan, Dublin 18, Ireland

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為癲癇症患者服務

enlighten  
action for epilepsy  
www.enlightenhk.org

## ENLIGHTEN HONG KONG LTD



### COUNTRY OF OPERATION

Hong Kong

### TYPE OF MEMBER

Associate Member

### DATE ORGANISATION WAS CREATED

7 August 2002

### DATE ORGANISATION WAS FIRST AFFILIATED TO IBE

2002

### TYPE OF ORGANISATION

Individual Membership and Family Membership

### RANGE OF OPERATION

National

### MISSION

To widen opportunities and choices for all those affected by epilepsy and to raise awareness of epilepsy issues in all sectors of the Hong Kong community.

### 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

Enlighten works towards the promotion of health care and awareness of epilepsy in Hong Kong. Enlighten provides this community service in the form of bilingual

- Community Epilepsy Support
- Community Epilepsy Education, Training and Raising Awareness

#### ENLIGHTEN HONG KONG'S EFFORTS TO IMPROVE THE QUALITY OF LIFE OF PEOPLE WITH EPILEPSY ARE DIVIDED INTO 2 MAJOR GROUPS OF SERVICES:

- OUR COMMUNITY EPILEPSY SUPPORT SERVICES:**  
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 the members to overcome stigma

#### OUR SUPPORT SERVICES INCLUDE:

- Provide formation, knowledge a
- Work with other agencies
- Practical and professional advice
- Community based projects
- Rehabilitation
- Family support activities
- Helplina
- Parent groups
- Befriending services
- Emotional and psychosocial support
- Individual/family counseling and group therapy
- Employment counseling and legal assistance



#### 2. OUR COMMUNITY EPILEPSY EDUCATION, TRAINING AND RAISING AWARENESS PROGRAMMES:

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

#### OUR TRAINING COURSES COVER ASPECTS SUCH AS:

- What is Epilepsy
- Causes of Epilepsy
- Myths and Misconceptions about Epilepsy
- Types of Seizures
- What Triggers Seizures
- Treatment of Epilepsy
- First Aid Management of Epileptic Seizures

### ADVOCACY

Enlighten advocates rma the rights and benefits of the people affected by epilepsy in the light of Government legislature and ordinance striving rma equal opportunities rma 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 **1:70** 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 rma 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 rma Epilepsy by a Hong Kong Neurosurgeon in 2005. He stated that he believe the number is much higher than recorded as many people are either misdiagnosed or do not come forward rma treatment rma fear of being discriminated against.**

### CONTACT DETAILS

**ENLIGHTEN – ACTION FOR EPILEPSY**  
Room 12-A, Shun Pont Commercial Building  
No. 5-11 Thomson Road, Wanchai, Hong Kong  
**website** www.enlightenhk.org

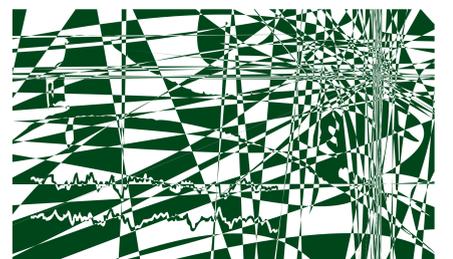
**THE CONTACT PERSON TO INTERNATIONAL LIAISON**  
Ms Orla Gilroy **e-mail** orla.gilroy@enlightenhk.org



## B U D A P E S T 28th INTERNATIONAL EPILEPSY CONGRESS

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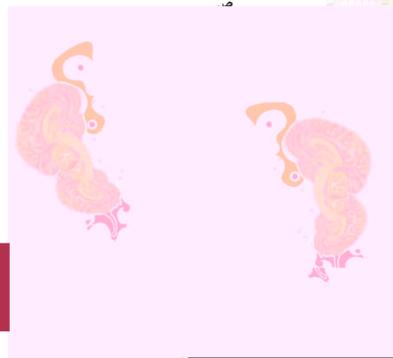




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## IRANIAN EPILEPSY ASSOCIATION



### TYPE OF IBE MEMBER

Full Member

### DATE ORGANISATION WAS CREATED

1995

### TYPE OF ORGANISATION

Individual Membership

### RANGE OF OPERATION

National

### MISSION

IEA is a national non-governmental organization whose mission is to increase public awareness & knowledge about epilepsy to enhance the quality of life for people with epilepsy through changing attitudes towards epilepsy.

### GOALS

1. To improve medical services for the care & cure of people with epilepsy & their families.
2. To strive to increase knowledge about epilepsy by providing educational congresses & seminars for the public & professions.
3. To communicate with other societies to profit from latest research & new technologies in epilepsy treatment.
4. To survey the prevalence of epilepsy in Iran & working to prevent epilepsy through the promotion of health programs.

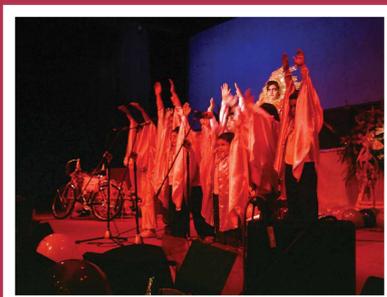
### ACTIVITIES

1. Promoting good diagnosis & appropriate treatment for people with epilepsy by providing professional seminars.
2. Enhancing quality of life of people with epilepsy through educational sessions in the media; also preparing brochures and pamphlets.
3. Co-operating with the Health Ministry to undertake research about epilepsy prevalence in Iran.
4. Encouraging neurologists to identify the needs of people with epilepsy through appropriate research.
5. Preventing the occurrence of epilepsy through the promotion of public awareness of the etiology of epilepsy (e.g. head trauma, prenatal care, delivery care...)
6. Developing the correct attitude towards epilepsy through the provision of educational programs in the media; also public congresses.

### OTHER INFORMATION

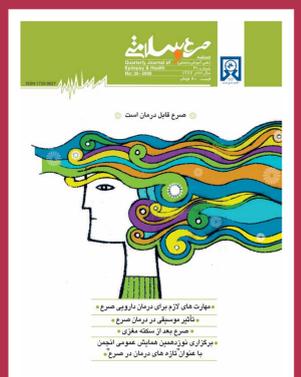
IEA was founded in 1995 and in during the last 12 years a group of specialists together with a person with epilepsy, the late Varzaghan, have worked hard to develop the association. As a result of this endeavor there are now 6 sections in the central office with different activities:

1. EDUCATIONAL UNIT: Providing professional seminars for specialists; managing educational sessions for people with epilepsy & their families; publishing flyers & pamphlets
2. RESEARCH UNIT: Providing congresses for the general public to increase knowledge; publishing the "Health & Epilepsy" journal; cooperating on research projects
3. COMMUNICATIONAL UNIT: Arranging outings to wonderful & beautiful sites in Iran for people with epilepsy; arranging ceremonies & celebrations; promoting 21st January as National Epilepsy Day; providing music concerts for fundraising.
4. MEDICAL CARE UNIT: Obtaining insurance for people with epilepsy; arranging self help groups for people with epilepsy & their families; encouraging people with epilepsy to obtain diagnosis & treatment.
5. FINANCE UNIT
6. CHILDREN'S UNIT: Preparing celebrations & tours for children with epilepsy; providing educational sessions for parents; Competitions in "Epilepsy in literature" (Short story & reminiscence) in high school students with Educational Ministry co-operation in order to increasing awareness toward Epilepsy.



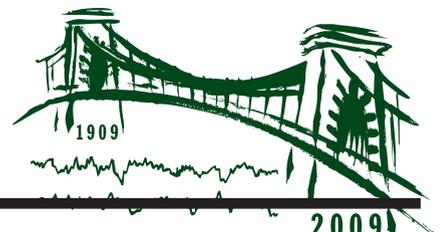
IN ADDITION, IEA HAS 8 REGIONAL BRANCHES IN IRAN:

1. Golesta
2. East Azerbaijan
3. Hormozgan
4. Hamedan
5. Kerman
6. Qom
7. Shar-e-kord
8. Shiraz



## B U D A P E S T

### 28th INTERNATIONAL EPILEPSY CONGRESS



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2009



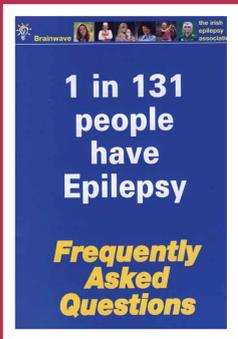
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## BRAINWAVE THE IRISH EPILEPSY ASSOCIATION



### MISSION & STRUCTURE

Brainwave was established in 1967 by a group of individuals concerned to improve the quality of life of people with epilepsy in Ireland.

Over the 40 years since its inception, the Association has grown and expanded and now provides a range of services throughout Ireland.

### VISION

Brainwave's vision is to achieve an Ireland in which no person's life is limited by epilepsy.

### MISSION STATEMENT

Brainwave is committed to working for everyone with epilepsy in Ireland, their families and carers and to meeting their needs.

### OBJECTIVES

- I To provide support, information and help-line to people with epilepsy.
- I To provide information to health professionals in dealing with epilepsy.
- I To improve public understanding of epilepsy (in order to eliminate fear and prejudice)
- I To undertake, encourage and assist research into the causes of, cure for and management of epilepsy and into the social and psychological effects of the condition.
- I To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them.
- I To assist in the development of support groups for people with epilepsy in the area of training and employment.
- I To provide information on issues related to driving: insurance, changing legislation.
- I To provide practical aids to people with epilepsy
- I To operate as a public forum and an advocate for the condition of epilepsy.
- I To raise funds to support its work in an awareness-creating manner.
- I To provide training on Epilepsy and Rescue Medication to Health Professionals

### SERVICES

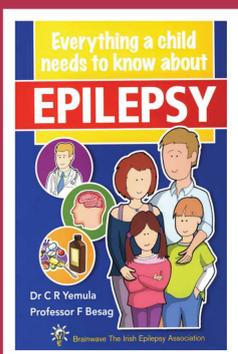
35,000 people in Ireland have some form of epilepsy.

At least 50% of people with epilepsy in Ireland continue to have on-going seizures or experience debilitating side effects.

Brainwave's most vital area of service to people with epilepsy is in the post-diagnosis phase, when information about epilepsy and coping strategies are essential to people living with the condition, their parents, families and friends.

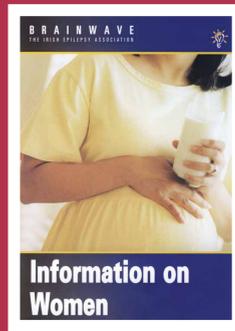
Brainwave also has strong input into the Joint Epilepsy Council of the UK and Ireland (JEC) and the International Bureau for Epilepsy (IBE) and stays abreast of legislative and social developments for people with epilepsy in Europe.

Brainwave is also involved with organisations such as the Disability Federation of Ireland, the Neurological Alliance of Ireland, the Irish Council for Training Development and Employment for Persons with Disability (cneasta), the Irish Association of Supported Employment etc.



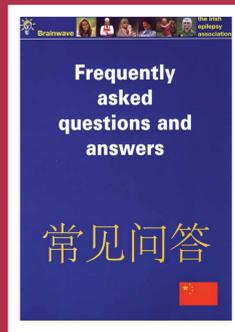
### INFORMATION

Brainwave provides information-meetings, which are held locally to provide an opportunity for people to discuss difficulties and explore issues around epilepsy.



### THE INFORMATION SERVICE INCLUDES

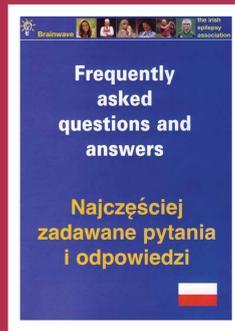
- I Over 40 leaflets about the condition, its effects and management.
- I Information on specific issues such as Driving and Epilepsy, Epilepsy and Pregnancy, Children and Epilepsy.
- I A parent's guide (book + video)
- I An Employer's Information Pack
- I A Doctor's Information Pack
- I A Teacher's Information Pack



### EDUCATION

Over and above information and advice services, this service specifically provides information and guidelines on best international practice to professionals.

This includes doctors, nurses, social workers, teachers, disability professionals and others whose work brings them into contact with People with Epilepsy.



### AWARENESS RAISING

Related to education, this service provides talks to schools, medical institutions and other groups.

### TRAINING

Brainwave runs a one-year pre-employment course in partnership with the Institute of Technology Sligo, in the West Health Service Executive Area, 'Training for Success'.

It is designed for young people who have difficulty in finding or keeping a job because of issues directly related to their epilepsy.

### AIDS & APPLIANCES

Brainwave provides information about a variety of aids, which serve to assist someone who has epilepsy, for its members.

### SUPPORT GROUPS

Brainwave co-ordinates and assists in the setting up of support groups for people with epilepsy, their families and friends in different parts of the country.

### ADVOCACY

Brainwave acts as an advocate in the areas of employment, law, education provisions and social welfare entitlements.

### OUTREACH CLINICS

These offer one to one support and information about living with epilepsy.

### SPECIALIST NURSING GROUP

Brainwave was instrumental in helping to set up this independent group. The group was established in 1999 to look at the specific issues of nursing and epilepsy.

The group is made up of nursing professionals nationwide from different care areas and the general care area.

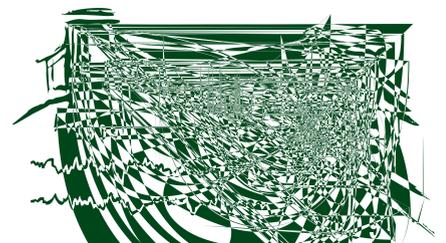
### DRIVING & EPILEPSY WORKING GROUP

This group was established to promote fair policy in legislation in regard to driving and epilepsy.

Brainwave with the assistance of this group was responsible in late 1999 for the change in licensing requirements bringing Ireland in line with other European countries such as the UK and The Netherlands and more recently with the changes in November 2004.

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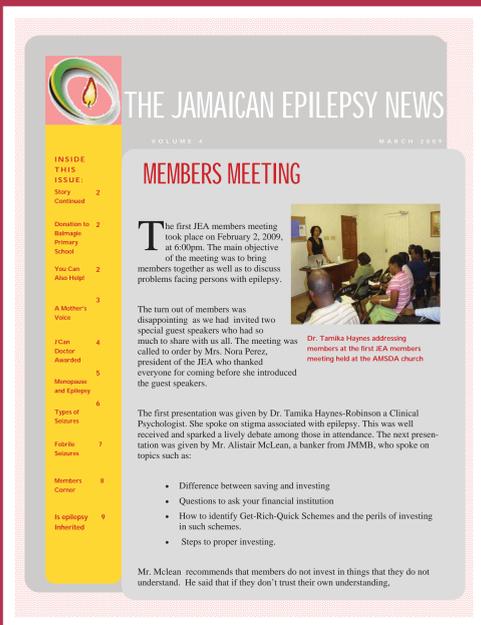


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## THE JAMAICAN EPILEPSY ASSOCIATION (JEA)



### TYPE OF IBE MEMBER

Full Member

### DATE ORGANISATION WAS CREATED

2002

### DATE ORGANISATION WAS FIRST AFFILIATED TO IBE

2003

### TYPE OF ORGANISATION

Individual Membership Organization

### RANGE OF OPERATION

We operate locally.

### GOAL OF THE ORGANISATION

I To improve the quality of life of persons with epilepsy in Jamaica.

### OTHER INFORMATION

I The JEA has approximately 56 members. All members have epilepsy or have a family member with epilepsy. The JEA is administered by a board of Directors comprised of seven persons who offer their advice and services free of charge. The JEA opened an administrative office at Andrews Hospital in October 2008 and now have a permanent Secretary who works five days per week.

#### THE JEA OFFERS THE FOLLOWING SERVICES TO MEMBERS:

1. Subsidised counselling with Psychologists
2. Assistance with resume preparation and job placement in conjunction with a Job placement company.
3. Financial Aid for patients needing Video-EEG monitoring.
4. Biannual newsletter which is circulated to all members.
5. Members' meetings with special guest speakers in an effort to educate members on epilepsy and other matters of interest.
6. Educational brochures, pamphlets, posters, medical alert cards and a children's book about a horse with epilepsy are given to all new members.

The JEA works very closely with the Jamaican League Against Epilepsy (JLAE) to advance clinical management through better diagnostic precision with the launch of the Video-EEG Centre in 2004, a unique private-public effort with the Government of Jamaica. This Centre is administered by the JEA. Financial aid is offered to those unable to pay full fees.



Together with the JLAE the JEA has hosted many medical conferences to improve knowledge about epilepsy in the medical community. The most recent conference – The First North American Regional Caribbean Congress on Epilepsy – was hosted by the North American Regional Commission of the ILAE on May 31, 2008. The congress was attended by physician from North America, Europe and the Caribbean with many prestigious specialists speaking on epilepsy. Over 100 persons attended the conference. The congress was opened by the Minister of Health, The Hon Rudyard Spencer who pledged to work closely with both the JEA and the JLAE in an effort to improve epilepsy care in Jamaica.

The JEA continues to work towards improving the social aspects of persons with epilepsy in Jamaica as well as educating the general population about epilepsy.

### CONTACT DETAILS

#### JAMAICAN EPILEPSY ASSOCIATION (JEA)

c/o Andrews Memorial Hospital, 27 Hope Road, Kingston 10

phone (876) 968 8274 e-mail jaepilepsy@cwjamaica.com

#### THE CONTACT PERSON TO INTERNATIONAL LIAISON

Mrs Nora Perez – President

Ms Jennifer McCallum – Administrative Secretary



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