

International Bureau for Epilepsy

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

Brainwave, The Irish Epilepsy Association

MISSION & STRUCTURE

Brainwave was established in 1966 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

- To provide support, information and help-line to people with epilepsy.
- To provide information to health professionals in dealing with epilepsy.
- To improve public understanding of epilepsy (in order to eliminate fear and prejudice)
- 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.
- To promote legislative and civil rights for people with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them.
- To assist in the development of support groups for people with epilepsy in the area of training and employment.
- To provide information on issues related to driving: insurance, changing legislation.
- To raise funds to support its work in an awareness-creating manner.
- To provide training on Epilepsy and Rescue Medication to Health Professionals.

INFORMATION

According to the recent Prevalence of Epilepsy in Ireland study, there are up to 36,844 people over the age of 5 living with epilepsy in Ireland. At least 50% continue to have on-going seizures or experience debilitating side effects.

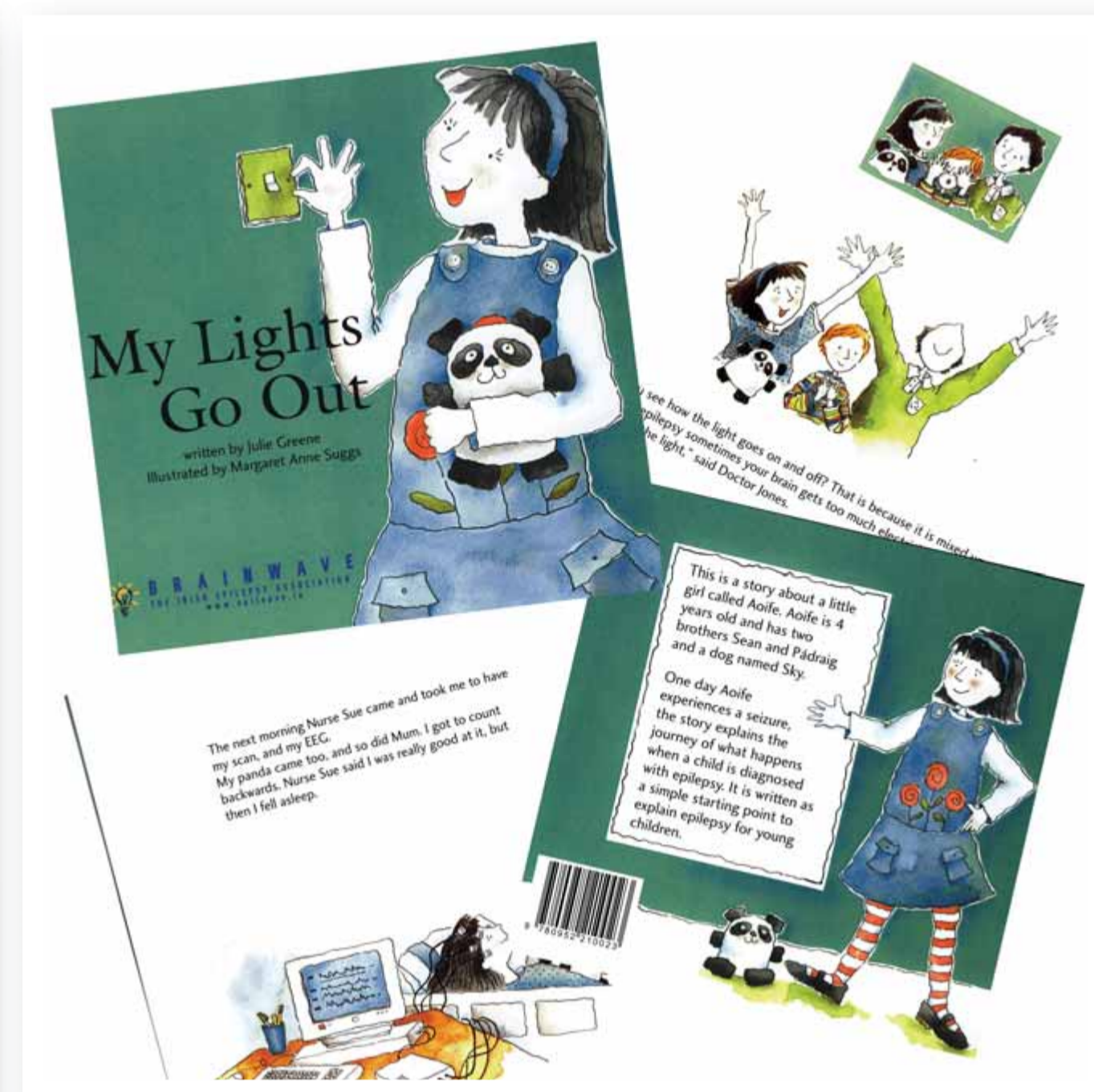
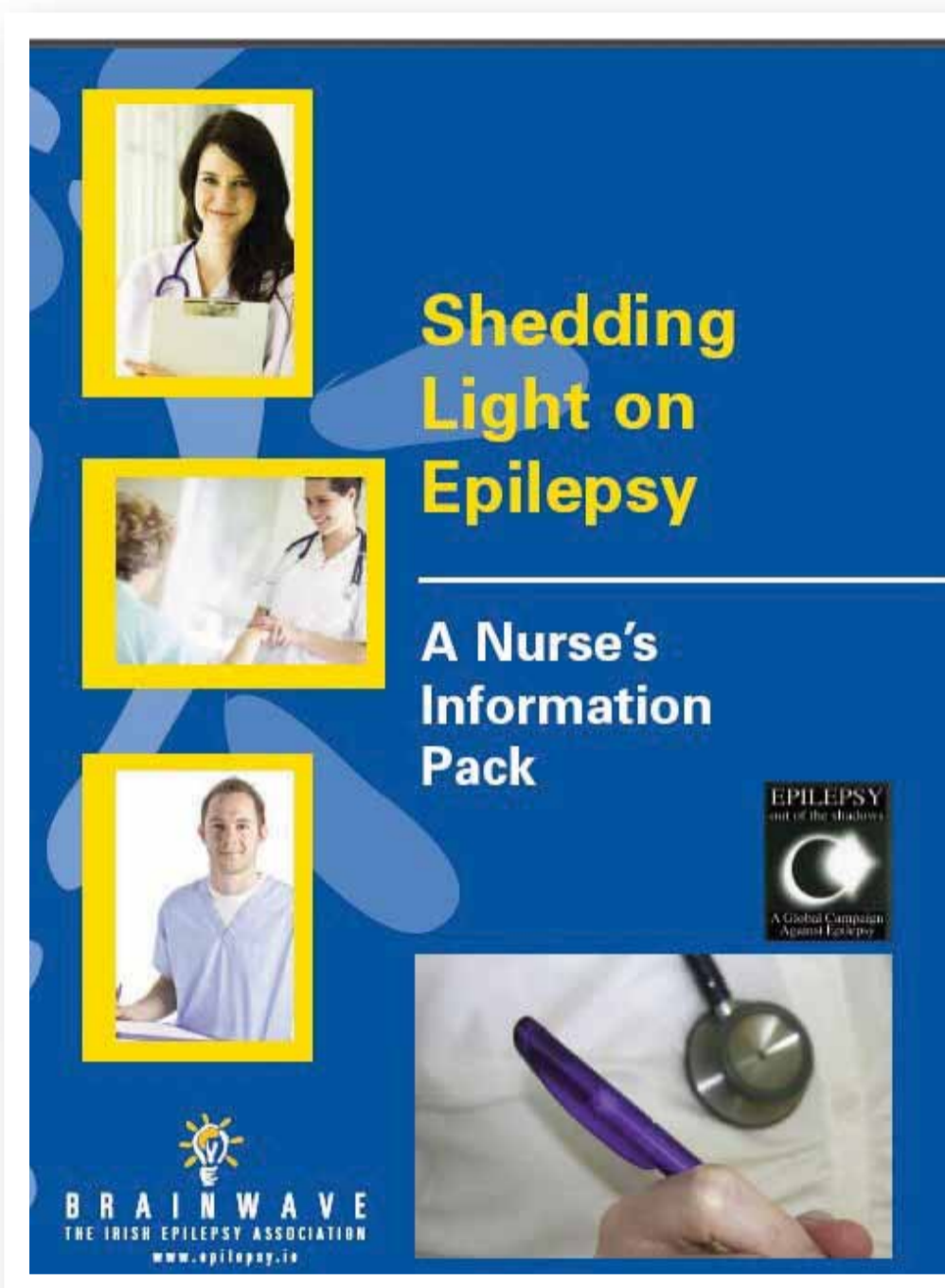
Brainwave's most vital area of service to people with epilepsy is in the post-diagnosis phase, when information about epilepsy and coping strategies are essential to people living with the condition, their parents, families and friends.

Brainwave 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, the Irish Association of Supported Employment etc.

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EDUCATION & AWARENESS RAISING

Brainwave provides information and guidelines on best international practice to medical and non-medical professionals, and others whose work brings them into contact with people with epilepsy.

TRAINING

Brainwave runs a one-year pre-employment course 'Training for Success' in partnership with the Institute of Technology Sligo, in the West Health Service Executive Area. The programme, now in its 11 year, is designed for young people who have difficulty in finding or keeping a job because of issues directly related to their epilepsy.

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.

HOSPITAL AND 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 and is made up of nursing professionals nationwide from different care areas

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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LITHUANIAN ASSOCIATION OF INTEGRATION FOR PEOPLE WITH EPILEPSY (LESIA)



COUNTRY OF OPERATION

Lithuania

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

November 24, 2004

DATE ORGANIZATION FIRST AFFILIATED TO IBE

2006

TYPE OF ORGANISATION

Organizational Membership

RANGE OF OPERATION

National

MISSION

- To participate in the processes of shaping the country's social policy.
- To restore the ability of people with epilepsy to lead independent lives and to integrate into society.

GOALS

- Protection of the rights of people with epilepsy;
- Reducing discrimination in education and the labour market;
- Improving the quality of life of people with epilepsy by providing complex rehabilitation services, closer to residential areas.

NUMBER OF PEOPLE WITH EPILEPSY IN COUNTRY

24,000

LESIA MEMBERS

Seven regional associations, which unite people with epilepsy, medical professionals, and others.

LESIA SUPPORTERS

- Bethel Epilepsy Centre (Germany)
- Vilnius University (Lithuania)
- Vilnius pedagogical university (Lithuania)

CAMPAIGN ACTIVITY

2008 - 2009 LESIA completed an initiative "I am the Same as You", aimed at decreasing stigma in society, using all available mass media: radio, TV, the press.

OVERVIEW OF SERVICES

- Preparation of legislation amendments regarding the needs of people with epilepsy;
- Provision of psychosocial services through regional associations;
- Information dissemination for people with epilepsy, their relatives and society about epilepsy and its outcomes, integration possibilities.

- Provision of psychosocial rehabilitation services with the purpose of restoring the bio-psychosocial functions of people with epilepsy and to prepare them for professional rehabilitation, according to LESIA created methodology.

STRUCTURE OF LESIA:

LESIA leads methodical governmental coordination and control over service provision in regional associations. Regional associations provide information, consultation and psychosocial rehabilitation services in their region. They organize outgoing service closer to residential areas for people with epilepsy through self-help groups

HISTORY

LESIA was founded in 2004 on the base of the Vilnius association of people with epilepsy. LESIA initiated the creation of new associations, which gradually joined together to become the structure of LESIA. In 2007 LESIA had already introduced 7 associations acting in 6 regions. In the near future there will be new associations founded in the remaining 4 regions of the country.

Since year 2007 LESIA has participated in the National Program of Social Integration of the Disabled, which is financed from the Government Budget.

An indication of LESIA's work

Year	Number of people who accessed services	Of those who accessed services, number who obtained social rehabilitation care	Number of children receiving service support
2007	261	144	17
2008	497	278	31
2009	545	403	51

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Caritas Malta Epilepsy Association: on the side of people in need



INTRODUCTION

The Caritas (Malta) Epilepsy Association was set up in 1996, in order to help people with epilepsy and their families. It is estimated that in the Maltese Islands there are over three thousand persons who have the condition. At the moment the association has about 235 members, of whom 160 have been diagnosed with epilepsy.

AIMS

The mission of the association is to improve the quality of life for people with epilepsy. The association's aims and ideals are:

- To promote public awareness and education about epilepsy and the needs of people who have the condition.
- To improve the public image of the person with epilepsy.
- To enhance the self-image, self-confidence and self-reliance of people with epilepsy.
- To stifle local discrimination of people with epilepsy and minimise the social consequences brought about by epilepsy.
- To counsel and educate persons with epilepsy and their families or their legal guardian/s on coming to terms with and adapting to the condition.
- To present the interests, rights, needs, grievances and problems of persons with epilepsy to the notice of policy makers.
- To promote the exchange of information with other organisations.
- To co-ordinate with other persons wishing to form other organisations for the welfare of persons with epilepsy and/or Caritas (Malta) Epilepsy Association their families or their legal guardians.
- To encourage and promote research.

ACTIVITIES

All these aims are achieved through the association's activities:

- Talks and interviews on local radio, TV stations and daily papers.
- Press releases on local newspapers.
- Printing and distribution of leaflets on various aspects of epilepsy in schools, hospitals and clinics.
- A one hour video film about epilepsy in Maltese, describing the various types of seizures, medication and local experiences. This video is being shown in schools and sold to various organisations.
- Various meetings with the Health Authorities, Ministries of Health and Social Policy regarding improvements at Mater Dei Hospital with respect to equipment and service and also for the keeping of a register for statistical purposes in order to know better the number of persons with the condition.

- Membership with IBE and local Federation of Organisations for Persons with a Disability.
- Frequent committee meetings and group meetings every two months.
- Fund raising activities.
- Participation in EYIE activities and attendance at international conferences.
- Setting up a youth branch within the organisation.
- Choosing the 14th February as the National Epilepsy Day.
- Printing and distribution of leaflets on various aspects of epilepsy in schools, hospitals and clinics.
- National Epilepsy Conference inaugurated by His Excellency the president of Malta Prof Guido de Marco on the 3rd November 2001, with Mr Philip Lee and Ms Hilary Mounfield as special guest speakers.
- National Epilepsy Conference inaugurated by His Excellency the president of Malta Profs Guido de Marco on the 2nd February 2003 with Mr John Bowis and Mr John Chaplin as special guest speakers.
- Hosted the IBE 9th European Conference on Epilepsy & Society: 'Focus on Change' in March 2004
- Co-ordinator of EU Grundtvig funded project: Curriculum development for PAMs in epilepsy
- National Epilepsy Conference February 2008 with Prof Martin Brodie and Dr Greg Rogers as special speakers
- National Epilepsy Conference February 2010 with Prof Brian Neville and Mr Rick O'Shea as special speakers
- Organization of in-service training courses for teachers and learning support assistants in conjunction with the Ministry of Education.
- Three talks about epilepsy and its management for 120 police officers, organised in conjunction with the Police Academy.
- Several talks to student nurses and nursing staff.



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Epilepsy Connections, Scotland

COUNTRY OF OPERATION

Scotland

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

2000

DATE ORGANIZATION FIRST AFFILIATED TO IBE

2001

TYPE OF ORGANISATION

Our services and activities are open to people affected by epilepsy in the areas we cover.

RANGE OF OPERATION

We operate in the Greater Glasgow & Clyde and Forth Valley areas in west and central Scotland. Approximately 39,000 people in Scotland have epilepsy and around a third of them live in our catchment area.

ORGANISATIONAL GOALS

Epilepsy Connections aims to make life better for people with epilepsy. Our work adds value to existing statutory services and our approach has 3 broad strands:

Service Delivery

- We develop and deliver community-based information, support, self-management, personal development and training services to people with epilepsy, their families, friends, carers and the professionals who work with them.

Effective Joint Working

- We work with statutory, voluntary and independent agencies to address epilepsy information and support needs.

Involving people affected by epilepsy

- We involve people affected by epilepsy in the process of planning, delivering, monitoring and evaluating our services and activities.

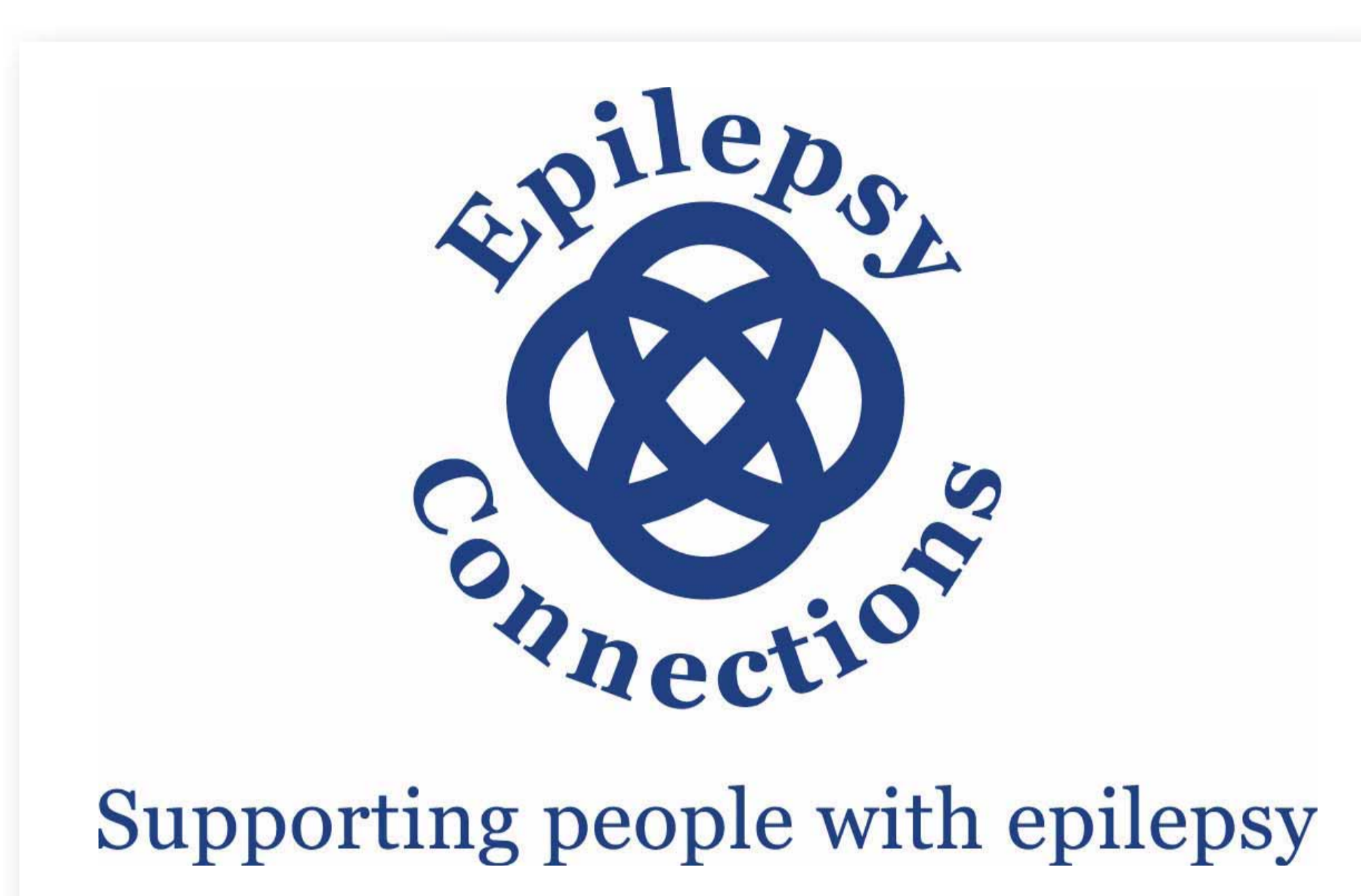
EXAMPLES OF WHAT WE DO:

Epilepsy Connections' Volunteers Forum is open to people who use our services. Its role is to provide feedback to the Board of Directors on aspects of our services and to offer ideas for service developments. Over the last year, Forum members reviewed our information leaflets and organised a fundraising event.

Epilepsy Connections' Befriending Project links people isolated by epilepsy with trained volunteers to support them to access local leisure and social opportunities such as bowling, going to the cinema, eating out and visiting local attractions.

"Friends Connected" is a social group for adults that meets regularly at weekends.

Epilepsy Connections' Schools Project deliver epilepsy awareness education sessions to around 4,000 students every year, helping us to raise awareness of epilepsy and challenge stigma. We also provide epilepsy training for teachers, to ensure that they understand how to manage seizures and the possible negative impact of epilepsy on learning, behaviour and confidence.



The Schools Project team provide a programme of fun activities and events for children with epilepsy and their siblings, including indoor climbing, cinema trips, theatre workshops and yoga.

Our Epilepsy Fieldwork Team provide information, listening ear support and practical advice to hundreds of people with epilepsy each year and to their families, friends and carers. The team work closely with epilepsy specialists, and other health professionals, housing and social care staff, teachers and employers to improve standards of care and support for people with epilepsy in the community.

Our Multicultural Project meets the specific information and support needs of Glasgow's Black and Minority Ethnic Communities, providing bi-lingual, culturally-appropriate services to individuals and families.

Epilepsy Connections' Mainstreaming Project offers a second chance to people whose epilepsy has limited their education and employment chances. The project offers short to medium term training and personal development courses designed to help adults isolated by epilepsy to build the skills and confidence they need to make positive changes to their lives.

We also offer a range of sessional therapies including counselling; complementary therapies (Indian Head Massage, reflexology, shiatsu, reiki); art and drama workshops; growing fruit and vegetables on our allotment; events for special interest groups e.g. women's information days.



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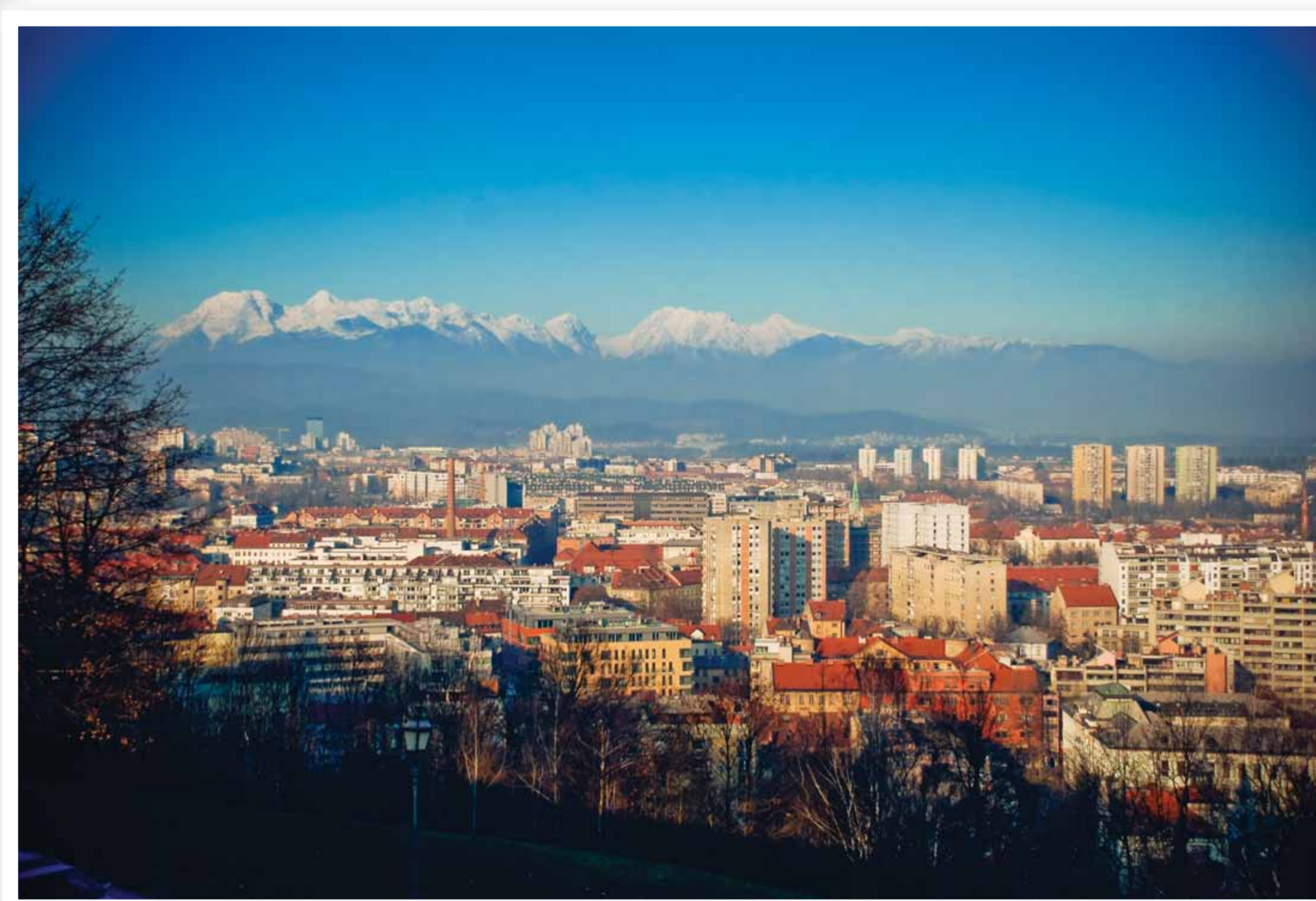
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Slovenian League Against Epilepsy



COUNTRY OF OPERATION

Lithuania

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

June 1, 1990

DATE ORGANIZATION FIRST AFFILIATED TO IBE

1993

TYPE OF ORGANISATION

Individual Membership

RANGE OF OPERATION

National

GOALS

- promotion of research in the field of epilepsy (medical, psychological)
- organizing a professional network for diagnosis and treatment of epilepsy in Slovenia
- organizing professional and scientific work in the field of epilepsy
- prevention of psychosocial problems in people with epilepsy
- promotion of appropriate circumstances for the best social, vocational and medical rehabilitation of people with epilepsy
- organizing and assisting in the organization of lectures, seminars and conferences about epilepsy
- stimulating, establishing and maintaining activities of self-help groups in different districts of Slovenia

SPECIAL ACTIVITIES

The Slovenian League Against Epilepsy has organized meetings to assemble people with epilepsy, who were sent abroad to specialized epilepsy centers for examination and surgical treatment, and their relatives in order to share practicalities of this procedure, their experiences, and how they adapted to life after the operation. People with epilepsy who were surgically treated, candidates for such treatment, and their relatives including attendants/translators and people working in the field were invited to those meetings.



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