

International Bureau for Epilepsy

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

LITHUANIA SOCIETY OF PATIENTS WITH EPILEPSY AND THEIR SPONSORS



COUNTRY OF OPERATION

Lithuania

POPULATION

The population of Lithuania totals 3.2 million.

OFFICIAL LANGUAGE

Lithuanian (one of the oldest Indo-European languages, and is similar to Latvian). Russian and Polish are also spoken.

ETHNIC GROUPS (2007)

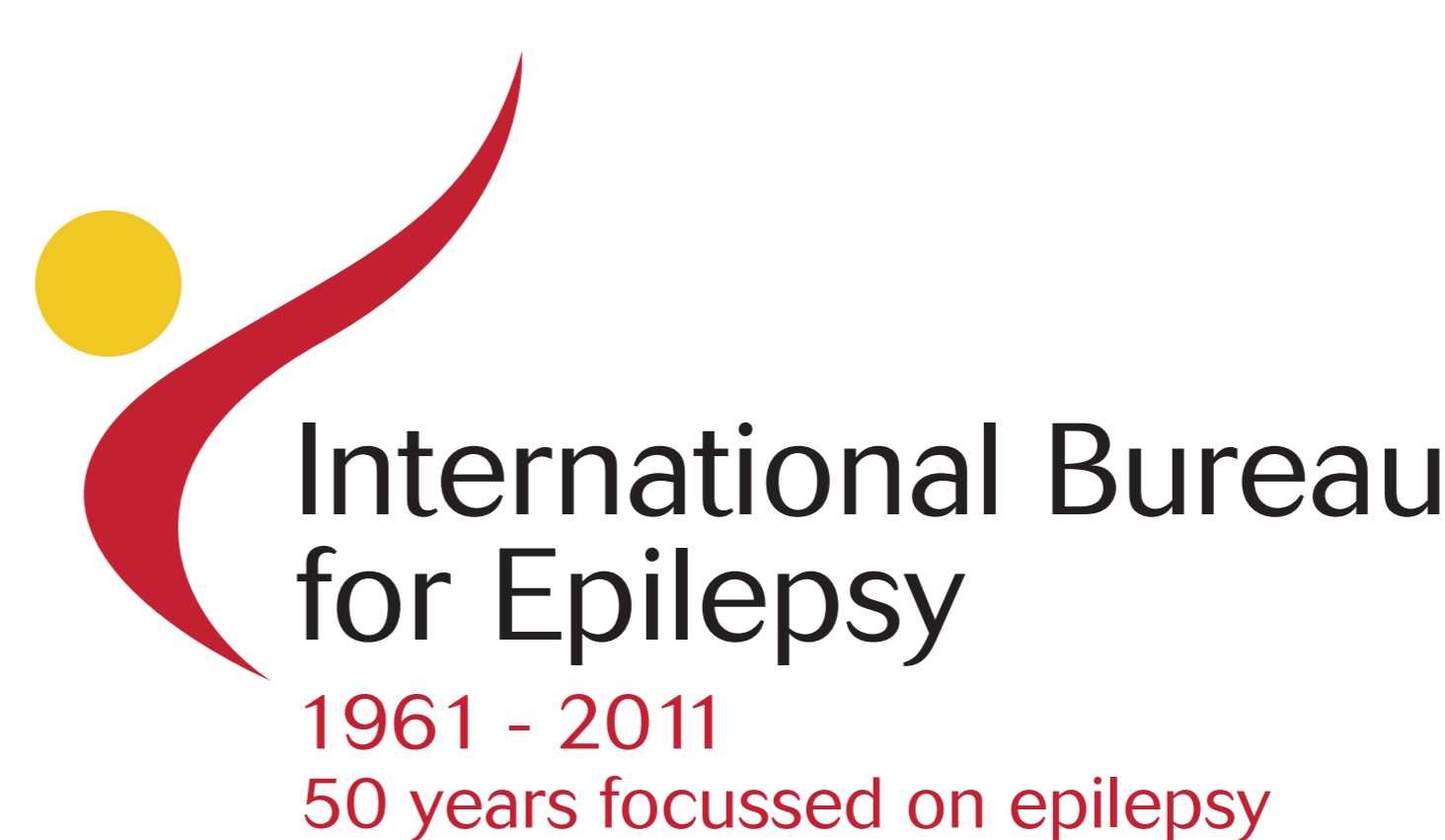
Lithuanians 84.6%, Poles 6.3%, Russians 5.1%.

Lithuania is the biggest of the three Baltic states. It is situated along the southeastern shore of the Baltic Sea, and across the Baltic Sea to the west lie Sweden, Norway and Denmark. It shares borders with Latvia to the north, Belarus to the southeast, and Poland to the southwest.

Prior to the global financial crisis, Lithuania had one of the fastest growing economies in the European Union. Lithuania is a member of NATO, the Council of Europe, and the European Union.

CONTACT DETAILS

Lithuanian Society of Patients with Epilepsy and their Sponsors,
Kaunas Medical University Hospital,
Dept of Microneurosurgery,
Eiveniu 2,
LT 3007 Kaunas, Lithuania.
T: +370 37 326 727
epilepsy.lsmu@gmail.com
Contact: Dr Arunas Kobakas



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

THE ASSOCIATION OF PARENTS WITH CHILDREN WITH EPILEPSY, BULGARIA



The Association of Parents with Children with Epilepsy was registered as a non-governmental organisation on 13 July 1998 in Sofia, Bulgaria. Since its conception as a foundation in Sofia, APCE has developed into a National Association, with a membership of 1,002 families across the country, including relatives of people with epilepsy, people with epilepsy and social professionals. It is one of the 11 NGOs, working in the sphere of health care, which founded the Confederation 'Health Protection' in 2005 - the first patients' organisations union working in this field.

APCE is the unique representative of people living with epilepsy at an institutional level, and takes an active part in policy and legislation formation, in particular after 2002 when the Association became a member of the National Council for the Integration of People with Disability at the Council of Ministers, a consultative body responsible for the development and monitoring of politics in the field of disability. The Association took an active part in the drafting of the Law for the Integration of People with Disability in 1998 and has won a court case in the Commission Against Discrimination. It has been an associate member of IBE since 2008 and is currently applying for full membership.

Crucially, APCE is the unique provider of services for people with epilepsy and their relatives in the country. All efforts of the organisation aim to overcome the stigma towards epilepsy. The goals of the Association encompass a holistic approach to the tackling of the issues of the illness in all its aspects: health, psycho-social and educational. APCE's main objective is the social integration of people with epilepsy, as special attention and effort is made to target the specifics of the social integration of children and young people. Although the statistical data of people with epilepsy in Bulgaria is inconsistent, according to the National consensus of neurologists in Bulgaria, there are more than 75,000 people living with the illness in the country, of whom approximately one-third are children. Epilepsy is still largely unfamiliar in Bulgaria, hence it is approached with fear and misunderstanding. As a result people with epilepsy are socially isolated, many children do not attend public kindergartens and schools, and young people have limited access to the job market. These factors affect detrimentally their quality of life and development as active and equal members of society.

APCE has structures in 16 regions of the country and organises educational seminars and training around the country for parents, institutions and specialists. APCE was the

first organisation in the country to introduce casework as the main approach to achieving integration of people with epilepsy, and is promoting it as a method of work with people with any kind of disability by educating specialists. It includes the formulation of an individual programme and personalised approach, and ensures necessary resources for integration, including psychologists, neurologists, speech therapists, clinical social workers, pedagogues and specialists from the organisation for consultation and support, as well as personalised work with the families of people with epilepsy.

Moreover, the provision of services for people with epilepsy and their families includes the organization of interest groups for children and young people, art and music therapy groups, unique specially-targeted karate training for children with resistant epilepsy and syndromes, English language tutoring, summer camps, educational trips, as well as individual case work, consultations (including medical), and parents' support groups.

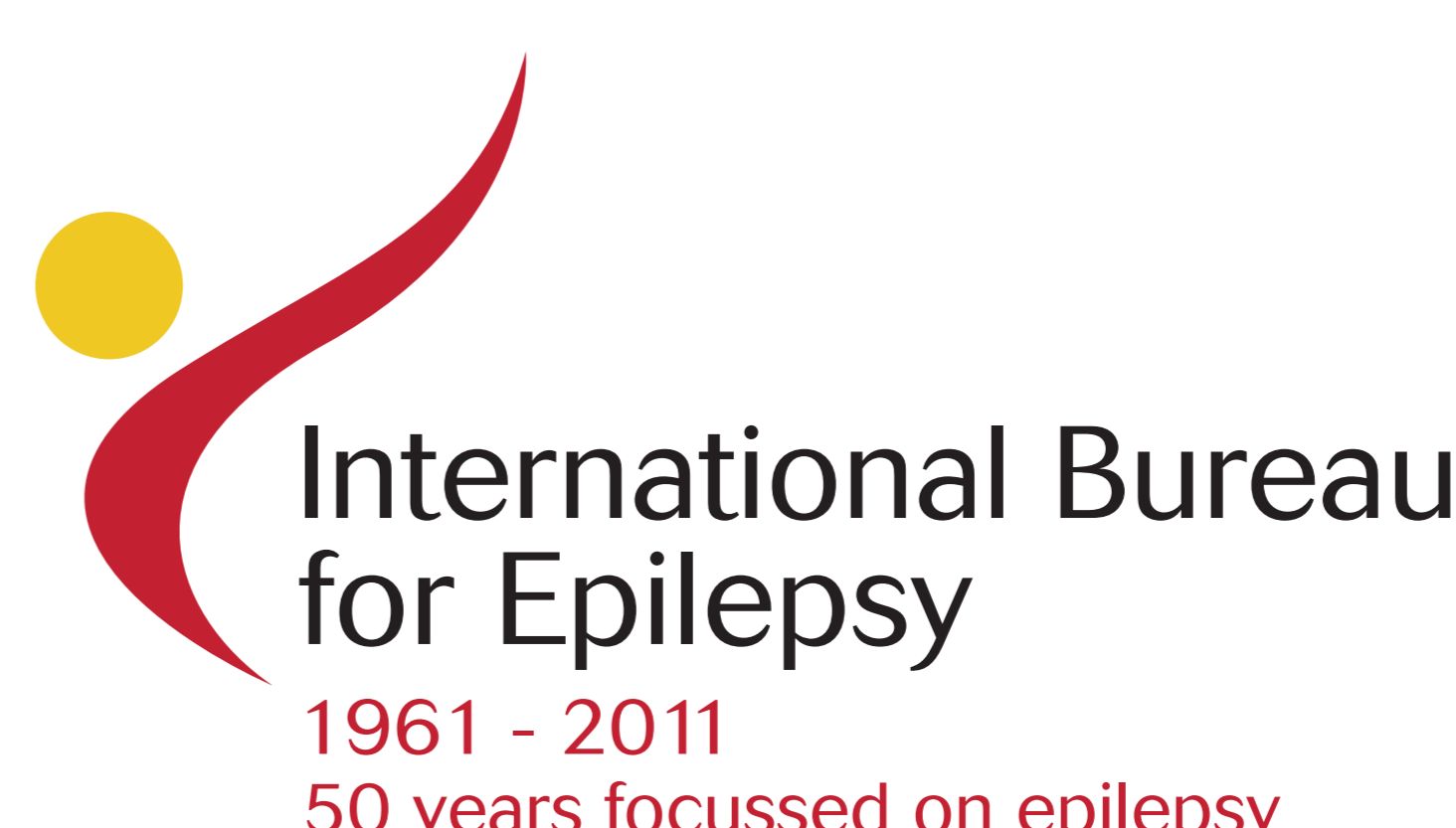
Finally, the Association conducts its own research, and is in participation with institutions of higher education where members of the Association regularly give lectures. It also provides internships and voluntary work, on the basis of which so far four master theses have been defended.

Internationally, APCE co-operates with the European Patients' Forum, lobbies for the Directive of EU for the people with disability via the Bulgarian members of the European Parliament and participates regularly in congresses of epilepsy.



CONTACT DETAILS

Address: Office 602, 5 B Triaditsa St, Sofia, 1000, Bulgaria
Tel.: +359 24 833 594
Mobile: +359 884 937 752
E-mail: frde@abv.bg,
Webpage: www.frde.org



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

"SME" - GROUP OF YOUNG PEOPLE WITH EPILEPSY CZECH REPUBLIC



COUNTRY OF OPERATION

Czech Republic (regional branches in 3 major Czech cities - Pilsen, Brno and Ostrava)

TYPE OF IBE MEMBER

Associate Member

FOUNDING DATE

November 18, 2005

INITIAL AFFILIATION TO IBE

2007

RANGE OF OPERATION

National

MISSION

To bring together young people with epilepsy, their families, friends and all other concerned people

GOALS (SME)

- To bring together young people with epilepsy and integrate them into the society
- To create regional clubs in the Czech Republic
- To increase public awareness about basics of epilepsy
- To plan and realize a wide range of leisure activities
- To struggle with traditional public prejudices against people with epilepsy by enabling unusual activities and experiences (e.g. swimming under medical supervision)
- To publish specialized materials related to epilepsy, e.g. publications such as "Epilepsy and employment", brochures such as "Men and epilepsy", leaflets such as "All about epilepsy", etc.
- To cooperate with other organizations, associations and societies with similar goals
- To provide vocational assistance (e.g. social work) and to provide contacts to professionals
- To create sheltered workrooms for improving labour skills of young people with epilepsy

STATISTICS

EPI-RODINA is divided into two subgroups:

- ER: for parents of children with epilepsy
- SME: for young people (age 15+) with epilepsy

SME has 141 members currently. It connects people who wish to live with epilepsy actively and not just in the disease's shadow. The group is open to anyone – friends, family members or anyone else with an interest in epilepsy. The motto of the group is "Be happy with epi".



REGULAR ANNUAL ACTIVITIES

- Skittle tournament: twice per year (has been held for 5 consecutive years)
- Bowling tournament: 3 - 4 times per year
- Swimming under medical supervision: once per year (has been held for 4 consecutive years)
- Lectures focused on various topics related to epilepsy: 3 times per year
- Weekend camping: once per year (has been held for 5 consecutive years)
- Other outdoor leisure activities (e.g. mini-golf tournament, horseback riding, tours, etc.): 3 times per year
- Monthly meetings of regional branches
- Artificial wall climbing: once per year (has been held for 2 consecutive years)
- Go-kart racing: once per year (has been held for 3 consecutive years: 2006-2008)
- Salt-cave stays: 24 times per year
- River boating courses (planned for summer 2010)
- Concert for National Day of Epilepsy – SME organizes a large-scale concert (many famous Czech artists join the event). Its purpose is to increase awareness among the public about the disease.



CONTACT DETAILS

SME - Group of young people with epilepsy (part of civic association EPI-RODINA)

Address: Sobeslavská 2377/1, 130 00 Prague 3 - Vinohrady, Czech Republic

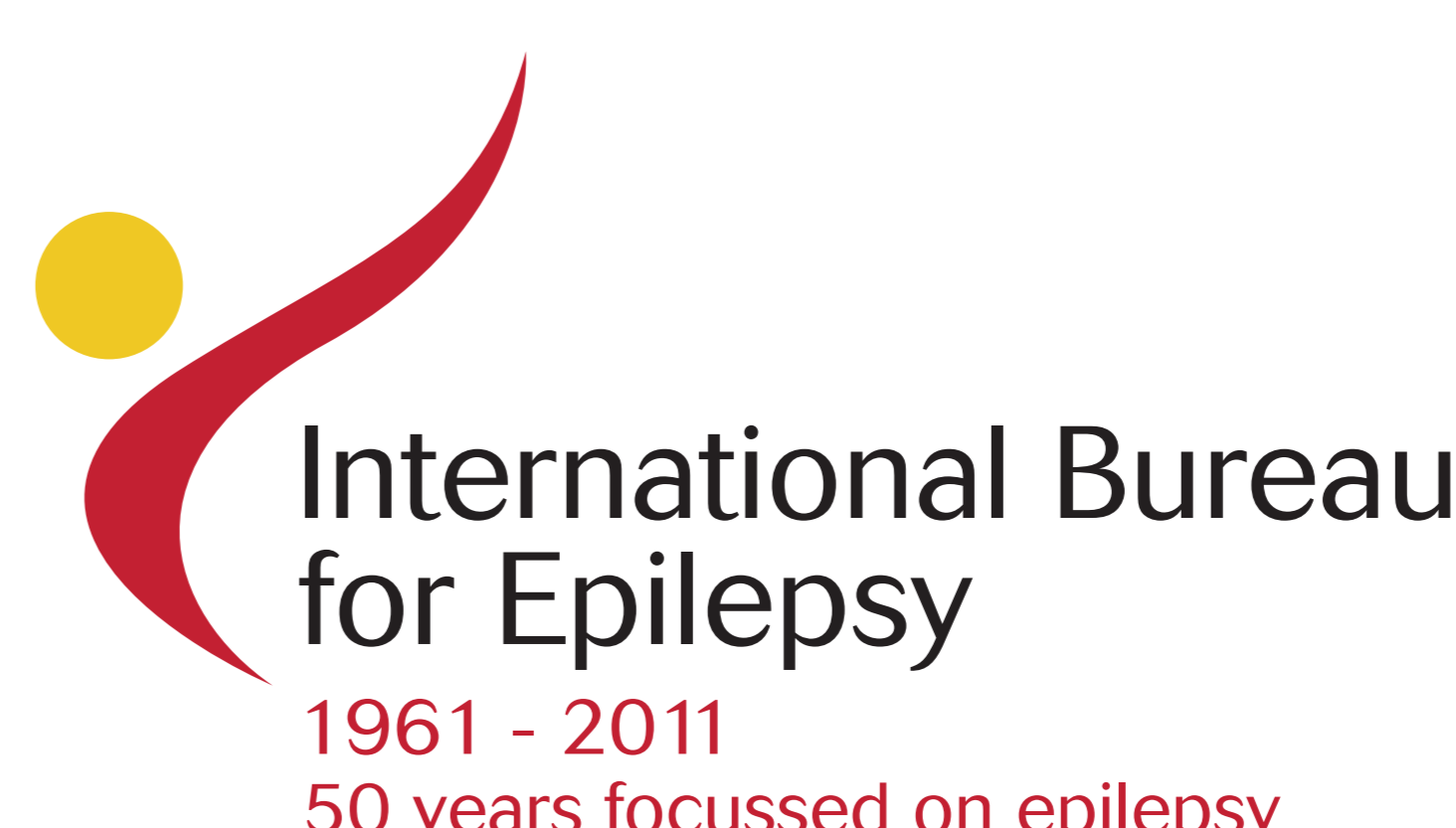
Team of social workers for patients with epilepsy in the Czech Republic, Leaders of SME's regional branches:

Pilsen: Lucie Valouchova, email: valouchoval@fnplzen.cz

Brno: Marta Michnova, email: marta.michnova@fnusa.cz

Ostrava: Antonin Liska, email: tonda.liska@seznam.cz

Website: <http://www.er-sme.cz/>



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

THE "EPISTOP" ASSOCIATION CZECH REPUBLIC



COUNTRY OF OPERATION

Czech Republic

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

December 20, 2007 (during period 1995 - 2007 operated as a support group)

INITIAL AFFILIATION TO IBE

2009

TYPE OF ORGANISATION

Membership organization

RANGE OF OPERATION

National

SPECIAL ACTIVITIES DURING 2009 - 2010

- Creating a Facebook profile and partnering with public media in order to increase awareness about the association's activities and to employ new methods of communication and promotion
- Free online professional consultations on patient's questions
- Cooperating with other local organizations and developing/updating professional websites
- Partnering with public media, especially with "Classic FM" radio broadcasts in talk show "Beetles in the head" (autumn 2008 to spring 2009 - 13 broadcasts) and "Stop to epilepsy, green to people with epilepsy" (September 2009 to February 2010 - 22 broadcasts)
- Publishing information about the association in the journal Pharmbusiness (February 2009)
- Participating in JobDays 2009 (the largest international trade fair of job opportunities in the Czech Republic), distributing a letter addressed to employers about employment possibilities for people with this disease
- Releasing a new publication (e.g. "Epilepsy and employment")
- Presenting association activities at "XIII. Postgraduate course of epileptology - Days of Jiri Dolansky" in Prague and "28th International Epilepsy Congress" in Budapest
- Developed a plan for the creation of a "Complex care center". Unfortunately financial support from the EU's structural funds was not approved

MISSION

To create a platform for meeting, cooperation and activities of all groups and persons related to people with epilepsy, in order to improve their social status.

GOALS

- To improve the quality of life of people with epilepsy
- To bring together experts related to people with epilepsy for mutual cooperation
- To solve employment and social problems of people with epilepsy
- To create expert analysis and legislation proposals concerning people with epilepsy (e.g. driver licences, disability pensions, etc.) and to disseminate this information
- To improve healthcare standards at all levels
- To educate people with epilepsy, persons caring for them as well as the general public
- To increase public awareness about the disease through continuous projects and media presentations
- To publish specialized materials (publications, brochures and leaflets) related to epilepsy (e.g. "Minimal Diagnostic and Therapeutic Standards in People with Epilepsy" etc.)

STATISTICS

The main communications tool is the association's website. Activities are focused mainly on two areas - social legislation and healthcare.

REGULAR ANNUAL ACTIVITIES

- Association members meetings: twice per year
- Support of boating triathlon: once per year (has been held for 7 consecutive years)
- National Day of Epilepsy

PREPARED PROJECTS

Lectures for emergency and rescue workers focused on practical aspects of epilepsy diagnosis and treatment
Supporting scientists in their research - e.g. dissertation thesis: "Factors affecting quality of life of children with epilepsy"
Preparing a specialized publication "Epilepsy and traveling" by a team of social workers
Renewing an intensive training course "Moses" by social workers for people with epilepsy and their families



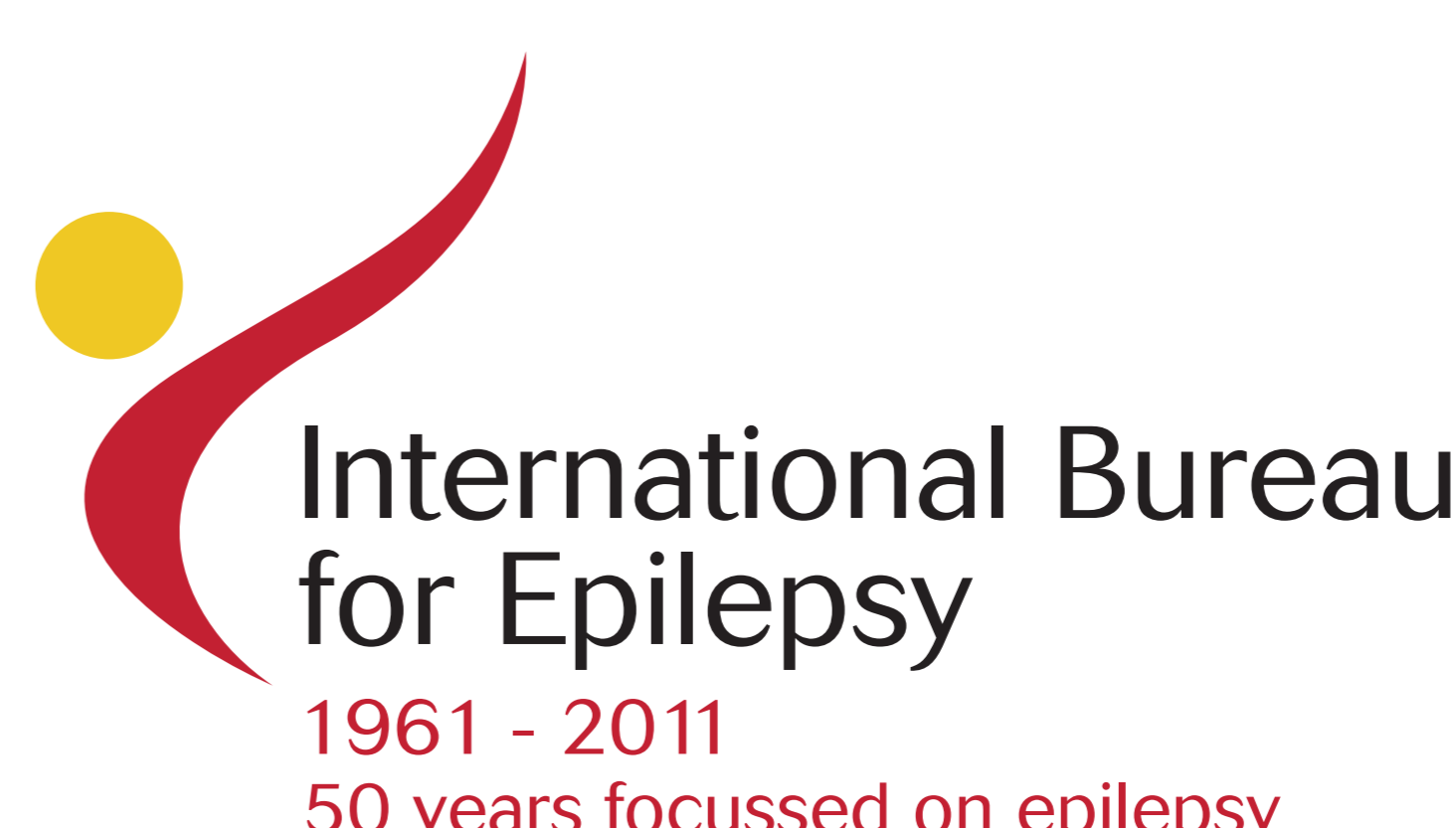
CONTACT DETAILS

The „EpiStop“ Association

Address: Thomayer University Hospital with Polyclinic, Videnska 800, 140 59 Prague 4, Czech Republic

Contact Person: Jana Zarubova, M.D.

Website: <http://www.epistop.cz/>



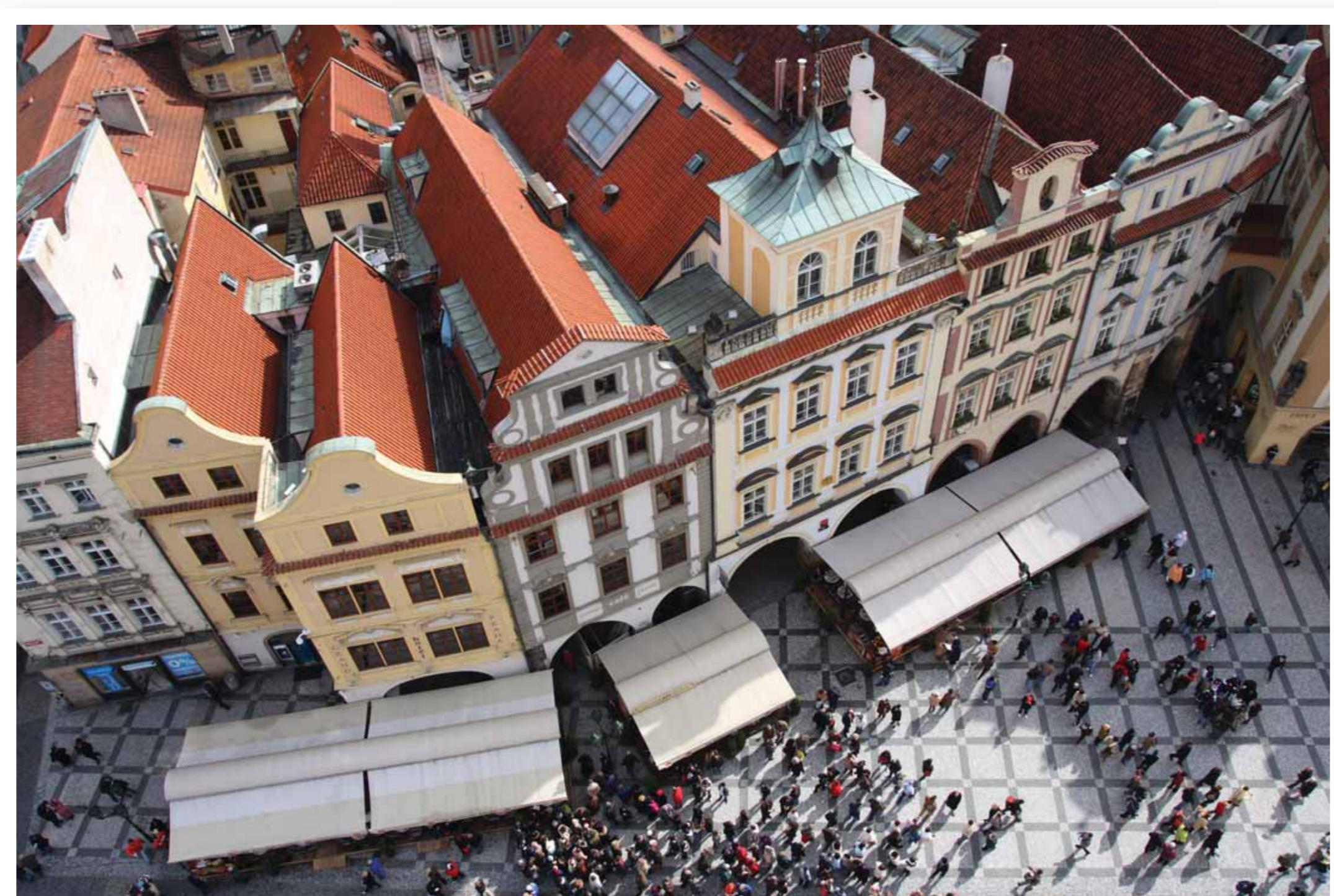
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

SPOLEČNOST „E“ / CZECH EPILEPSY ASSOCIATION, O. S., CZECH REPUBLIC



COUNTRY OF OPERATION

Czech Republic

TYPE OF IBE MEMBER

Full member

YEAR OF ENTRY INTO IBE

1995

TYPE OF ORGANISATION

Not for profit charity

RANGE OF OPERATION

National

BRIEF SUMMARY OF TARGETS AND MISSIONS OF OUR ORGANIZATION

Společnosti „E“, Czech Epilepsy Association, spreads information about living with epilepsy and epilepsy itself, not only between its clients and their relatives, but also in the general public. The aim of this work is to reach the point where no one will be afraid of epilepsy and will be able to engage fully with people with epilepsy, without any hint of stigma, and will also be able to help them if necessary. Our biggest target is to show as many people as possible, that people afflicted with epilepsy can lead normal happy lives.

NUMBER OF PEOPLE AFFLICTED BY EPILEPSY IN THE CZECH REPUBLIC

Approximately 1% of the population, which is 100,000 people

Number of members of our organization: 1,200

Who are our clients:

- People who have epilepsy, their relatives and closest friends.
- Others, who support the association:
- External collaborators, experts from the medical sphere, lawyers, social workers, etc., supporters of government organizations and private companies, media (television, radio, printed materials)

SUMMARY OF OUR ACTIVITIES AND PROJECTS

Společnost „E“, Czech Epilepsy Association, is a civic organization founded in 1990 by parents and friends of people with epilepsy. Its aim is to spread knowledge and information about epilepsy among its clients - from people with epilepsy and their families,

to the general public. Every month we publish a magazine – Aura – with information about epilepsy, with special articles focusing on some particular topic, and other materials related to epilepsy and living with the condition. We organize seminars and lectures about epilepsy, first aid for seizures and the possibility of living with epilepsy.

We also organize summer camps for children and holidays in the Czech Republic or abroad for adults with epilepsy and their families. We also provide additional training and recreational activities including workshops, classes and club activities. These focus on vocational counseling and social services.

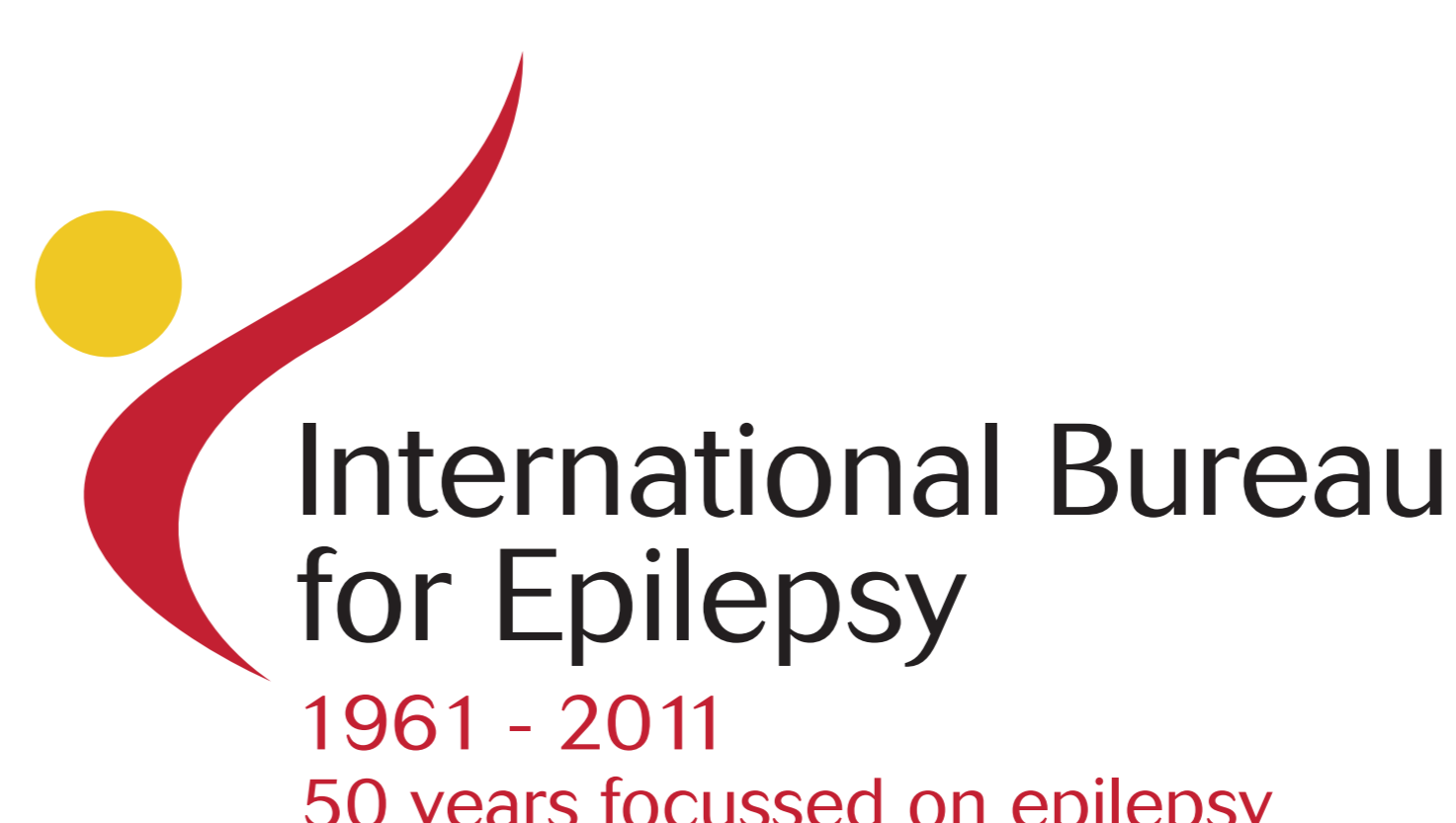
MEETING DEMAND FOR SERVICES:

Thanks to our nationwide scope, the club's activities in regional towns, publishing of our monthly magazine Aura, production of other thematic publications and materials and their distribution in neurological surgeries, exhibitions, congresses and at other theme events, and through media coverage, we are confident that we provide information and assistance as widely as possible.



CONTACT PERSON:

Alena Cervenková, Chairwoman
Společnost „E“, / Czech Epilepsy Association, o. s.
Liškova, 959/3, 142 00, Prague 4, CZECH REPUBLIC
Tel.: 042 241 722 136
E-mail: info@splecnost-e.cz
Web page: <http://www.splecnost-e.cz>



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPILEPSIE VERENIGING NEDERLAND (EVN) NETHERLANDS



Established in 1979 by parents who sought improved care for their children and who also wished to have more influence in how that care was provided.

EVN has 4,980 members with 65 trained and experienced experts working on a voluntary basis and an office with 5 staff members. Persons with epilepsy are our main target group and we provide a mix of activities, with the goal of empowering them through shared experiences, support in improving decision-making and access to education in order to reduce the negative impact of epilepsy. We work with target groups and in special areas such as the Ketogenic diet.

In 2011 are focus is on:

1. Increasing quality of life for persons with epilepsy and their families
2. Developing the organization from a voluntary organisation to a professional organization with trained experience based experts

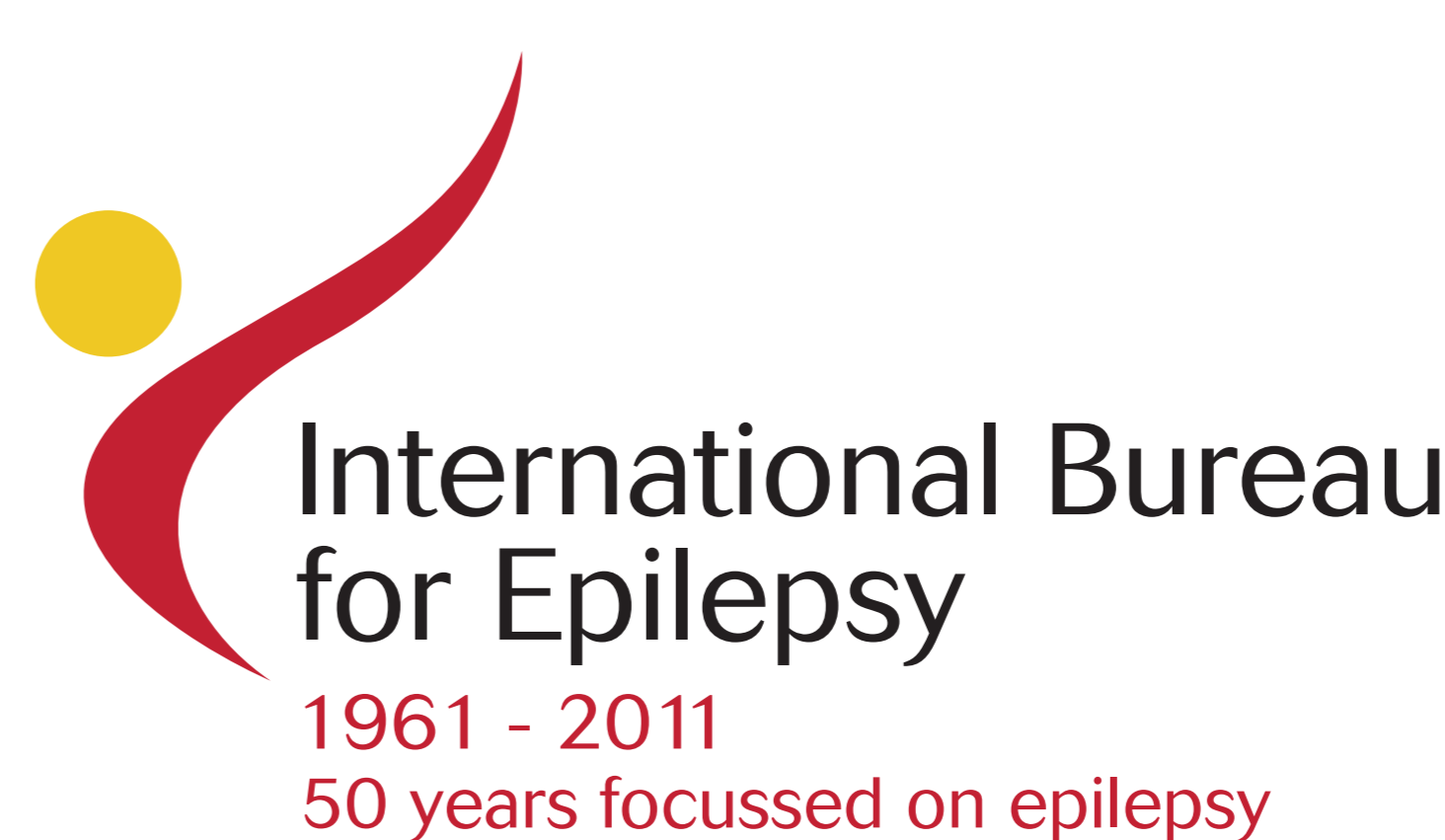
Only a good professional and experienced doctor will diagnose epilepsy and will provide the best options for treatment in the best sequence and with a accurate timing. And from the beginning of the diagnosis there we will provide professional guidance to help persons with epilepsy to cope and to find the way to by the director of their own lives!!! We introduced a new professional in epilepsy care in the Netherland - the epilepsy coach – who is responsible for that process of empowerment and self management. The coach supports the patient and together with the patient and the doctor the best epilepsy care route is decided.

At the present time we have 8 coaches as well as the results of scientific research that “proves” the extra value of the coach. And the health insurance companies are willing to reimburse the cost of the epilepsy coach fees. Health insurances are cooperate because they have known for years that the success in care for people with a chronic disease is never successful when the patient is not actively involved.

To claim and play your role as the partner in the three way partnership with care providers and health insurers, the association has to become professional with a well equipped office that is responsible for the quality and the continuity of the organisation as well as the quality of the experienced experts representing persons with epilepsy. A next step will be to find a solution to link the experienced expert to EVN, for example by giving them more influence in policy decisions of the association.

CONTACT

EVN, Epilepsie Vereniging
Nederland, Postbus 8105,
6710 AC Ede, The Netherlands.
T: +31 318 672 772,
info@epilepsievereniging.nl
Contact: AWB Tempels



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

FINNISH EPILEPSY ASSOCIATION (FEA) – 40 YEARS OF VOLUNTEERING AND ACTION, FINLAND



The Finnish Epilepsy Association promotes equality for people with epilepsy and supports them and their family members to achieve the aim. The FEA is a non-governmental social and health care organisation which values respect of every human being, equality of people with epilepsy, users' experiences and continuous development of its own activities.

The FEA, established in 1969, became a full member of IBE in 1972. The FEA is the national umbrella organisation for the 28 local affiliates in Finland. The number of members is 8000.

They are mostly people with epilepsy and their family members. There are about 300 volunteers in the association and the affiliates. Furthermore the FEA has 2000 donors who support economically the activities of the FEA.

The FEA has not reached all the potential members yet. There are about 56 000 persons with epilepsy in Finland. About 36 000 of these use their right actively to have their epilepsy medication covered by the state.

OUR STRATEGY AIMS TO

- 1 Achieve a world without prejudices of epilepsy. The aim is to educate the public about the different kinds of epilepsy syndromes and the individual symptoms of the disease
- 2 Promote good quality of epilepsy care and rehabilitation
- 3 Foster inclusion
- 4 Guarantee adequate level of assistance, services, benefits and support

WORKING TOGETHER

The FEA is governed by trustees. There is an annual meeting (general assembly) of the representatives of the local affiliates. In the meeting a board is elected. There are a chair and 6 members with personal deputies in the board. The board has 6-10 meetings in a year. There are 17 full time employees in the FEA. In addition, about 100 professionals receive fees for their work in the rehabilitation services of the FEA. The annual budget of the FEA is about 2 million euro. Income sources are governmental grants, service provision, membership fees and fundraising.

LOBBYING FOR BETTER LIFE

Lobbying on behalf of the people with epilepsy in order to achieve improved legislation and to ensure that such legislation is implemented. This is done at national and local level with the municipalities; by position statements, expertise in different kinds of commissions and teams, dissemination of correct epilepsy information, etc.

CONTACT DETAILS:

Finnish Epilepsy Association, address: Malmin kauppatie 26, FIN - 00700 Helsinki, tel: +358 9 3508 2320, fax: +358 9 3508 2322, e-mail: epilepsialiitto@epilepsia.fi
Website: www.epilepsia.fi

The contact person to international liaison:
Sari Tervonen, Executive Director
e-mail sari.tervonen@epilepsia.fi

An essential part of the work of the FEA has always been co-operation with the public social and health care sector and close connections to the Finnish Epilepsy Society, the Finnish ILAE Chapter. This co-operation is evident in daily activity at local, national and international level.

WIDESPREAD INFORMATION SERVICES

Publication of a newsletter and guidance material both through a website and in hard copy; in total over 200,000 pieces each year. Almost 50,000 persons visit the website of the FEA every year.

People can call the help line of the FEA to get advice. It is very important to support the volunteers of our affiliates.

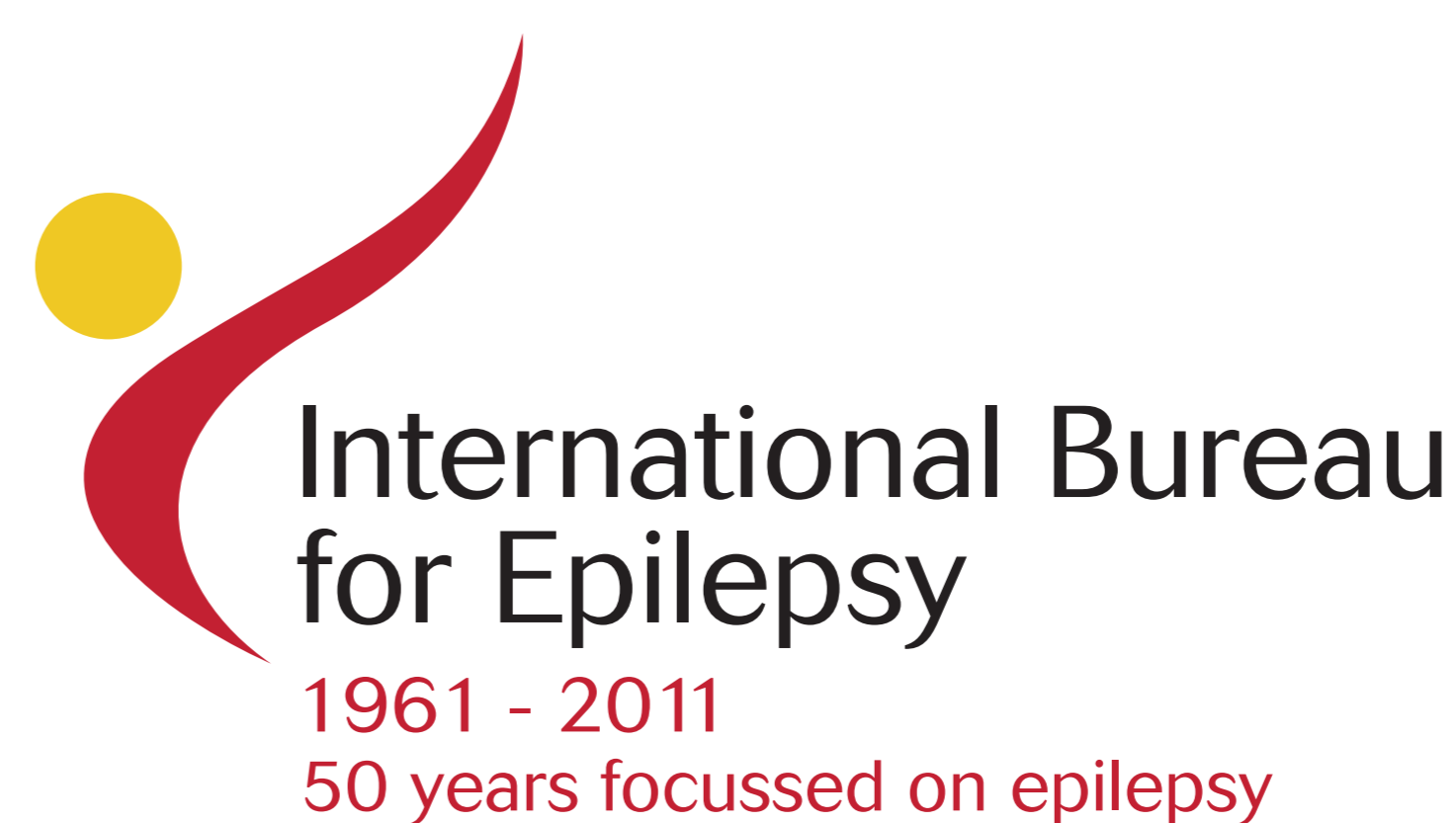
IMPORTANT REHABILITATION

Provision of rehabilitation; carried out together with the National Social Insurance Institution. There is a special model of rehabilitation course (adaptation training) developed by the FEA. The rehabilitation courses are professionally organised. In this training the experiences of other people with epilepsy are used as an important peer support element. About 500 people with epilepsy and family members participate in the courses each year.

CAMPAIGNING

The FEA has campaigned with our affiliates every year. The traditional epilepsy week in September takes place all around the country. In 2010 the theme is: 56,000 different true stories of epilepsy. The idea is to campaign by meeting people face to face in the street, at markets and in shopping centres. The main aim is to distribute information about epilepsy. Lectures about epilepsy will be held. Furthermore we will try to attain major publicity about epilepsy and our epilepsy week theme in the media.

The FEA will campaign also in February 2011 during the first European Epilepsy Day. As part of the campaign we will also have political lobbying while the parliamentary elections in Finland will take place in April 2011.



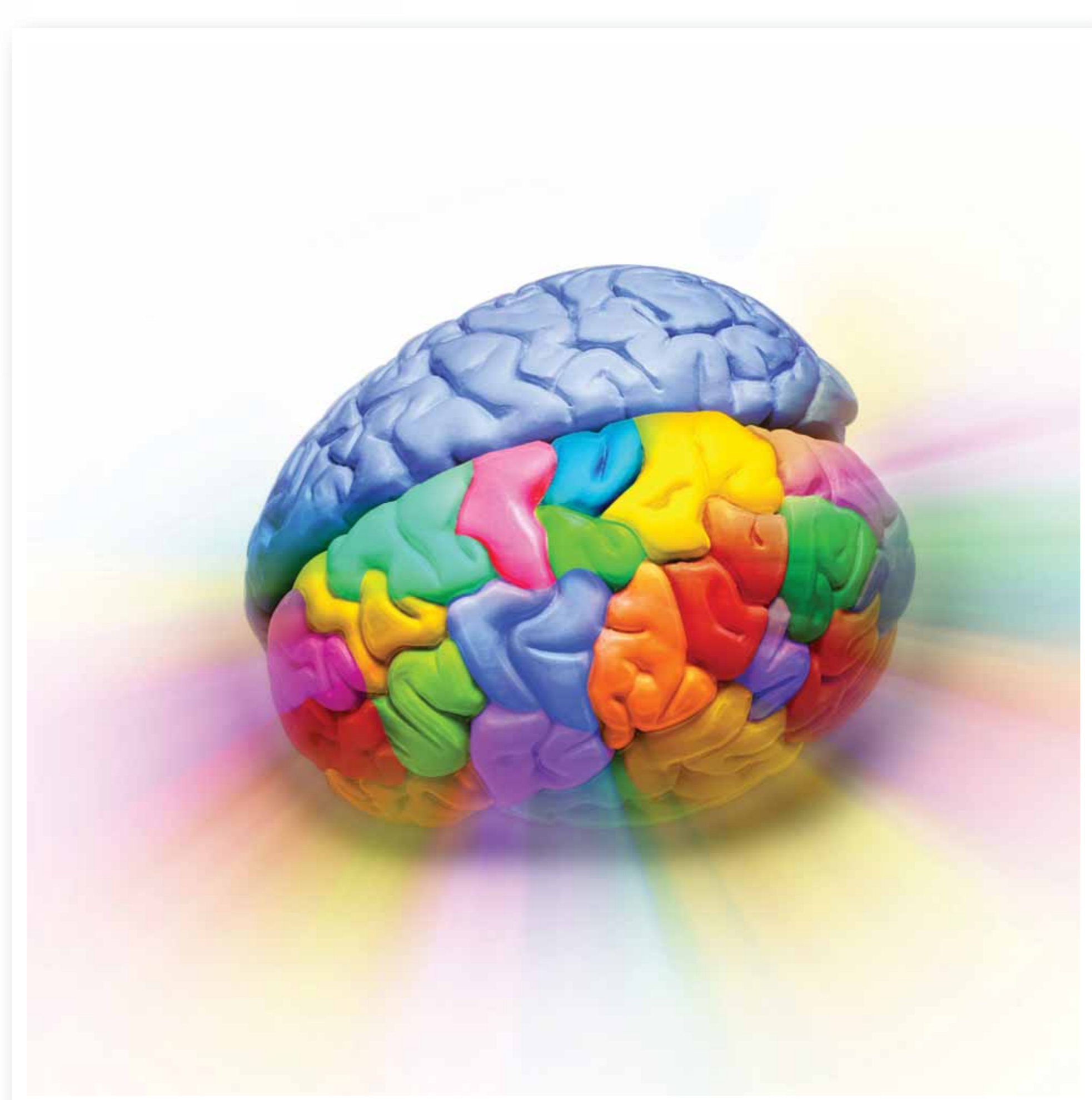
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

AISPACE, FRANCE



COUNTRY OF OPERATION

France and Francophone Countries

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

October 1981

INITIAL AFFILIATION TO IBE

1983

TYPE OF ORGANISATION

Individual membership

RANGE OF OPERATION

National and International

MISSION

- Acting, informing and educating people by improving understanding about epilepsies
- Serving individuals while acting together for all
- Breaking the silence about epilepsies

AISPACE is a national resource centre for information, counseling and interdisciplinary research in epileptology.

OBJECTIVES

- Caring for people and their families from the initial diagnosis of epilepsy
- Helping as many epileptic patients as possible to become agents of their own care and well being
- Answering inquiries for information about epileptic diseases and about the rights of patients with epilepsy
- Favouring social inclusion and professional integration in respect to skills and individual motivation
- Acting, for 30 years, as a permanent observatory of evolving needs and expectations

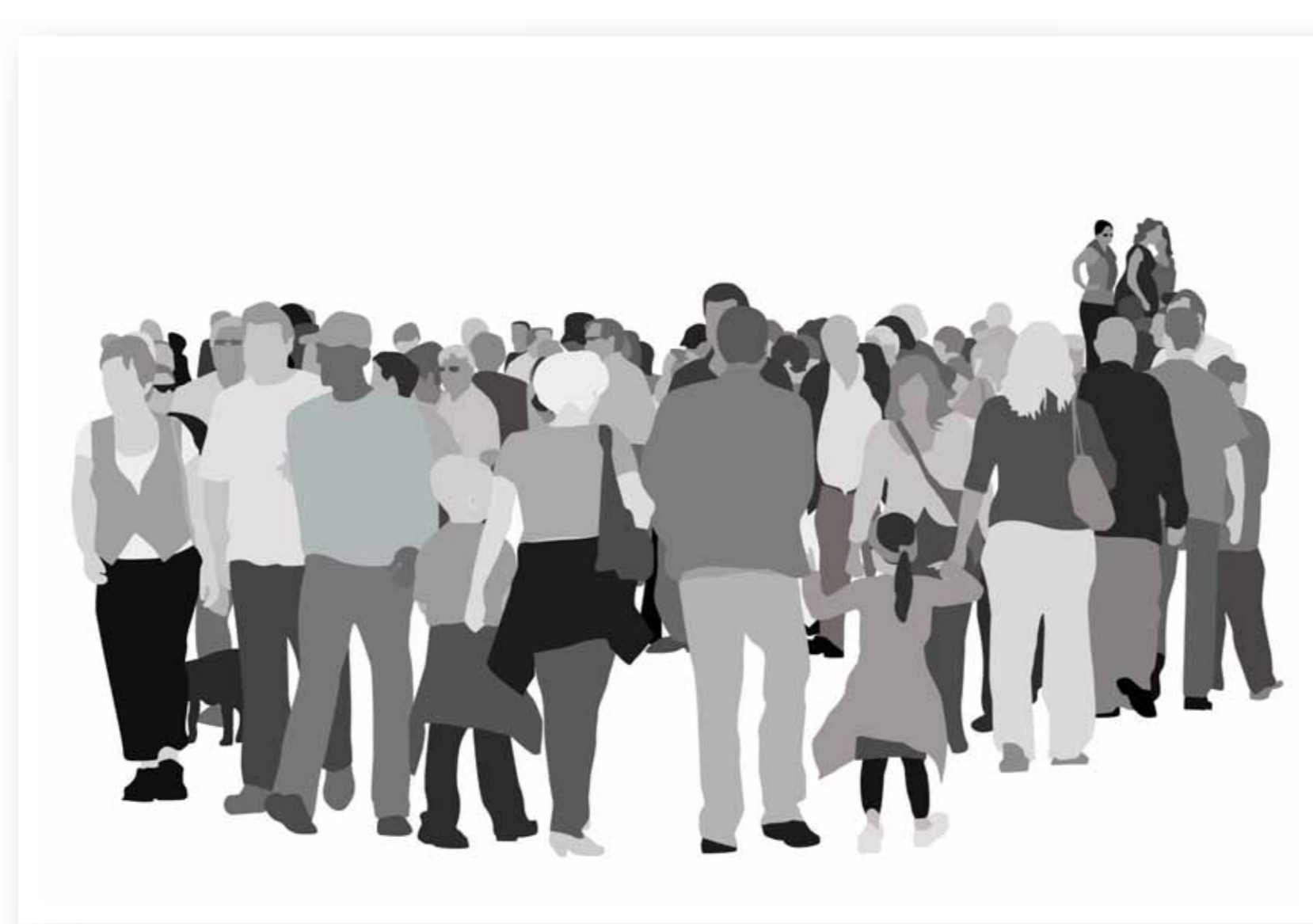
- Being a spokesperson for all by participating in the progressive changes in the organization of the French public health system
- Leading research on epilepsies and the resulting socio-economic and psychological impact
- Organizing conferences and debates about epilepsies
- Participating in training sessions for professional health care workers, for staff members responsible for socio-economic integration, and for volunteer members in health care associations.

PUBLICATION

AISPACE PLUS: quarterly revue since 1985

FINANCED BY

Members and public organizations



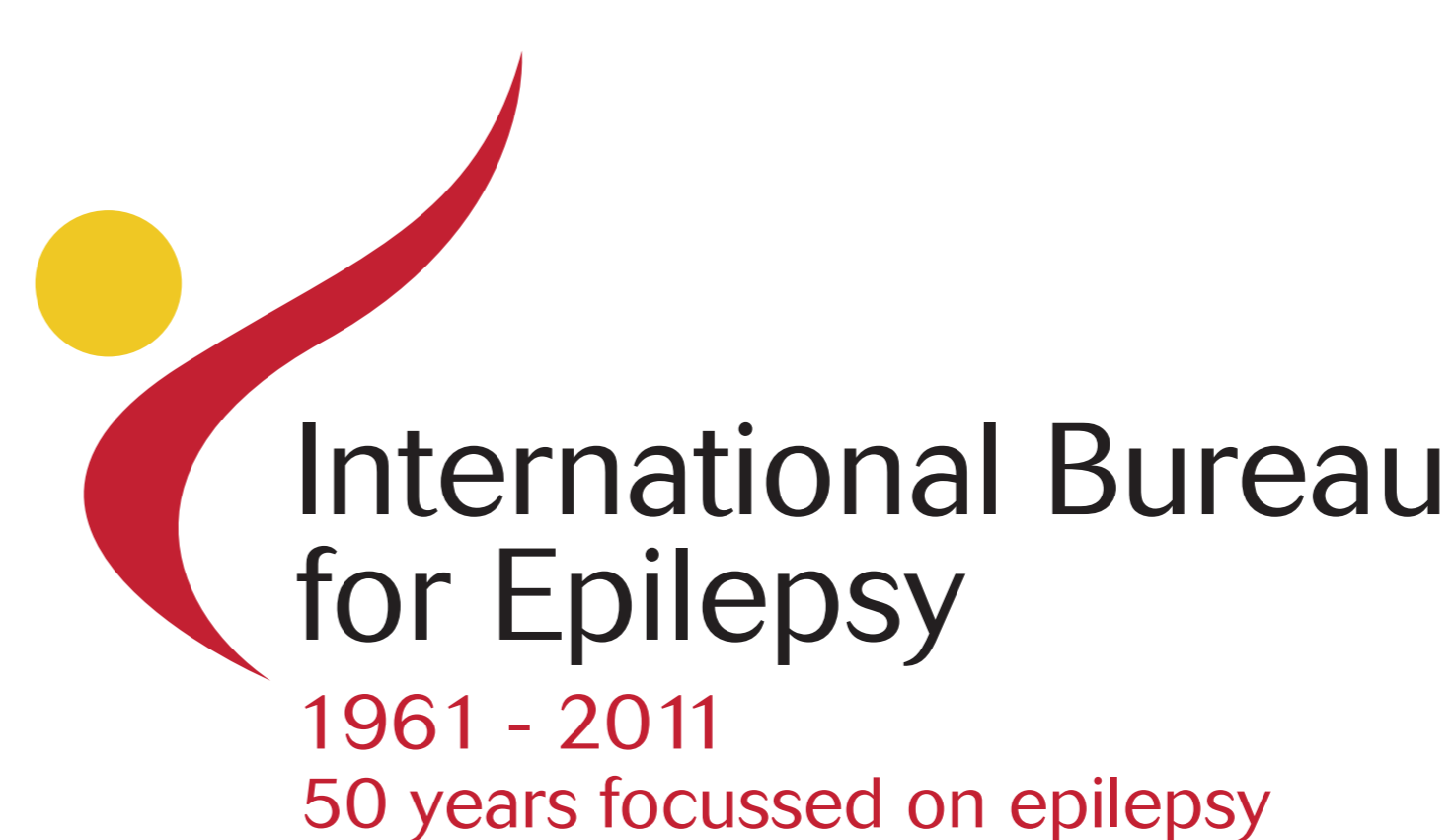
CONTACT DETAILS

Name: Jacqueline Beaussart-Defaye

Address: Maison des Associations, 72 rue Royale, 59 000 Lille, France.

Email: lille.aispace@orange.fr

Website: epilepsies-epileptiques.com



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ASSOCIATION "EPILEPSY AND ENVIRONMENT" GEORGIA

The Epilepsy and Environment Association, a non-governmental, not-for-profit organization, was established in February 1998 and registered in March 1998 in Tbilisi, Georgia. Our association is of the individual membership type, with a national range of operations. In 1999, at the General Assembly during the 23rd International Epilepsy Congress in Prague, our association was ratified as the Georgian Chapter (now Full Member) of the IBE.

MISSION OF OUR ORGANIZATION

To raise the quality of life of people with epilepsy and their families by reducing stigma, raising public and professional awareness, representing the interests of people with epilepsy and their families in governmental and non-governmental organizations, improving legislation, cooperating with authorities, and taking part in national, regional and international activities dedicated to the problems mentioned above.

The official launch of our association was performed in July 1998. Since its launch, our association has successfully cooperated with authorities, has performed a number of activities to raise public and professional awareness and to support people with epilepsy and their families. We also participated in different activities of the Global Campaign. The greatest achievement of our organization is to be involved in a major activity of the Global Campaign Against Epilepsy: a Demonstration Project titled "Epilepsy Management at Primary Health Care Level in Georgia".

OVERALL AIMS OF THE PROJECT

1. To generate procedures that will improve the identification and management of people with convulsive forms of epilepsy in 4 main districts of Tbilisi within the existing primary health care system and with community participation.
2. To develop a model of epilepsy treatment at primary health care level that can be applied nation-wide.

Duration of the project – 4 years (2008-2011). The project is carried out in 4 major districts of Capital of Georgia Tbilisi.

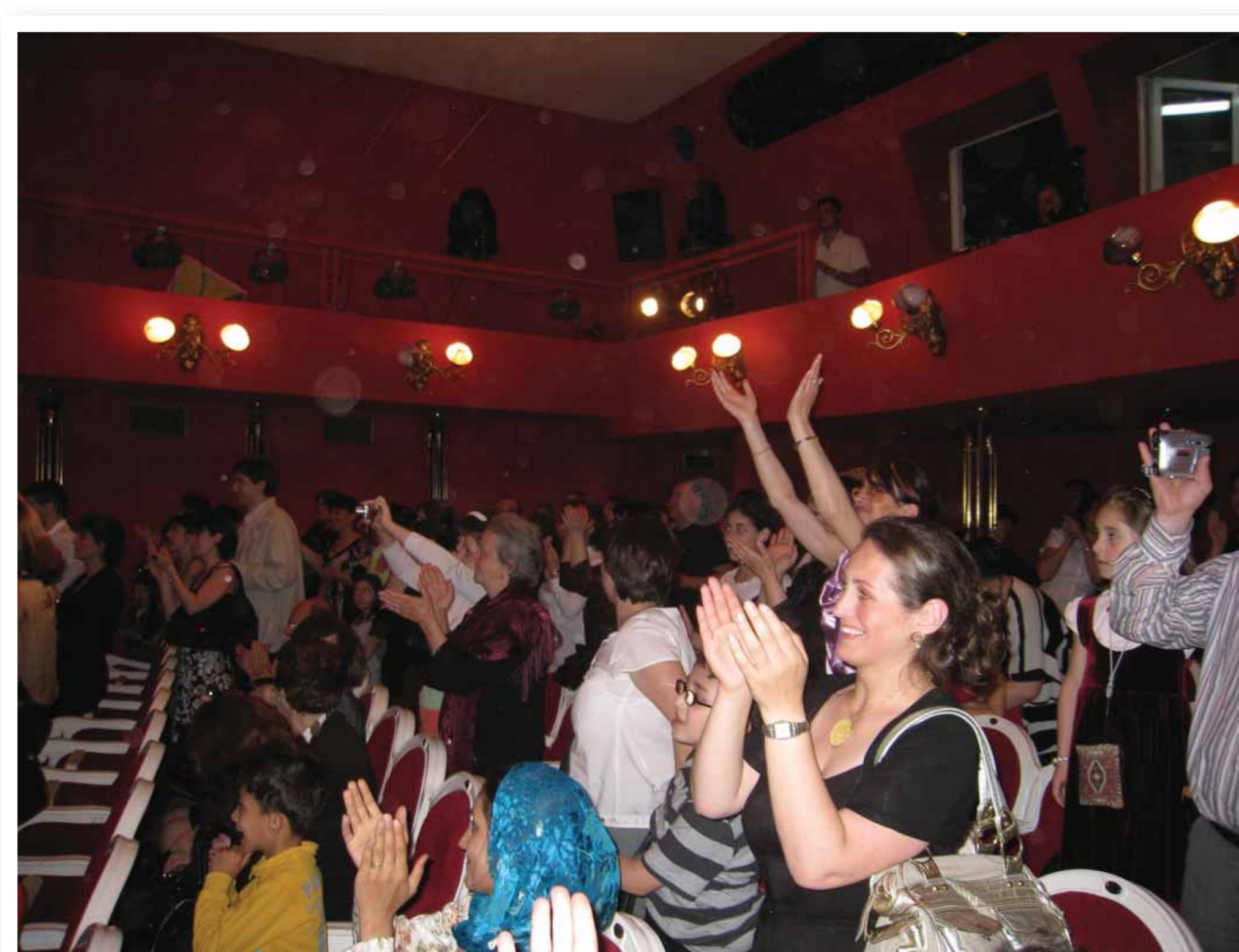
Execution of the project - delegated to the Centre for Epilepsy Management, Research and Education and to the Centre of Epilepsy Control and Prevention.

COMPLETED ACTIVITIES:

- Training for epidemiological investigation, Epidemiological exercise among 10042 inhabitants in order to estimate the prevalence of active epilepsy and the treatment gap in the capital of Georgia Tbilisi. Established prevalence of active epilepsy – 8.5/1000 and treatment gap - 66.2%;

CONTACT PERSON:

Mrs Natela Okujava, Md, PhD,
President, Association "Epilepsy and Environment"
Jacob Nikoladze str.6, 0179 Tbilisi, Georgia
email: natelaokujava@yahoo.com

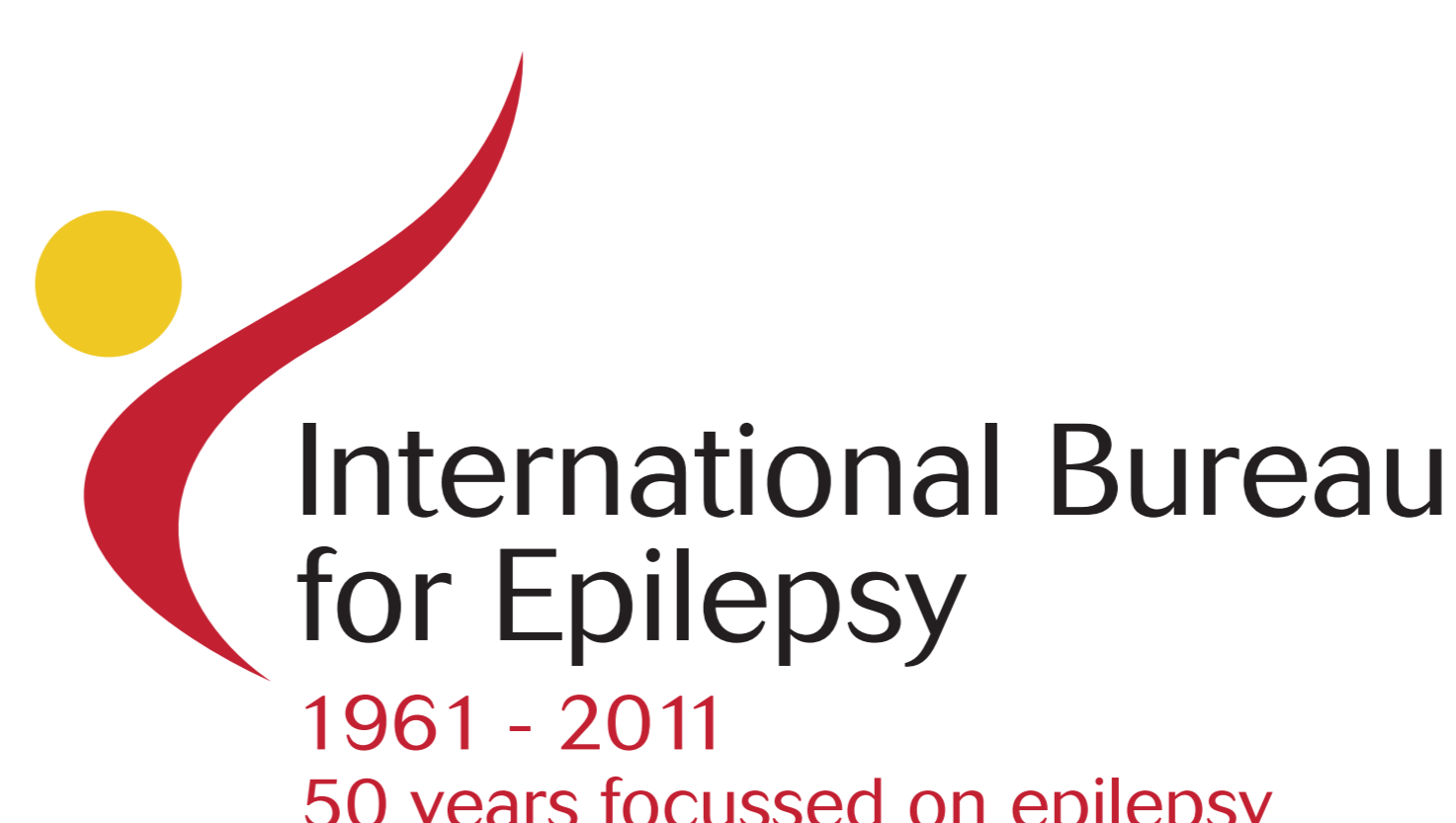


- Training and re-training of service deliverers (primary health care doctors);
- Service delivery: more than 350 patients have already entered the project;
- Educational campaigns in inclusive schools have been prepared and started;
- Meetings with local authorities, national WHO office and nongovernmental organizations;
- Public awareness campaign;
- Survey of population using KAP questionnaires, to establish public attitudes towards epilepsy in Georgian community;
- Publications on the project results prepared and printed.

ONGOING ACTIVITIES

- Refresher training for service deliverers;
- Expansion of service delivery;
- Further development of the educational campaign in schools and the public awareness campaign;
- Preparation of the second epidemiological study;
- Preparation of changes in legislation;
- Developing activities for the project's sustainability.

It is a great honour and enormous responsibility to be involved in this project. We hope to inform you about the progress during the next International Epilepsy Congress.



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

INTERESSENVEREINIGUNG FUER ANFALLSKRANKE IN KOELN (IFA) COLOGNE EPILEPSY INTEREST ASSOCIATION, GERMANY



COUNTRY OF OPERATION

Germany

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

11th March 1981

TYPE OF ORGANISATION

We are an Association of lay people

RANGE OF OPERATION

Local and National

GOAL OF OUR ORGANISATION

Our association's aims are to improve the quality of life and promote the interests of people living with epilepsy.

Epilepsy is one of the most common chronic diseases: 0,5% of all human beings suffer from epilepsy, which means that in Germany alone around 500,000 to 800,000 people are affected. Our association was established in 1981 in Cologne by a group of people with epilepsy and their parents to improve the quality of life of people with epilepsy in Germany. We have 200 members.

We publish a quarterly magazine - IfA Epilepsy Activity News. The association is run by volunteers, who hold regular meetings and offer a mixture of social events and informative talks and discussions.

The organization publishes the international epilepsy emergency card (ieec), as well as reports and booklets for a better understanding of epilepsy.

This is an association of people with epilepsy, providing support to people with epilepsy, working towards a better understanding of the condition and fighting against prejudice and stigma.

The German Epilepsy Internet Network is a platform from people with epilepsy for people with epilepsy and social workers. (www.epilepsie-online.de)

On this website there are more than 700 seizures-stories and more than 400,000 entries in the epilepsy chatroom.

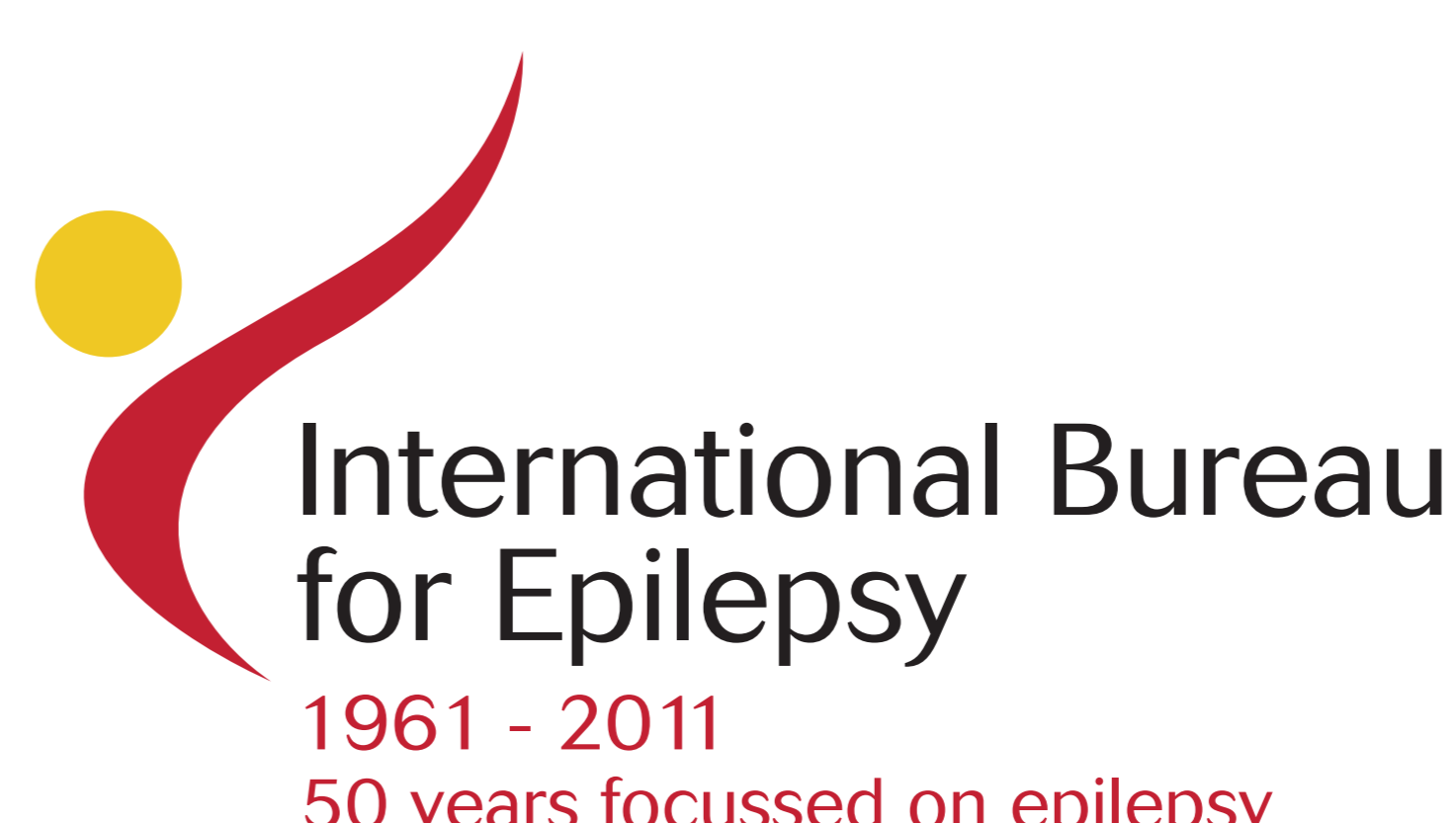
MOST IMPORTANT ACTIVITIES IN 2009/2010

- Weekly meetings of the epilepsy-sport-team in Cologne
- Participation in leisure activities including walking, playing games and boating trips to assist people with epilepsy improve their life quality
- Production and marketing of the international epilepsy emergency card (ieec). To date 150,000 cards have been produced
- Regular evening epilepsy discussion group meetings for people with epilepsy and their parents
- Production of reports and booklets for a better understanding of epilepsy
- Working sessions
- Internet evaluation about "epilepsy health care"
- Group discussions at specialist epilepsy hospitals and centres
- Discussions with social workers, employers, teachers and all those involved in the social aspects of epilepsy.



CONTACT DETAILS

Name: Thomas Porschen
Address: Höninger Weg 361
50969 Köln
Germany
Email: info@epilepsie-online.de
Website address: www.epilepsien.de and www.epilepsie-online.de



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

THE GREEK ASSOCIATION AGAINST EPILEPSY GREECE



COUNTRY OF OPERATION

Greece

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1956

INITIAL AFFILIATION TO IBE

1967

TYPE OF ORGANISATION

Individual membership

RANGE OF OPERATION

National

ACTIVITIES

Annual National Congress & Participation In The Global Campaign Against Epilepsy.

The association is a non-profit organization which promotes understanding and scientific enlightenment on epilepsy-related issues.

The Greek Association Against Epilepsy aims to:

- Provide scientific information to people with epilepsy, so that they may handle their condition more efficiently
- Promote knowledge to those with a special interest in epilepsy and increase public awareness
- Foster the unprejudiced integration of people with epilepsy in society
- Exchange information on an international basis regarding further scientific research and cooperation on epilepsy-related issues
- Identify the needs of people with epilepsy on a national and regional basis
- Encourage Governments and Ministries of Health around the world to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care, services and prevention.

MISSION

"Epilepsy: We Know, We Understand, We Care"

"Epilepsy: We Fight Ignorance"

"Epilepsy is not the Enemy"

"Epilepsy: Changing Attitude"

NATIONAL EPILEPSY DAY – PUBLIC AWARENESS CAMPAIGN

"Get out of the Shadow - You are not alone"

In order to increase public awareness, the Greek Association Against Epilepsy has joined forces with the IBE and the ILAE in the Global Campaign Against Epilepsy

The campaign in Greece is run through:

- The operation of information booths in various city centres
- The distribution of leaflets explaining epilepsy-related issues
- A poster campaign in universities, hospitals and public areas
- Press releases to the media
- E-mail bulletins for raising awareness.

DONATION STRATEGY

Despite its limited financial resources, the Greek Association Against Epilepsy has resolved to make an annual donation to non-profit organisations.

PUBLICATIONS

The Greek Association Against Epilepsy has published various leaflets and posters to support its activities.

CONTACT DETAILS

Name: Dr. Athanasios Covanis

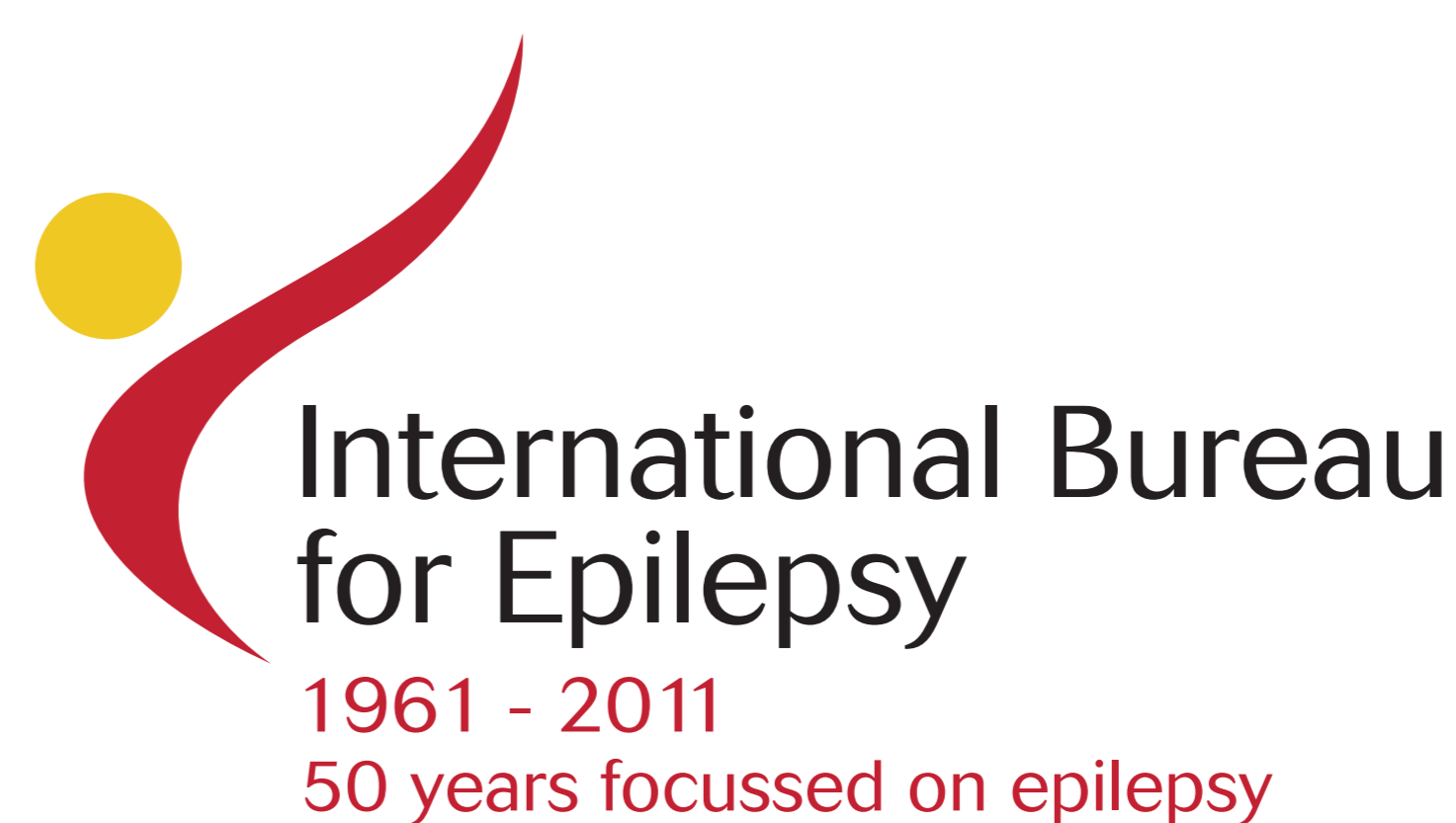
Address: Greek Association Against Epilepsy, Children's Hospital "Agia Sofia", Neurophysiology Laboratory, Thivon & Papadiamantopoulou, Goudi, 115 27 Athens, Greece

Telephone number: +30 210 775 16 37

Fax number: +30 210 770 57 85

Email: graaepil@otenet.gr

Website: www.epilepsy-greece.com



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

BRAINWAVE THE IRISH EPILEPSY ASSOCIATION, IRELAND

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.

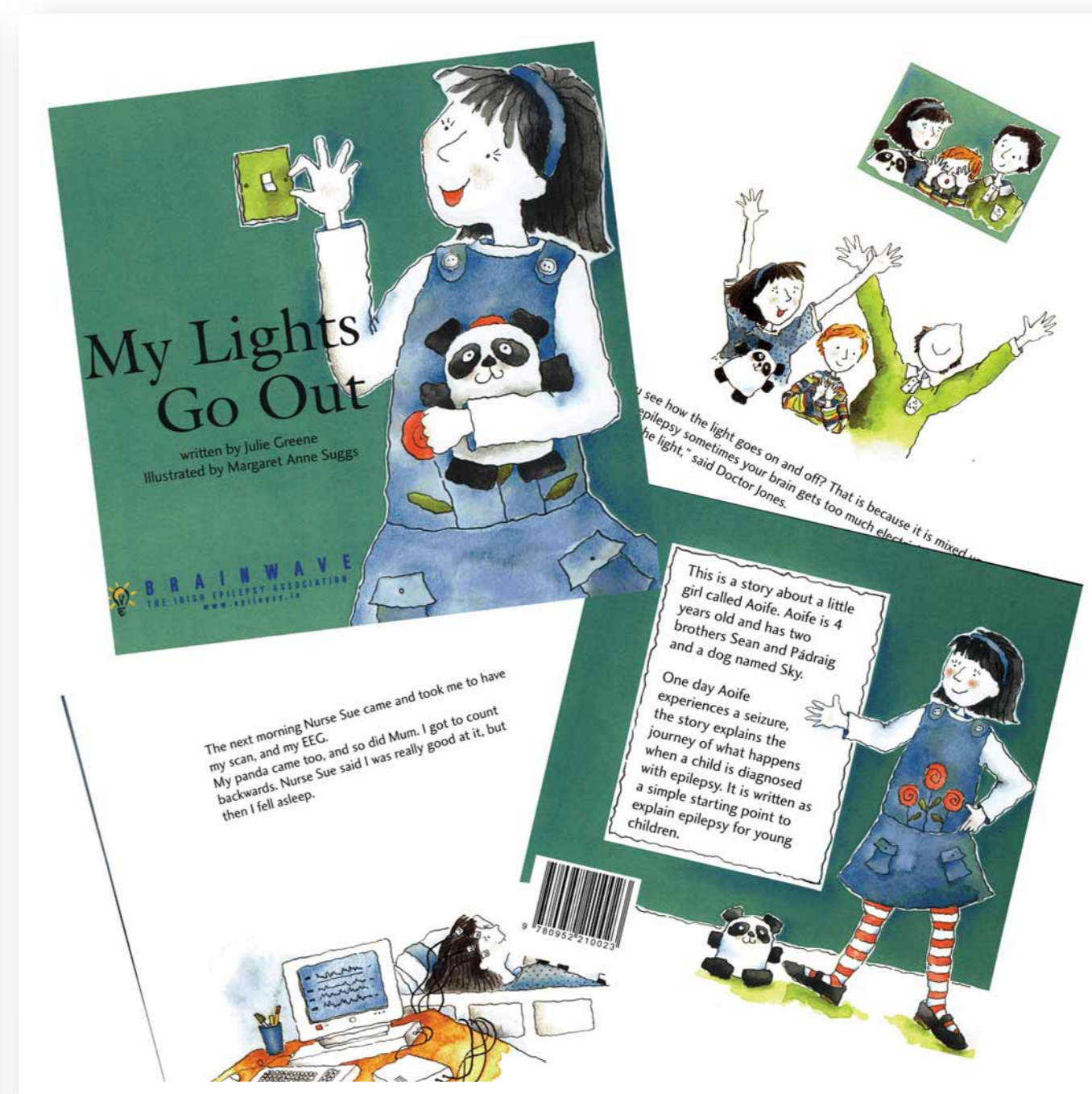
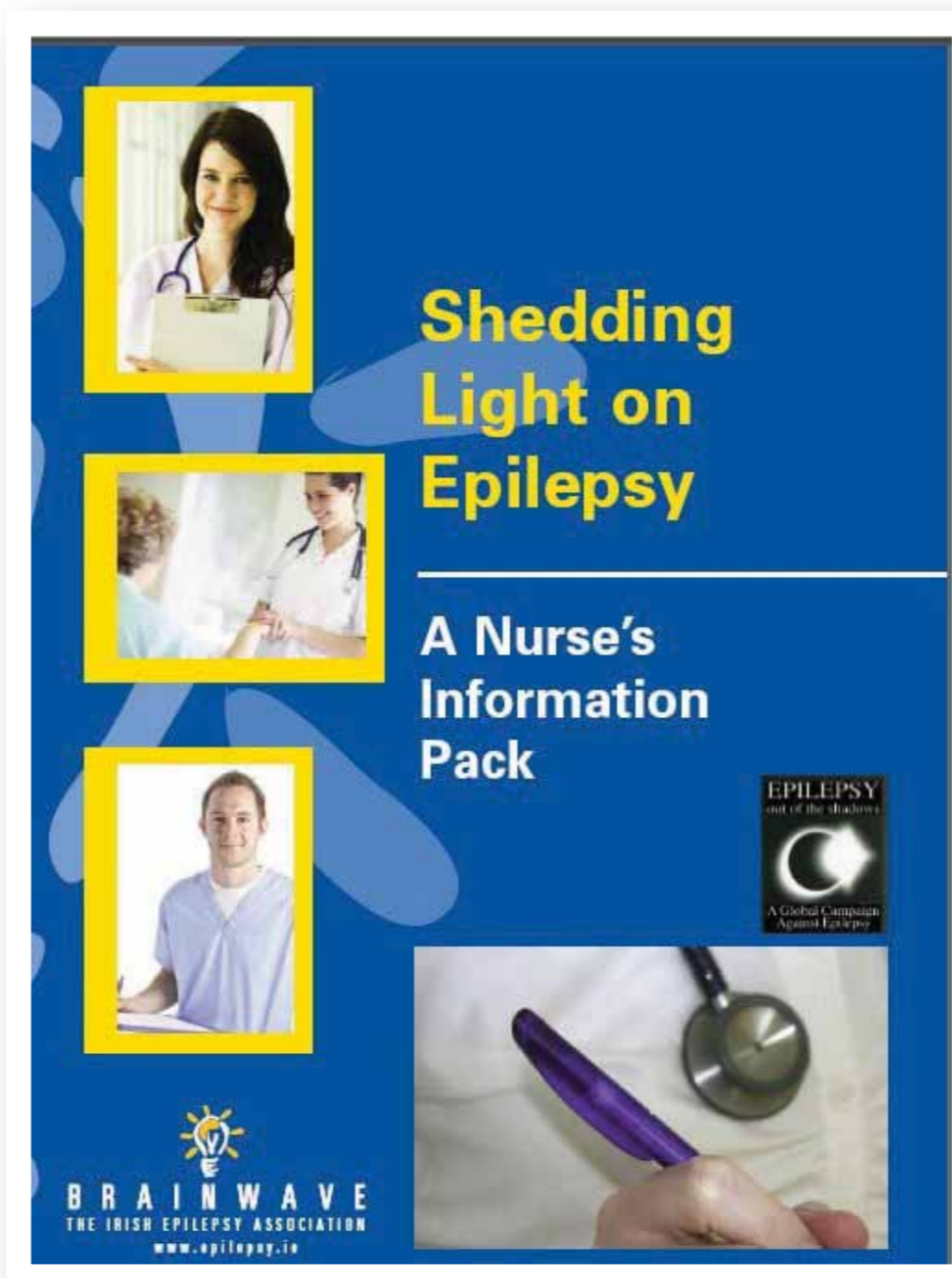
INFORMATION

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.

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.

CONTACT DETAILS

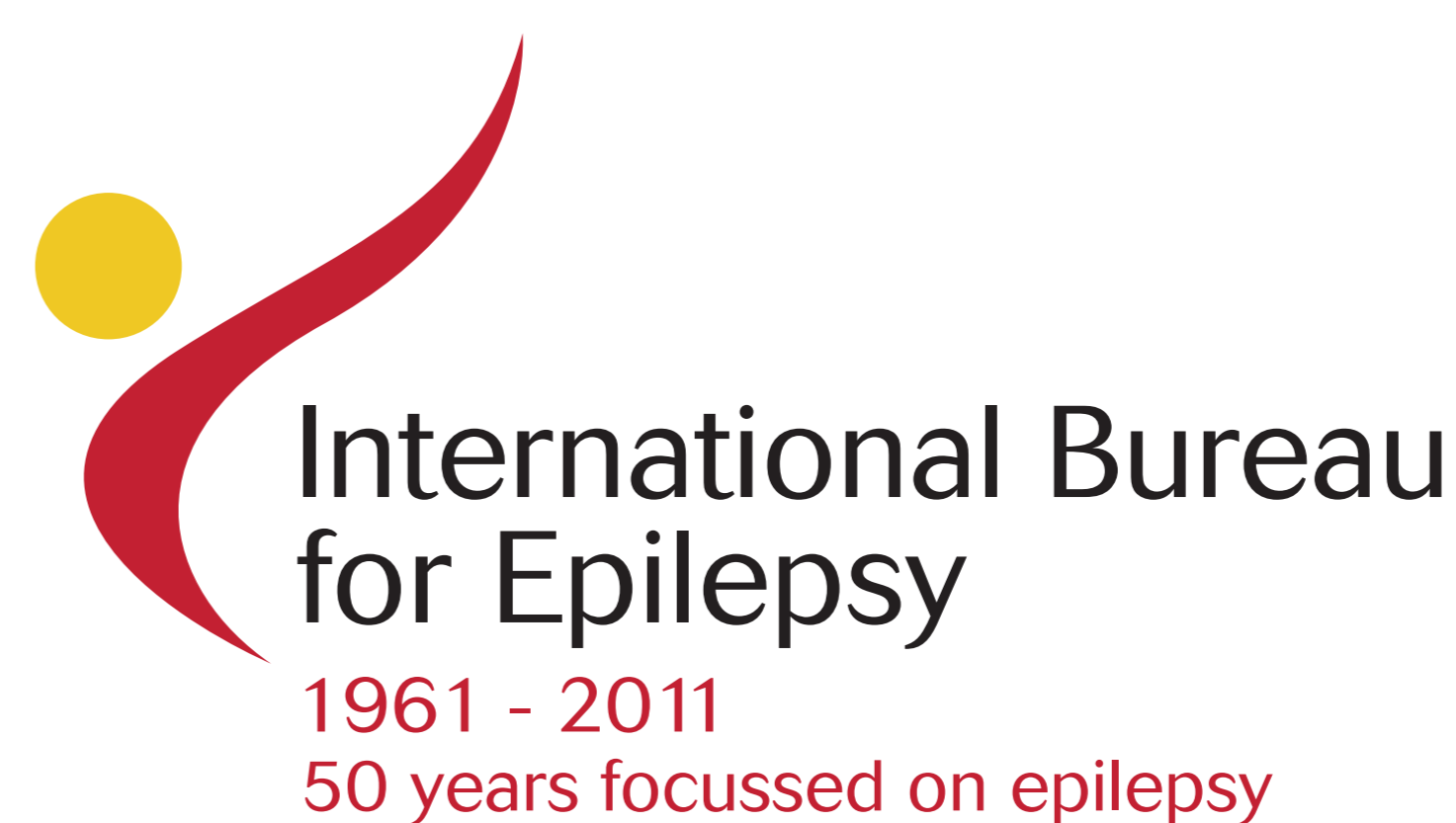
Mike Glynn

Chief Executive

Brainwave The Irish Epilepsy Association, 249 Crumlin Road, Dublin 12, Ireland.

T: +353 1 455 7500 Email: mikeglynn@epilepsy.ie

www.epilepsy.ie



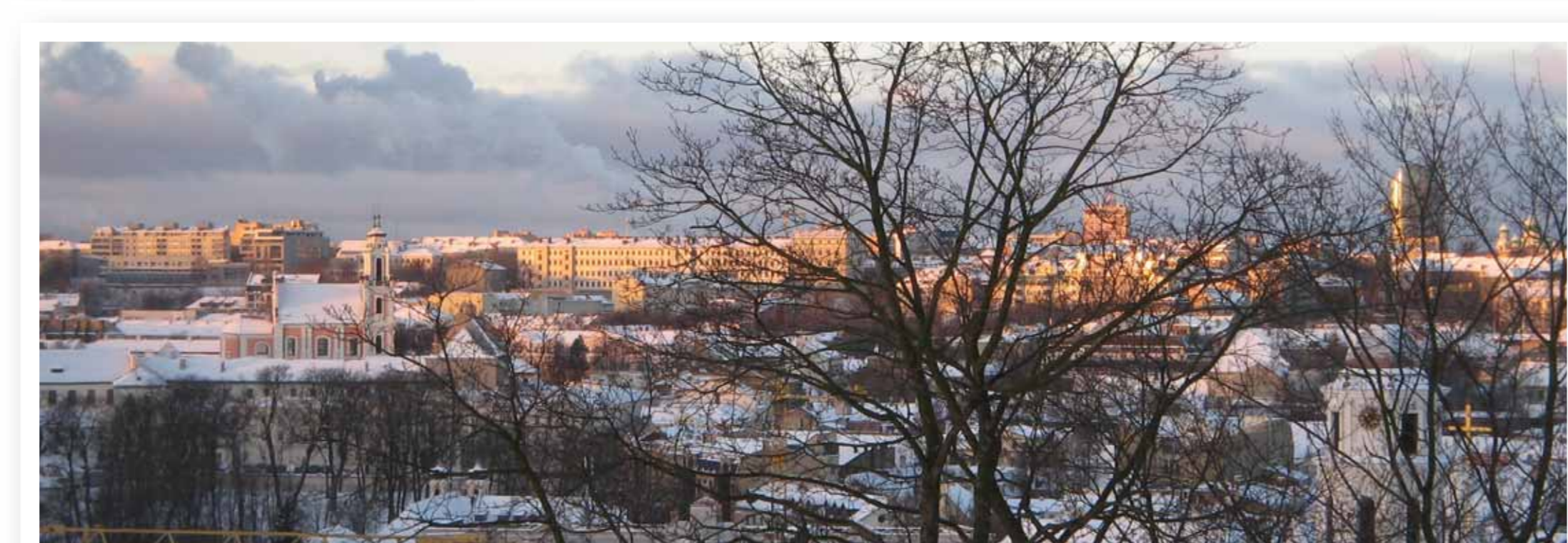
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

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.

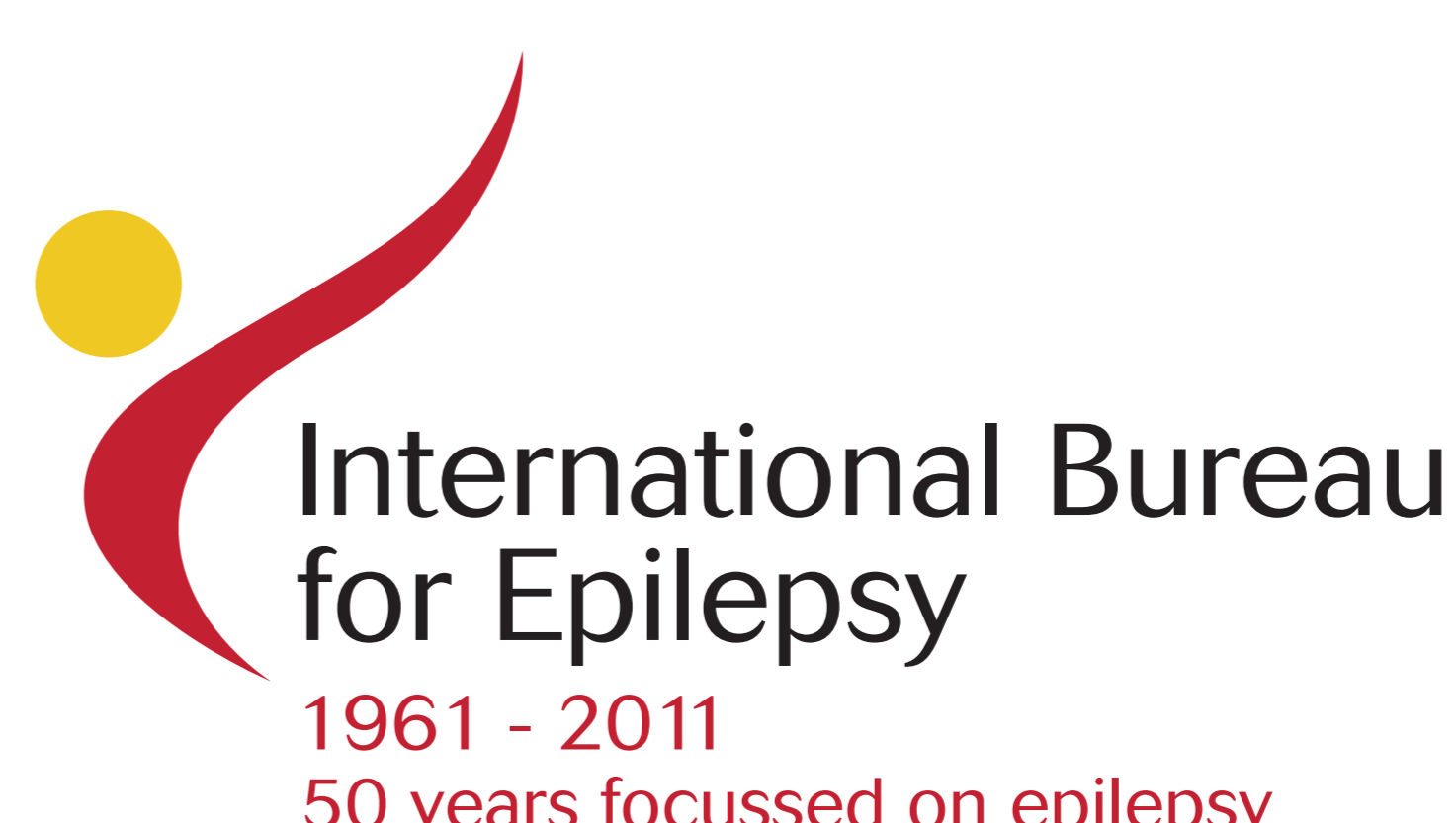
Since year 2007 LESIA has participated in the National Program of Social Integration of the Disabled, which is financed from the Government Budget.

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

CONTACT DETAILS

Name: Danute Murauskaite,
Address: Saltoniskiu g. 29-323, Vilnius, Lithuania
E-mail: epi@lesia.lt
Website: <http://www.lesia.lt>



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

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

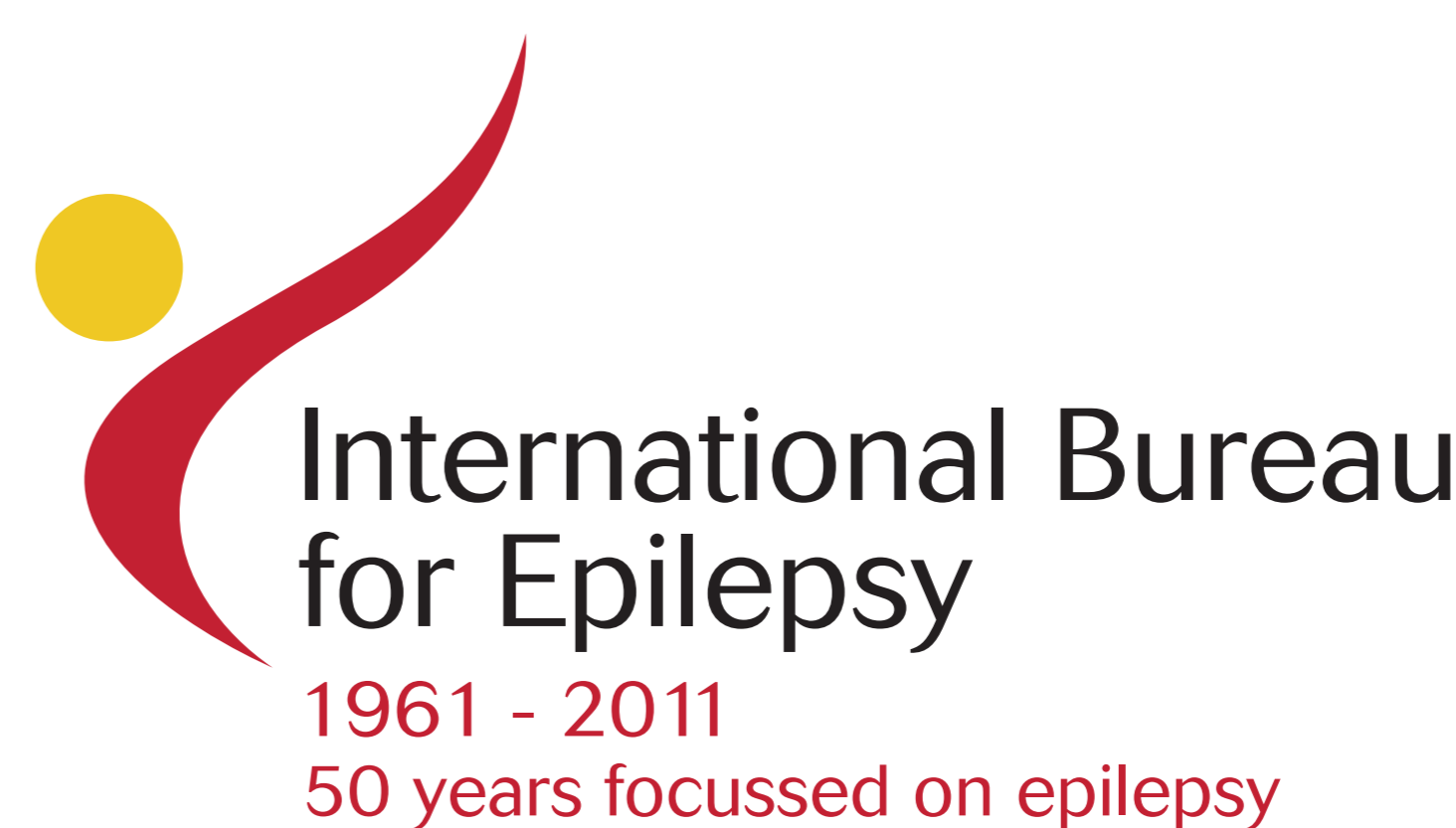
condition.

- 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.



CONTACT DETAILS

Mrs Victoria Dimech
Caritas Malta Epilepsy Association
7, Zenit
Paul Borg Street, Attard BZN 04, Malta
Phone: +356 2143 6442 Email: zenit@onvol.net
www.caritasmalta.org/epilepsy



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

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 delivers 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.

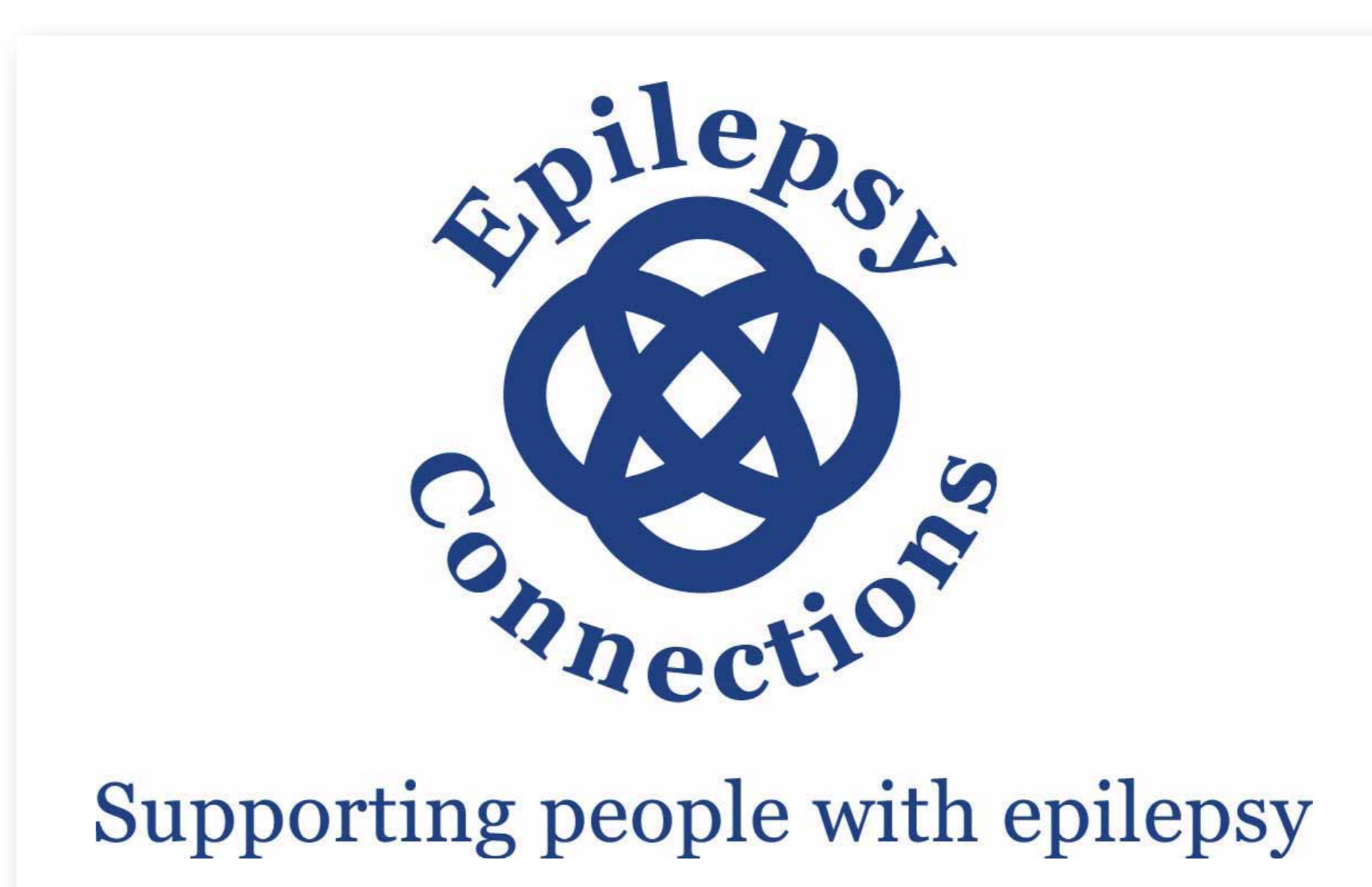
The Schools Project team provide a programme of fun activities and events for children with epilepsy and their siblings, including indoor climbing, cinema trips, theatre workshops and yoga.

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.



CONTACT DETAILS

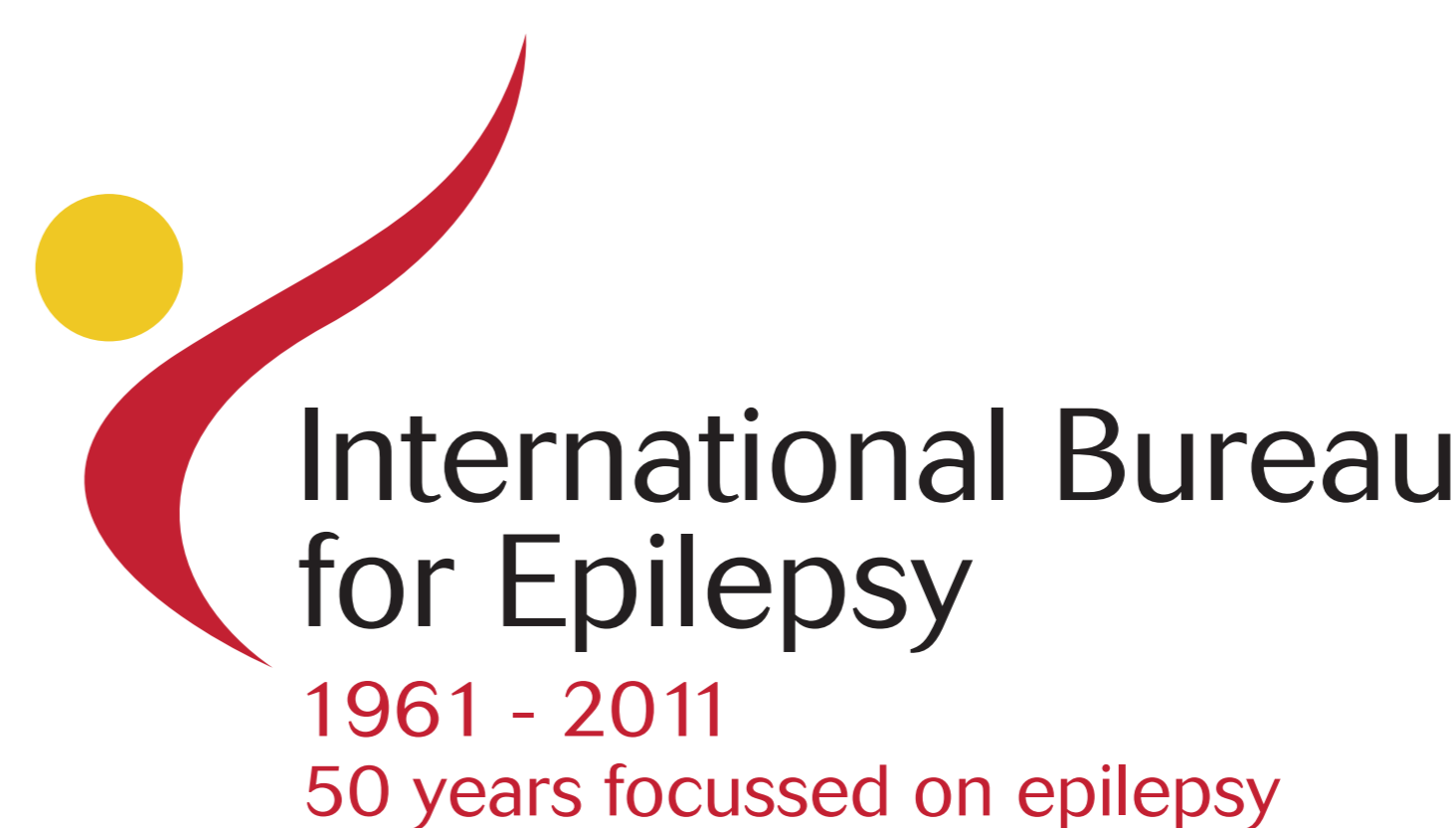
Shirley Maxwell

Executive Director

Epilepsy Connections, 100 Wellington Street, Glasgow, G2 6DH, Scotland, U.K.

Tel: 0044 141 248 4125 email: smaxwell@epilepsyconnections.org.uk

Website Address: www.epilepsyconnections.org.uk



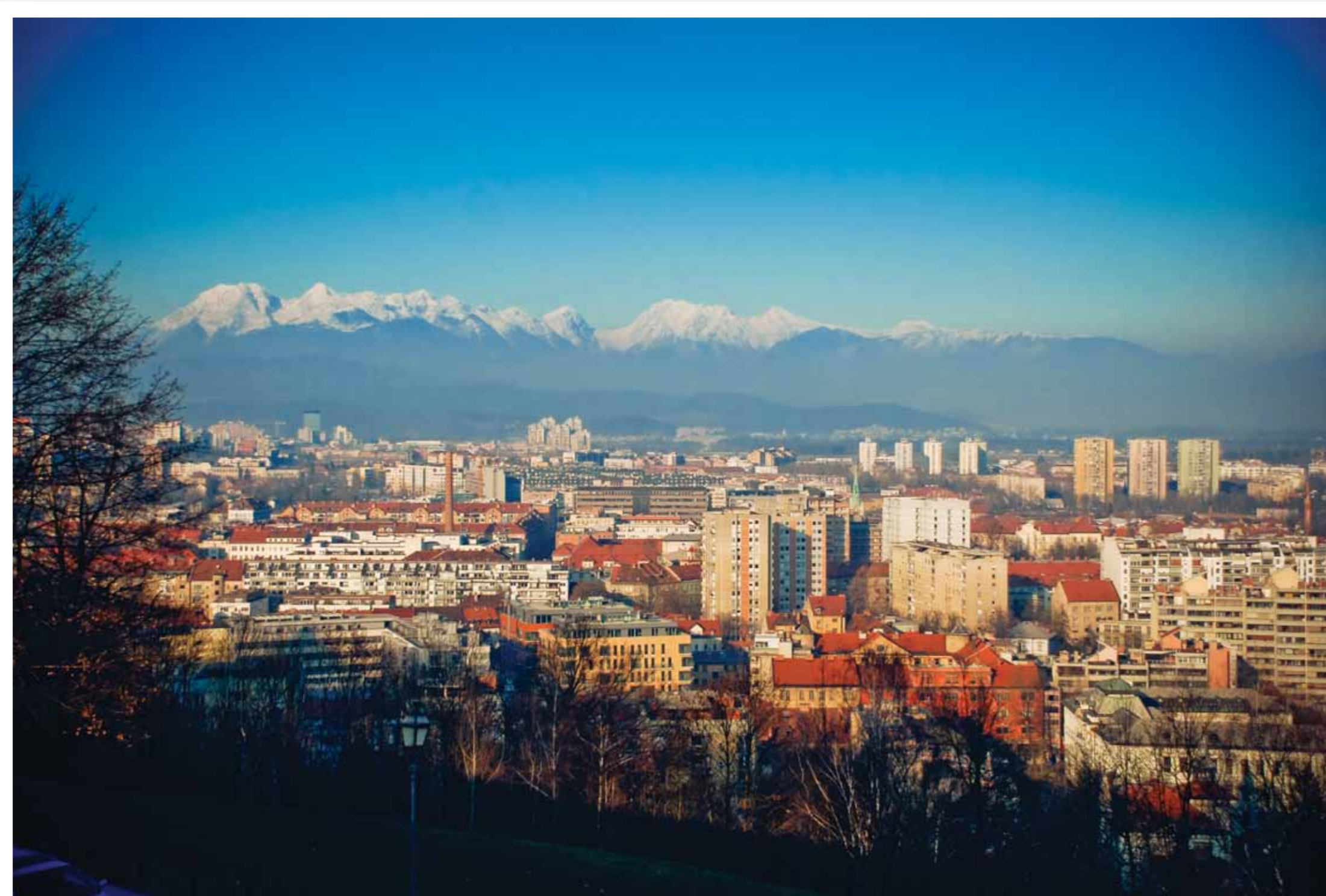
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

SLOVENIAN LEAGUE AGAINST EPILEPSY



COUNTRY OF OPERATION

Slovenia

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

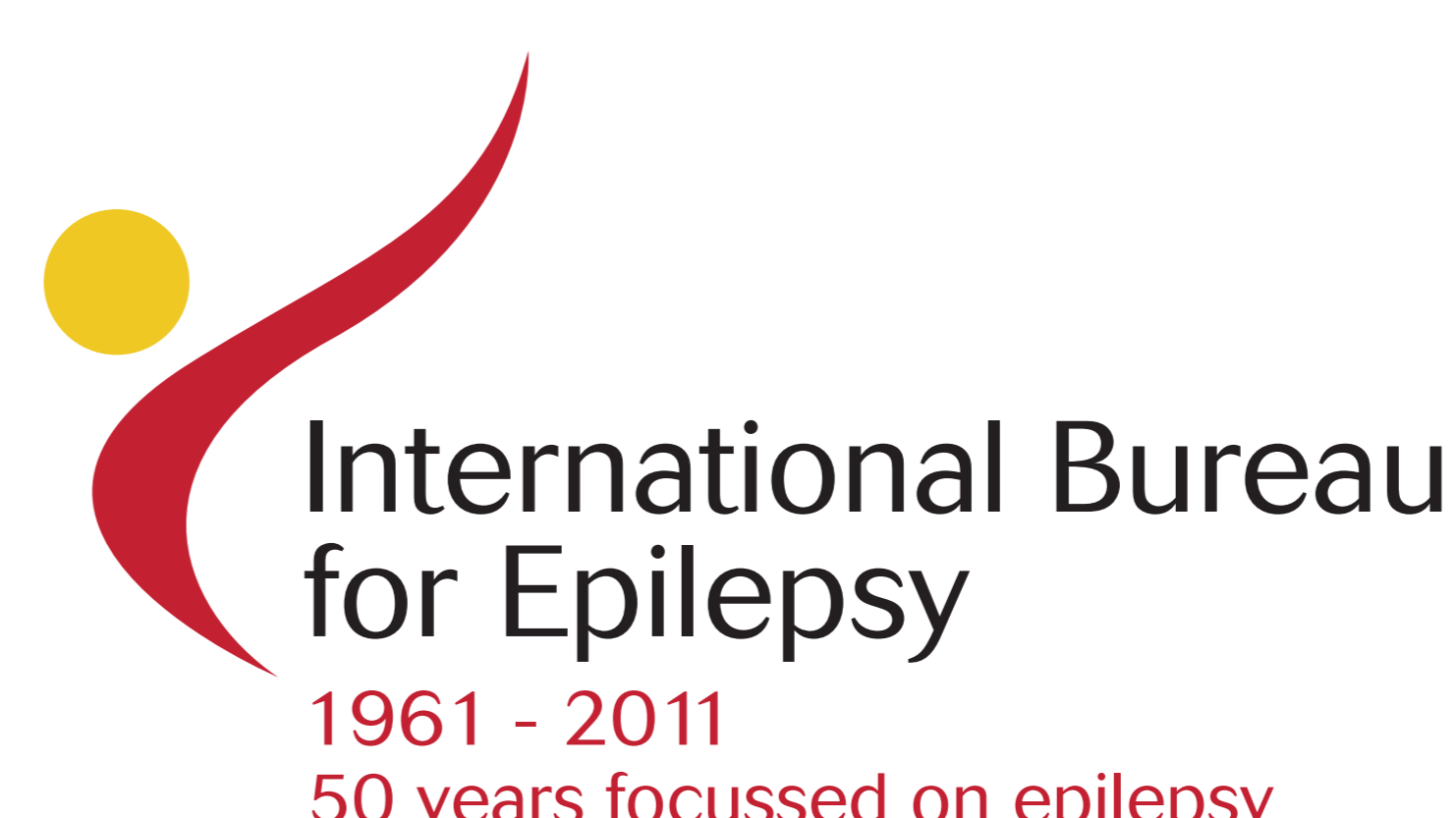
SPECIAL ACTIVITIES

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.



CONTACT DETAILS

Name: Svetlana Simic, Ljubica Vrba
Address: Ulica Stare pravde 2, SI-1000 Ljubljana, SLOVENIA
Email: epilepsija@epilepsija.org
Website: www.epilepsija.org



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

SWEDISH EPILEPSY ASSOCIATION SWEDEN



INTRODUCTION

The Swedish Epilepsy Association (SEF) was established in 1954 and has 5,000 members in 40 local affiliates. There are 60,000 people in Sweden with epilepsy; 10,000 of whom are children.

SEF is a national organisation with and for people with epilepsy and their carers. The main aims are to improve quality of life, to support individuals and groups and to empower them to make change.



The national office is situated in Stockholm with three employees. A national newsletter is produced quarterly. The members of the Association's board are all volunteers and consist of people with epilepsy, parents of children with epilepsy as well as people from the healthcare sector.

Important issues are public education and awareness campaigns, health care issues, counselling, camps and conferences to encourage and stimulate people with epilepsy.



Special initiatives are carried out for parents and young people with epilepsy.

GOLDEN CANDLE AWARD

A Golden Candle Award ceremony is held annually in the Swedish Parliament under the auspices of the former speaker of the Parliament. The award aims to highlight special initiatives in the field of epilepsy.

YOUTH ACTIVITIES

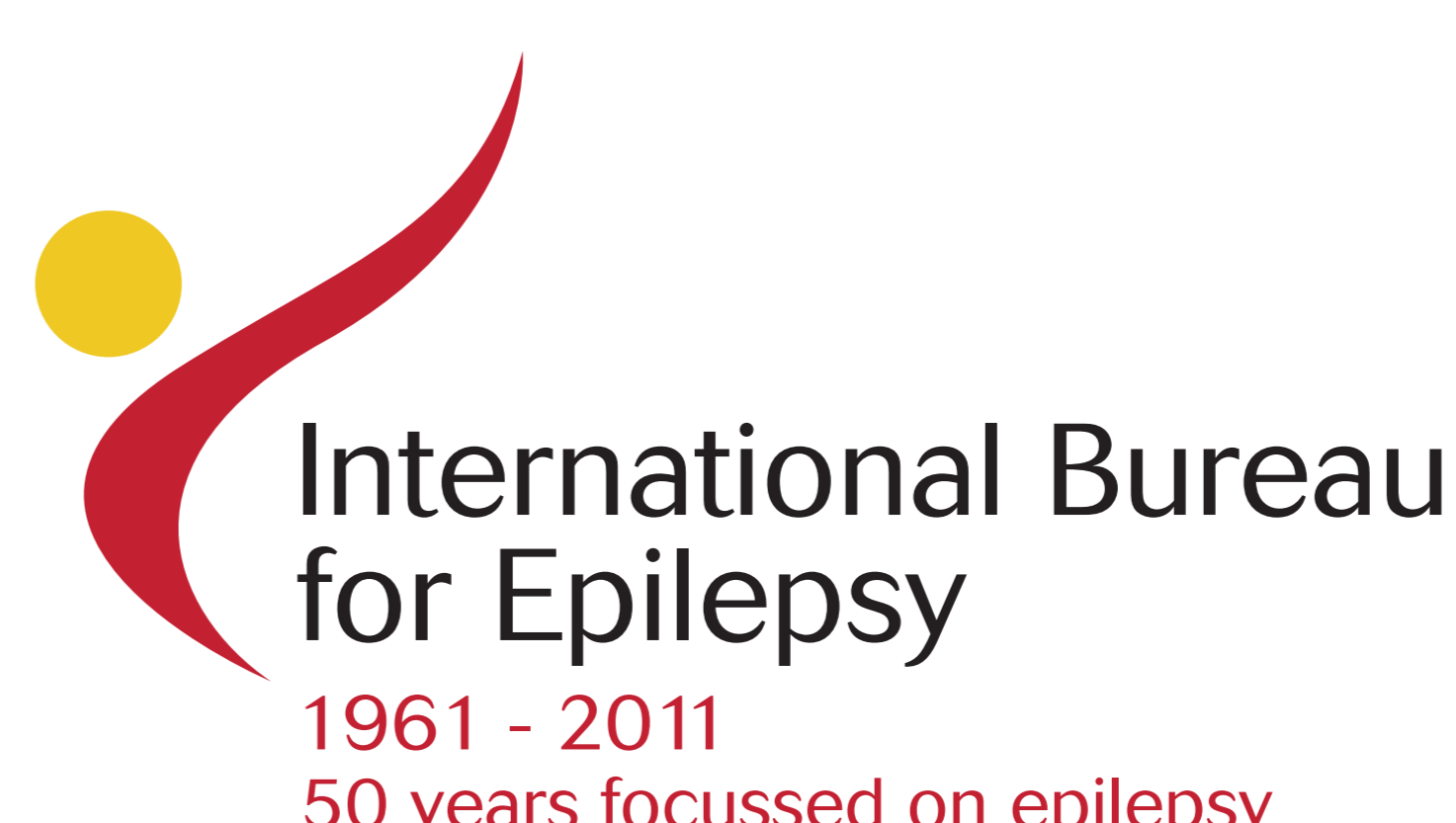
Annual summer camps for young people with severe epilepsy are provided by the Youth section. A special youth project has been performed with weekend forums aiming to encourage people to come out of the shadows about their epilepsy.

WEB SITE

The web site, www.epilepsi.se is continually undergoing development and improvements with an increasing number of visitors.

CONTACT DETAILS

Mrs Susanne Lund
Chief Executive
Swedish Epilepsy Association, PO Box 1386, 172 17 Sundbyberg, Sweden
Phone: +46 866 94306
Email: susanne.lund@epilepsi.se
www.epilepsi.se



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPILEPSY ACTION, UK



COUNTRY OF OPERATION

United Kingdom

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1950

DATE ORGANIZATION FIRST AFFILIATED TO IBE

1960

TYPE OF ORGANISATION

A charity and an incorporated company registered in England. An association of individual members that includes anyone with an interest in epilepsy.

RANGE OF OPERATION

Throughout the United Kingdom.

GOALS

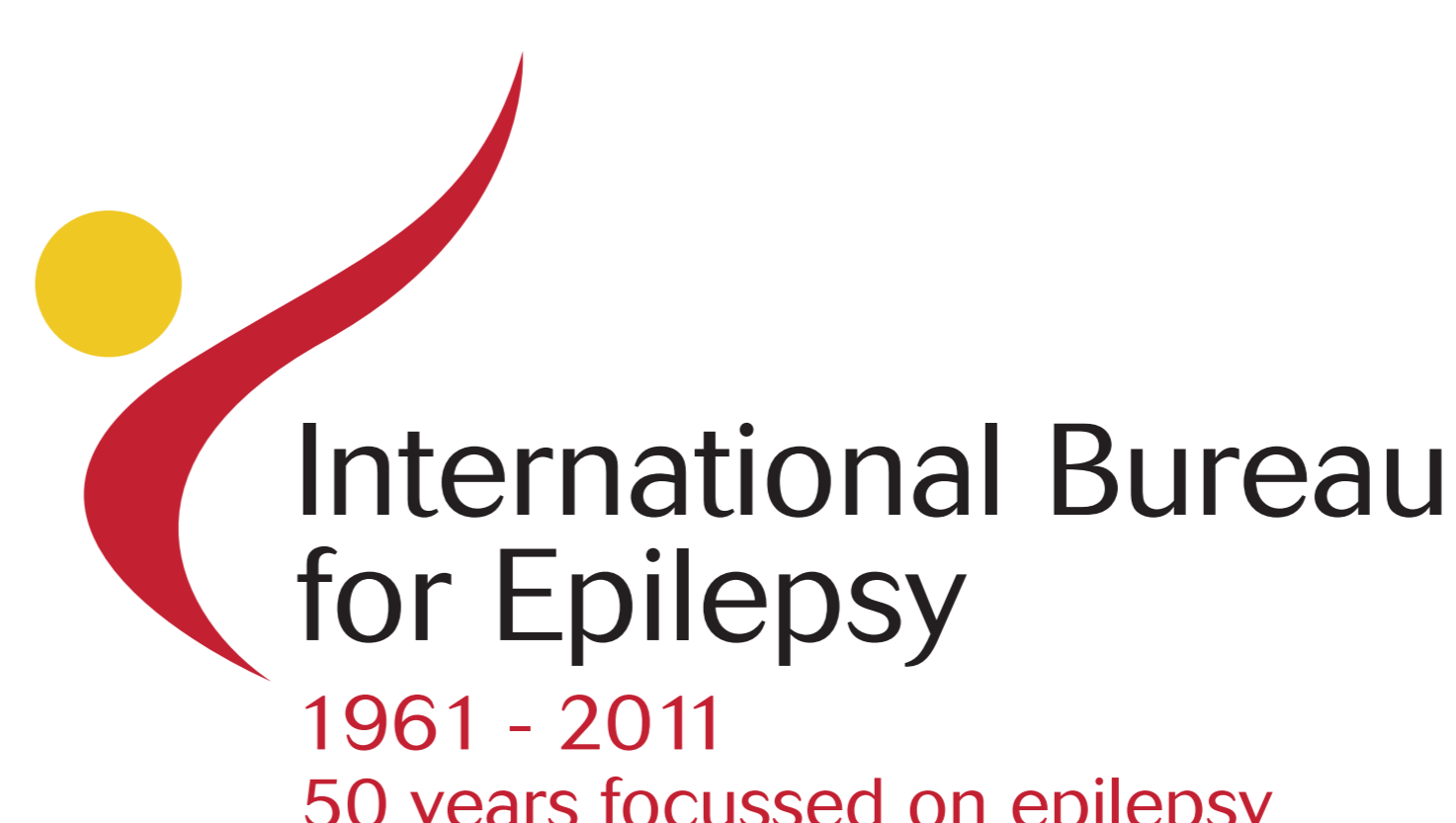
Epilepsy Action works to:

- Raise public awareness
- Provide advice and information
- Educate people
- Campaign for change
- Promote and carry out research
- Maximise its resources
- Engage with providers of health, education and social care



CONTACT DETAILS

Philip Lee
Chief Executive
Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY, England
plee@epilepsy.org.uk
<http://www.epilepsy.org.uk>



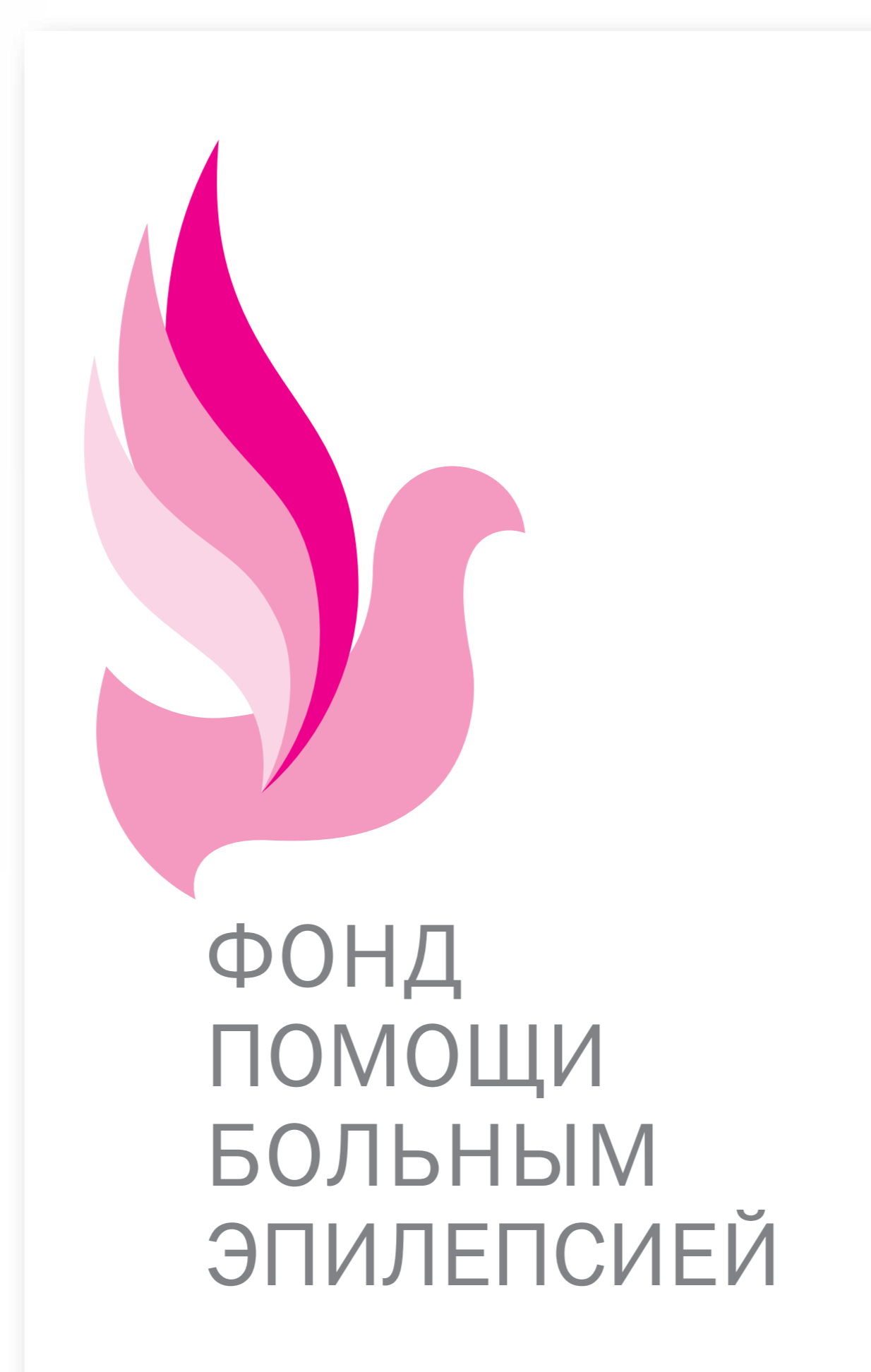
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ALL-RUSSIAN CHARITABLE FOUNDATION, RUSSIAN FEDERATION



COUNTRY OF OPERATION

Russian Federation

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

26 January, 2007

INITIAL AFFILIATION TO IBE

January, 2009

TYPE OF ORGANISATION

Individual membership and organizational membership

RANGE OF OPERATION

National

FOUNDATION'S MAIN OBJECTIVES ARE

- Assistance in the form of material, humanitarian and other help to people with epilepsy for the development of their capabilities; creation of equal opportunities and full integration in civil society;
- Maintaining international contacts; conclusion of agreements with international non-profit organizations and other institutions;
- Support of initiatives and projects; awarding of grants to certain scientists; representatives of research and development Epilepsy Centres;
- Assistance in the provision of quality medical aid;
- Attracting qualified specialists for the provision of legal, medical, educational and psychological assistance to people with epilepsy;
- Engaging in contracts with domestic and international organizations and non-profit foundations, the activities of which are related or may promote development of international cooperation;
- Organizing seminars and scientific conferences aimed at perspective trends in the development of healthcare research.

ESTIMATED NUMBER OF PEOPLE WITH EPILEPSY IN OUR COUNTRY

Up to 1,500,000

MEMBERS ARE

Medical professionals, people with epilepsy, members of their families, volunteers

SERVICES AND ACTIVITIES

- Lectures of prominent epileptologists for medical professionals in different Russian cities
- Sponsoring EEG videomonitoring in Moscow
- Printing and distribution of leaflets: "First Aid in case of Seizures" and "He Could be the Same as All Others if We Help"
- Edition of medical journal "Bulletin of Epilepsy"
- A rehabilitation schools for families of epilepsy patients in Ural region.



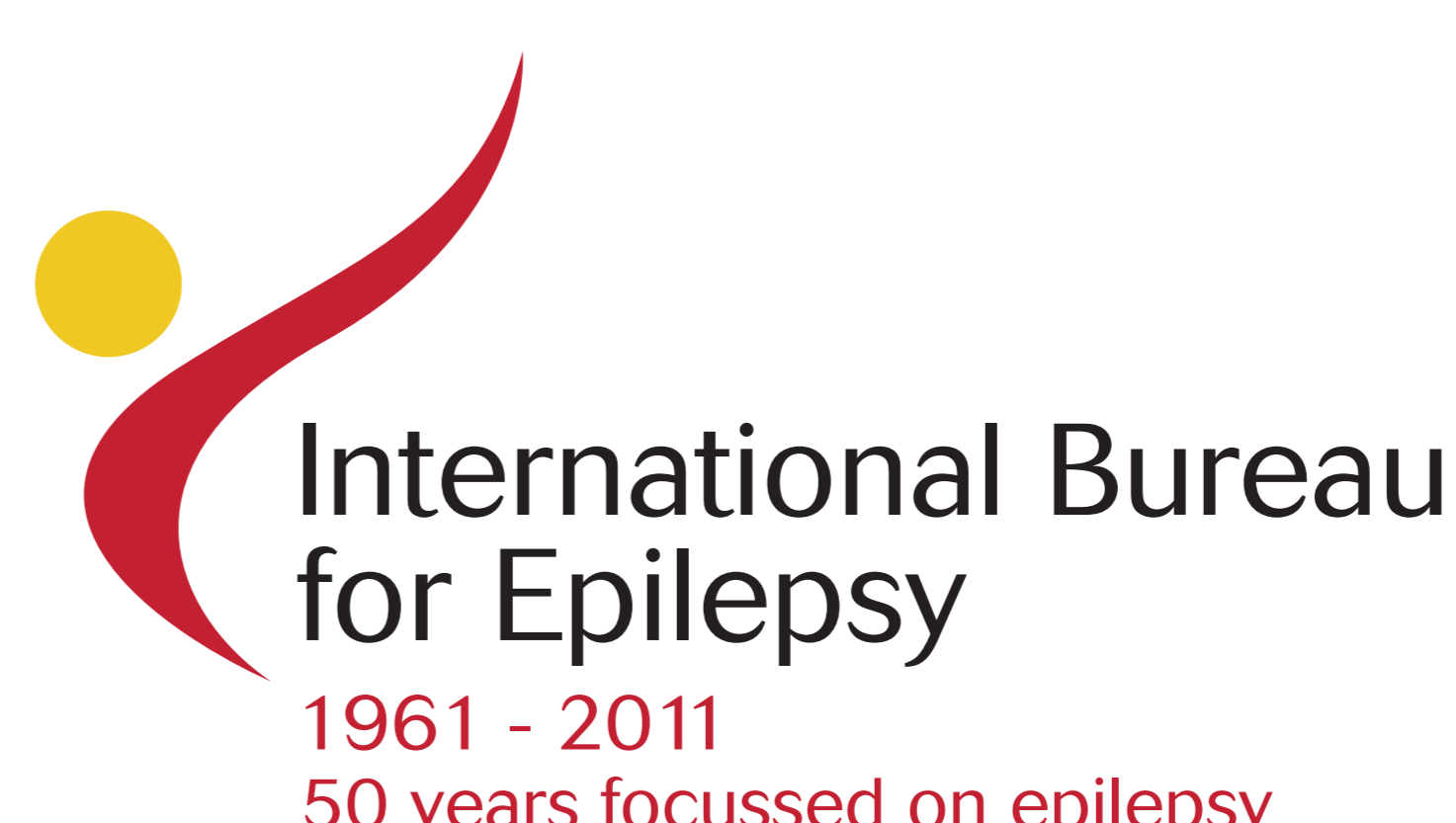
CONTACT DETAILS

Name: Dr Marina Dorofeeva, M. D.

Address: Leningradskoe shosse, 114 – 57, Moscow, Russian Federation

Email: mdorofeeva@inbox.ru

Websites: www.epileptologhelp.ru and www.epiur.narod2.ru



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

SEIN, THE NETHERLANDS



COUNTRY OF OPERATION

The Netherlands

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

1882

INITIAL AFFILIATION TO IBE

Prior to 1967

TYPE OF ORGANISATION

Foundation

RANGE OF OPERATION

National and international

MISSION

SEIN conducts research and training and provides treatment in order to improve epilepsy care. It strives to improve the quality of life of people with epilepsy through collaboration with other WHO Collaboration Centres as well as other NGO's on a global basis.

Research is an indispensable part of SEIN work for the ultimate benefit of all people with epilepsy.

GOALS

SEIN aims at providing optimal care and treatment to its patients, whilst respecting their emancipation and the professional responsibility of its employees.

HISTORY OF SEIN

1882 Foundation SEIN – aim: “nursing sufferers of the falling sickness”

1884 Purchase Estate Meer & Bosch

1934 Opening Queen Emma Clinic

1938 Opening first out-patient clinic, opening school

1939 Start Neurosurgery

1957 Opening sheltered workshop

1966 Opening De Cruquishoeve

1999 Opening clinic Zwolle (Heemstaete)

2000 Initiation first Demonstration Project (China) under the auspices of the ILAE/ IBE/WHO Global Campaign Against Epilepsy (GCAE)

2004 SEIN designated a WHO Collaborating Centre for Research, Training and Treatment in Epilepsy

2007 Initiation Demonstration Project in Georgia (under auspices GCAE)

2008 Development 5 year Research Plan and 4 year strategic management plan to stay in tune with developments in society

2009 Expansion number out-patient clinics to 12 spread out over the country

2009 Opening first out-patient sleep centre

2010 Start fellowships programme for national and foreign students

2010 First course on clinical epileptology for young doctors from resource-poor countries

2010 Finalisation Project on Legislation and Epilepsy by finalising publication

2010 Obtaining NIAZ (Netherlands Institute for Accreditation in Health Care) accreditation

2010 Opening newly built long stay departments

STATISTICS

SEIN provides services in clinical facilities in Heemstede and Zwolle (total 160 beds), offers long stay residential accommodation in Heemstede, Cruquius and Zwolle (400 beds) and operates 12 outpatient clinics providing care (over 11,000 patients a year). Its main catchment area includes the northern, eastern and western part of the country. Education is provided at the school “De Waterlelie” at special, primary and secondary level.

REGULAR ACTIVITIES

- Diagnostics and treatment (out-patient and in-patient)
- Long-stay (central and de-centralised)
- Research (clinical and basic)
- Public and professional education
- Special education

SPECIAL ACTIVITIES IN 2009 AND 2010

- Development and execution course on clinical epileptology for young doctors from resource poor countries
- Development fellowships programme for national and foreign students
- Start and finalisation building new long-stay departments
- Building respite care department providing short-term, temporary relief to carers of family members who might otherwise require permanent placement in a care facility
- In collaboration with WHO/HQ & WHO Regional Office for Europe develop, publish and launch regional report on epilepsy
- Assisting WHO in carrying out project on Epilepsy and Legislation
- Signing memoranda of understanding for collaboration in research with:
 - Chinese Epilepsy Association and Capital Medical University, Beijing - P.R. China
 - Department of Clinical Experimental Epilepsy, University College London (UCL) - UK
 - Free University (VU), Amsterdam – The Netherlands



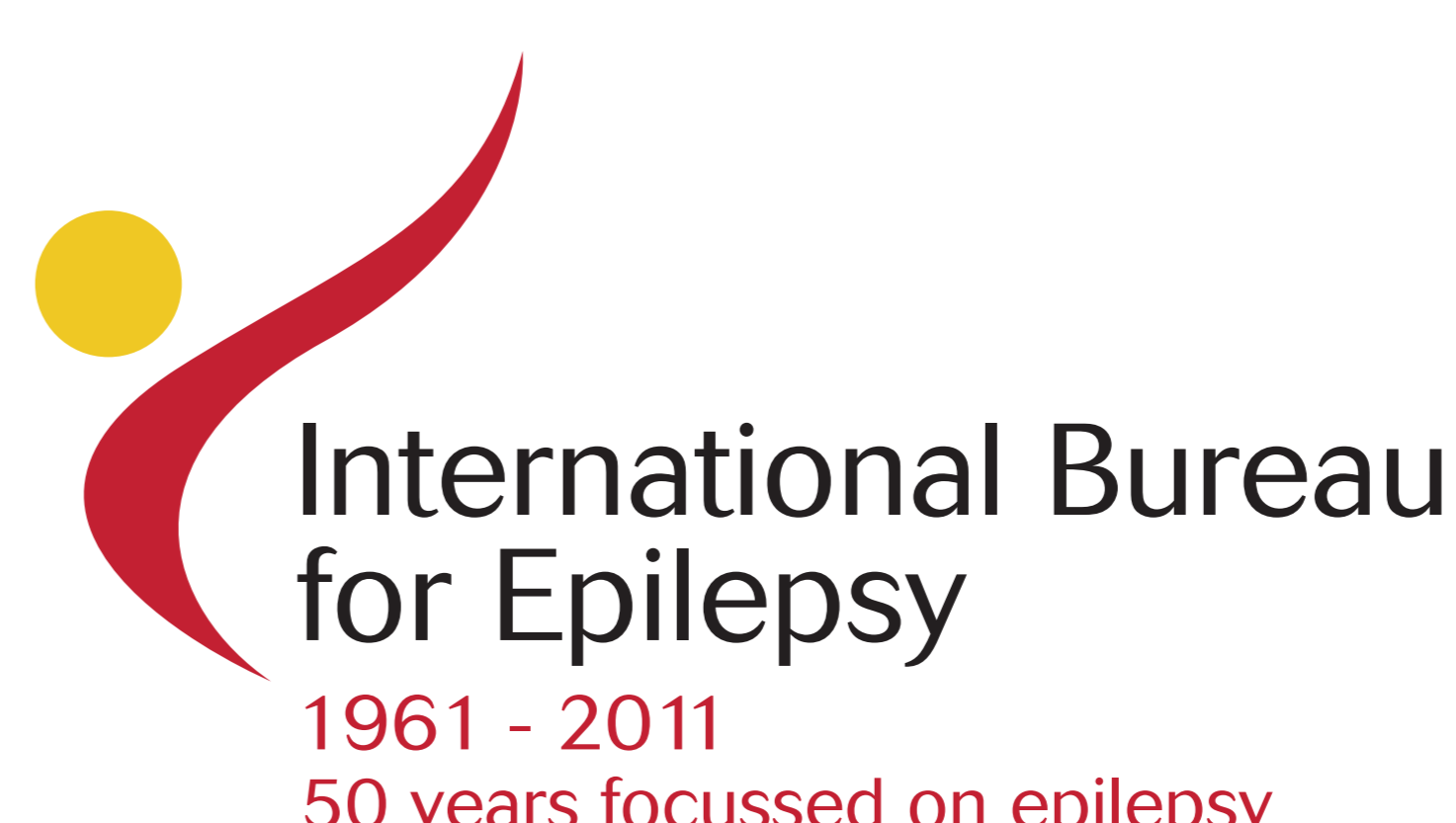
CONTACT DETAILS

Hanneke M. de Boer

SEIN, Achterweg 5, 2103 SW Heemstede, The Netherlands or

SEIN, P.O. Box 540, 2130 AM Hoofddorp, The Netherlands

www.sein.nl



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

STICHTING KEMPENHAEGHE, NETHERLANDS



Kempenhaeghe diagnoses and treats children and adults who have a complex form of epilepsy, severe insomnia and/or neurological developmental and learning disabilities. These problems may be associated with other disorders and also lead to problems in the areas of living, working, learning and relationships.

Diagnosis and treatment of often complex care issues, requiring the knowledge of several specialists. Medical specialists, behavioural scientists, social workers, paramedics and specialist nurses in working together develop a care and treatment approach tailored to the patient. This so-called multidisciplinary approach is essential in our approach and expertise.

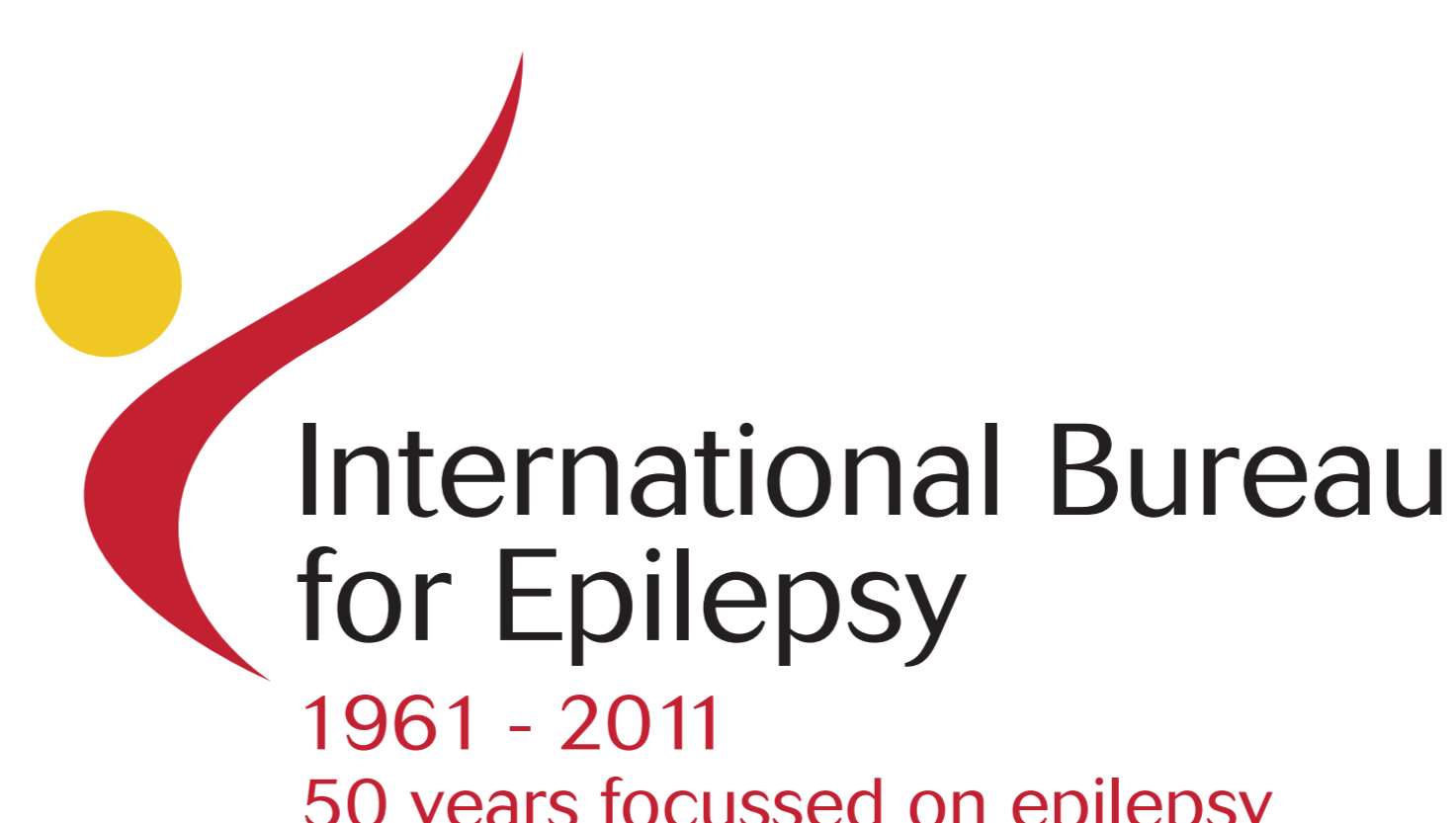
Besides its patient care, scientific research also forms a core element in the work undertaken at Kempenhaeghe. We are also the linchpin in a number of connected networks.

Working at Kempenhaeghe means working in a centre that is in the national and international limelight. We constantly seek new ways to support and care for people with epilepsy, sleep disorders and learning disabilities.

Patient care comes first, but research also plays an important role. Kempenhaeghe collaborates with academic hospitals, universities and other institutes. Development and transfer of expertise are always to the forefront in our service of care and quality of life for our patients.

CONTACT DETAILS

Stichting Kempenhaeghe
Sterkselseweg 65, 5591 VE
Heeze, Netherlands.
T: +31 40 227 9199
bomeri@kempenhaeghe.nl
Contact: Dr Nicolaas Bomer



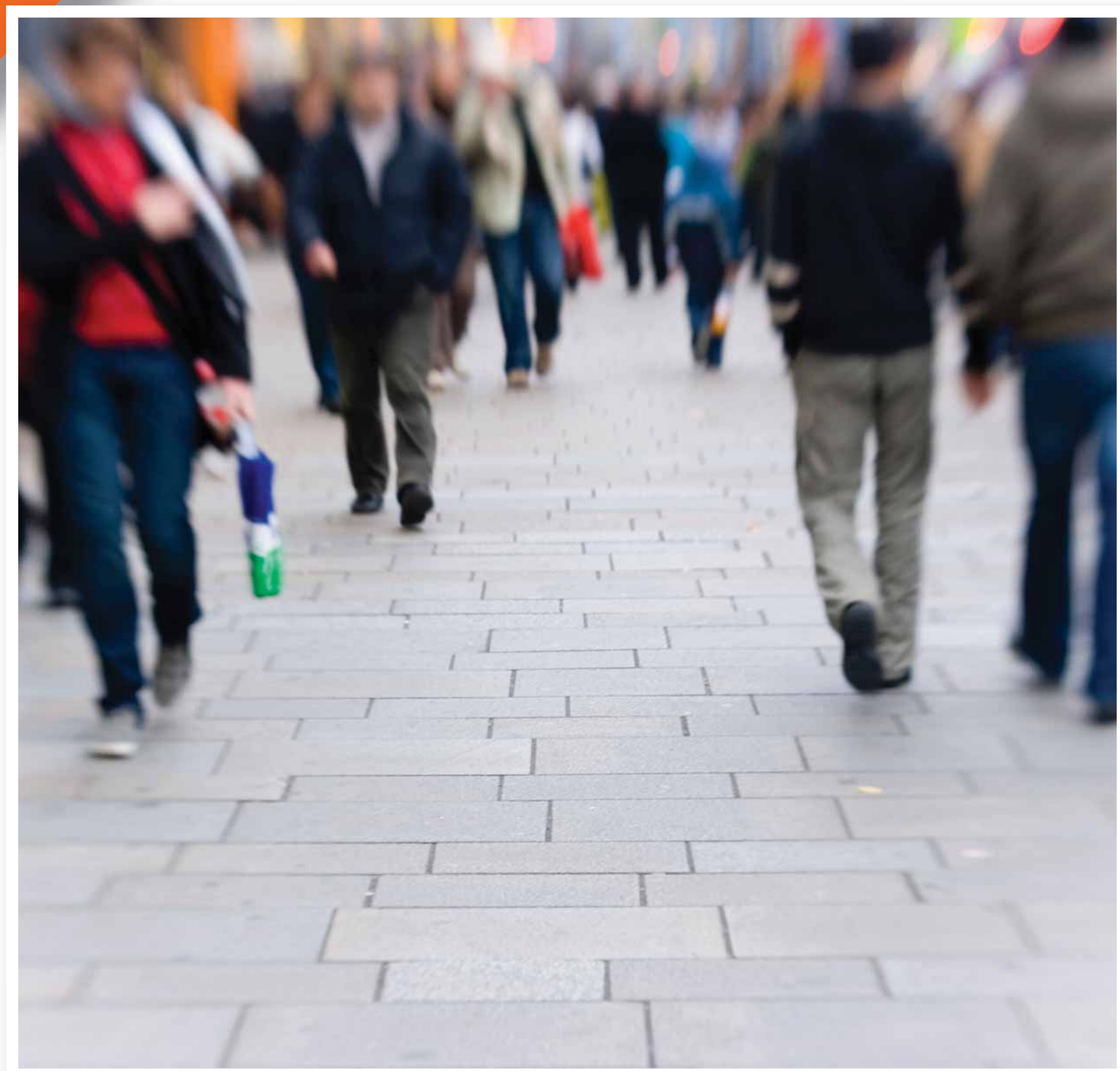
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPILEPSIE DACHVERBAND ÖSTERREICH (EPILEPSY ASSOCIATION OF AUSTRIA)



COUNTRY OF OPERATION

Austria

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1999 – also the first year of membership at the IBE

TYPE OF ORGANISATION

individual membership as well as organizational membership

RANGE OF OPERATION

National

MAIN AIMS:

The Austrian Epilepsy Association works as a partner for all persons and institutions. We are an active federation, which aims to maintain strong links with the medical profession to secure comprehensive quality standards in child, adolescent and adult care.

We want:

- to secure the quality of life for people with epilepsy through special care
- that people with epilepsy are taken seriously and are protected by appropriate legislation
- to advise people with epilepsy based on our expertise and, if necessary, represent them,
- to preserve our responsibilities, extend them and develop new ones,
- to work together with other organizations involved in the field of epilepsy and develop and implement projects,

ESTIMATED NUMBER OF PEOPLE WITH EPILEPSY IN AUSTRIA:

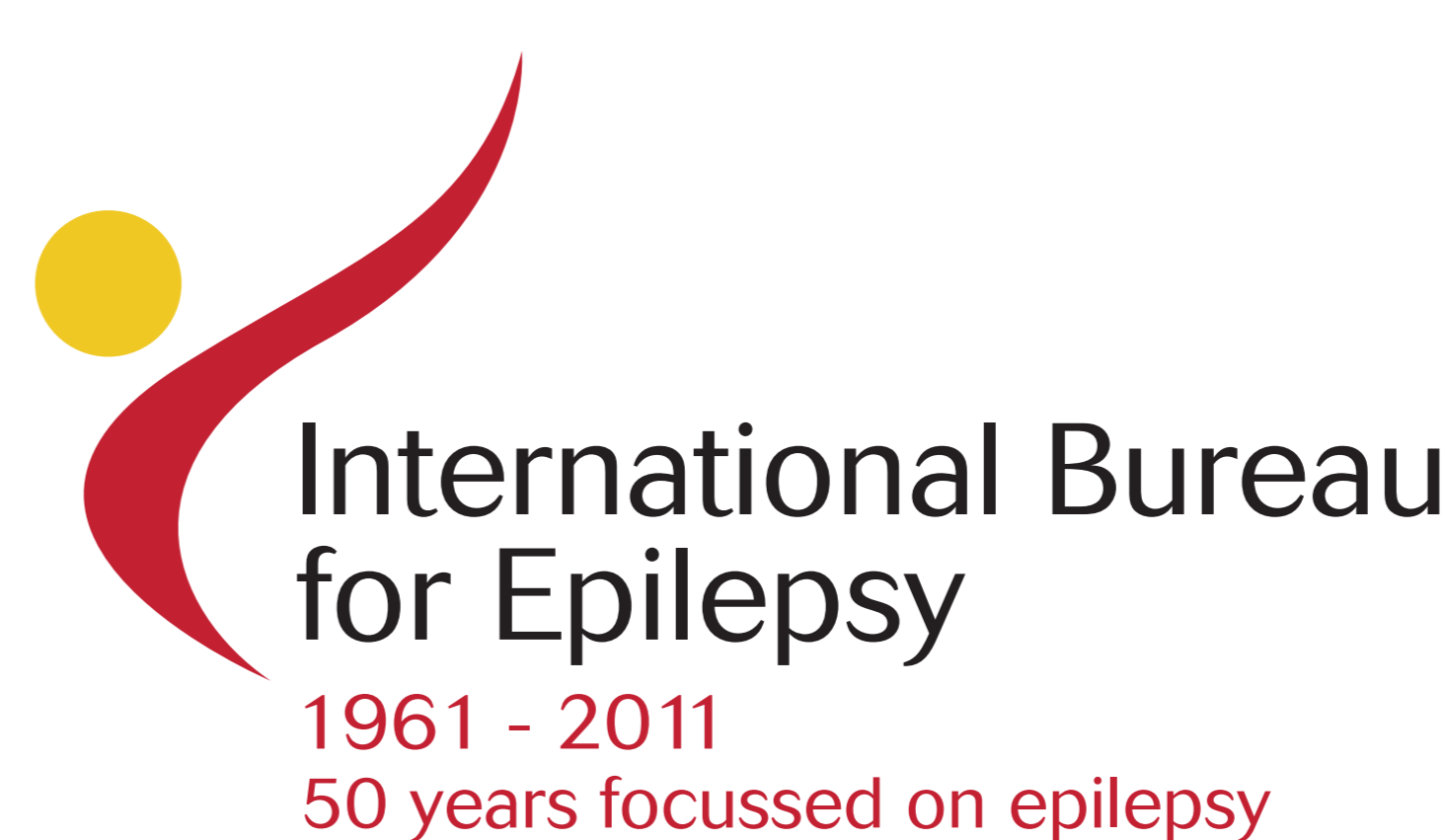
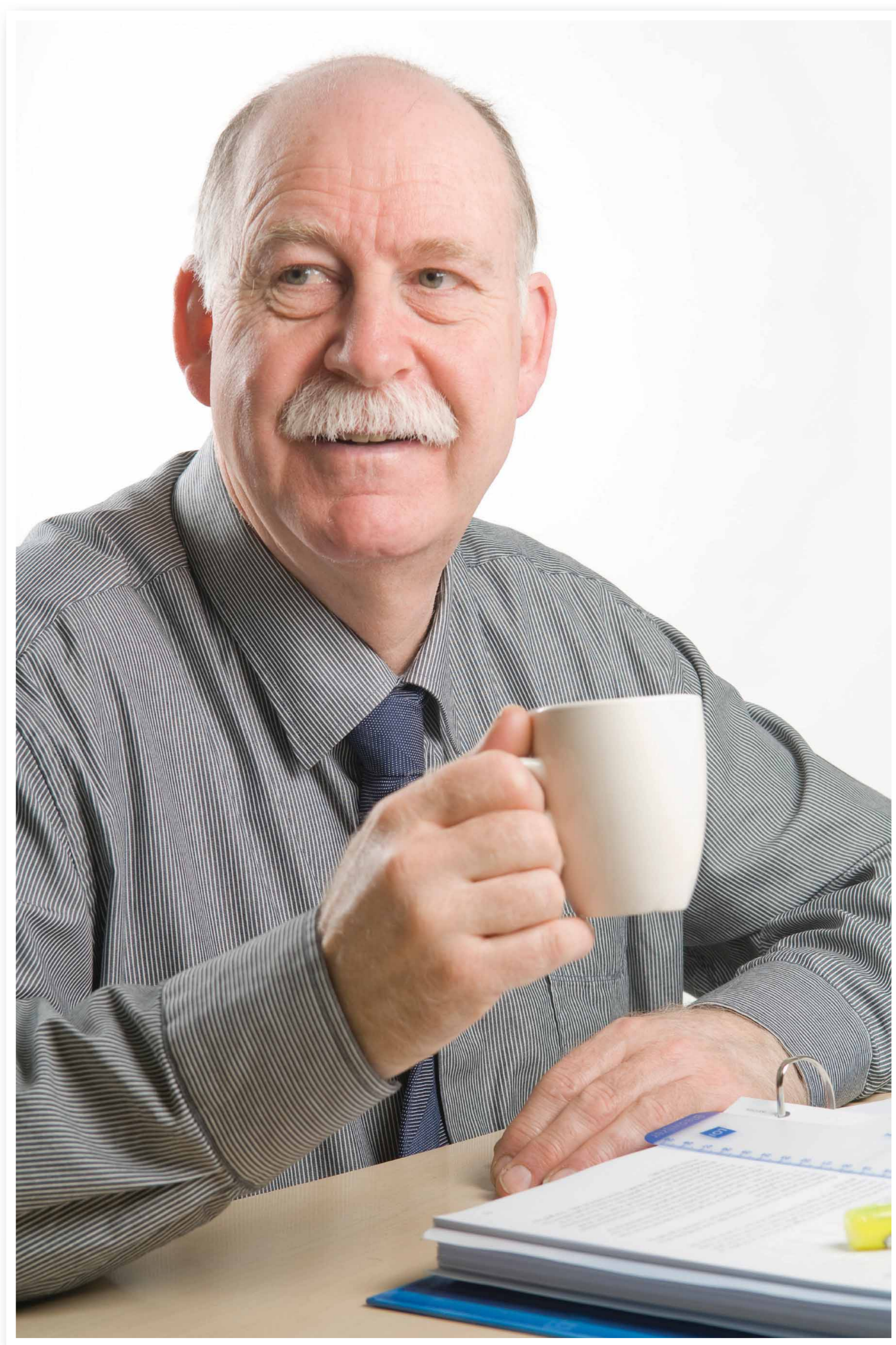
approximately 80,000

WHAT WE OFFER:

- Annual spring and autumn meetings as well as current training as a means of professionalization,
- Support and information through national and international ideas and experiences,
- An agenda for priorities such as for example „Epilepsy and their social environment,“
- Coordination and presentation of results and thus the optimal combination of theory and practice. These are suggestions and active participation of our members needed
- Publication of issues and reports in the magazine for people with epilepsy „ZAK“.

CONTACT DETAILS

Epilepsie Dachverband Österreich
Wichtelgasse 55/17-20, A-1170 Vienna
Telephone 0043 1 489 52 78 - mobile 0043 650 381 0024
President of the organisation: Liselotte Grössing-Soldan
International Contact Person: Mag. (FH) Michael Alexa
Email: michi19691@yahoo.de
Website: www.epilepsie.at



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

FRIENDS OF THE BELGIAN LEAGUE AGAINST EPILEPSY – BELGIUM



Epilepsy associations in Belgium work together in close collaboration. These associations include:

Friends of the Belgian League against Epilepsy (IBE Full Member) – Created in 1956

Regional branches of the Belgian League against Epilepsy (ILAE Chapter) – Created in 1955: the French speaking Belgian League against Epilepsy, the Flemish League against Epilepsy and Flemish Contact Groups

COMMON GOAL:

Promoting the wellbeing of people with epilepsy

RANGE OF OPERATION:

National

Over the years both organizations (professionals and lay people) have worked closely together to bring epilepsy out of the shadows and to successfully introduce activities to promote the wellbeing of people with epilepsy:

- information services, counseling and support for people with epilepsy and their families information meetings on medical and social aspects of epilepsy;
- public education campaigns with press releases, and radio and TV interviews;
- promotion of research and education of professionals;
- information on public healthcare provision and support services;

THE REGIONAL LEAGUES AGAINST EPILEPSY

CURRENT ACTIVITIES:

Each League has an information centre and five social centers. Services are open to all people concerned; there is no need to be a member. Contact is made with social workers by phone, letters, mails, in the centers, at home, etc.

They provide:

- counseling (education, school, work, family, relations, everyday life issues)
- discussion groups for adults, parents, children, young people
- open conferences on medical and non-medical aspects, with questions and discussions
- special group insurance for members of the Friends
- commissions for evaluation of risks (driving, work situations, insurance matters, etc...)
- information and conferences for professionals, students, teachers, employers, first aid services

- leaflets, booklets, posters, videos, websites, library, public education campaigns and actions in the media
- open epilepsy days, activities and information desks on meetings
- collaboration with and support for contact groups

CONTACT GROUP ACTIVITIES:

Contact Groups for Epilepsy – information and support by volunteers! Ten contact groups have developed each in different ways. Six act as the Flemish contact groups; four are in Wallonia. All of their contact information can be found on <http://users.skynet.be/ikaros/>

There are general information sessions about medical and social aspects for people with epilepsy, their relatives and people interested in the condition. Every two years an 'Epilepsy-day' is organized together with the Flemish League against Epilepsy.

SOME RECENT ACTIVITIES IN BELGIUM:

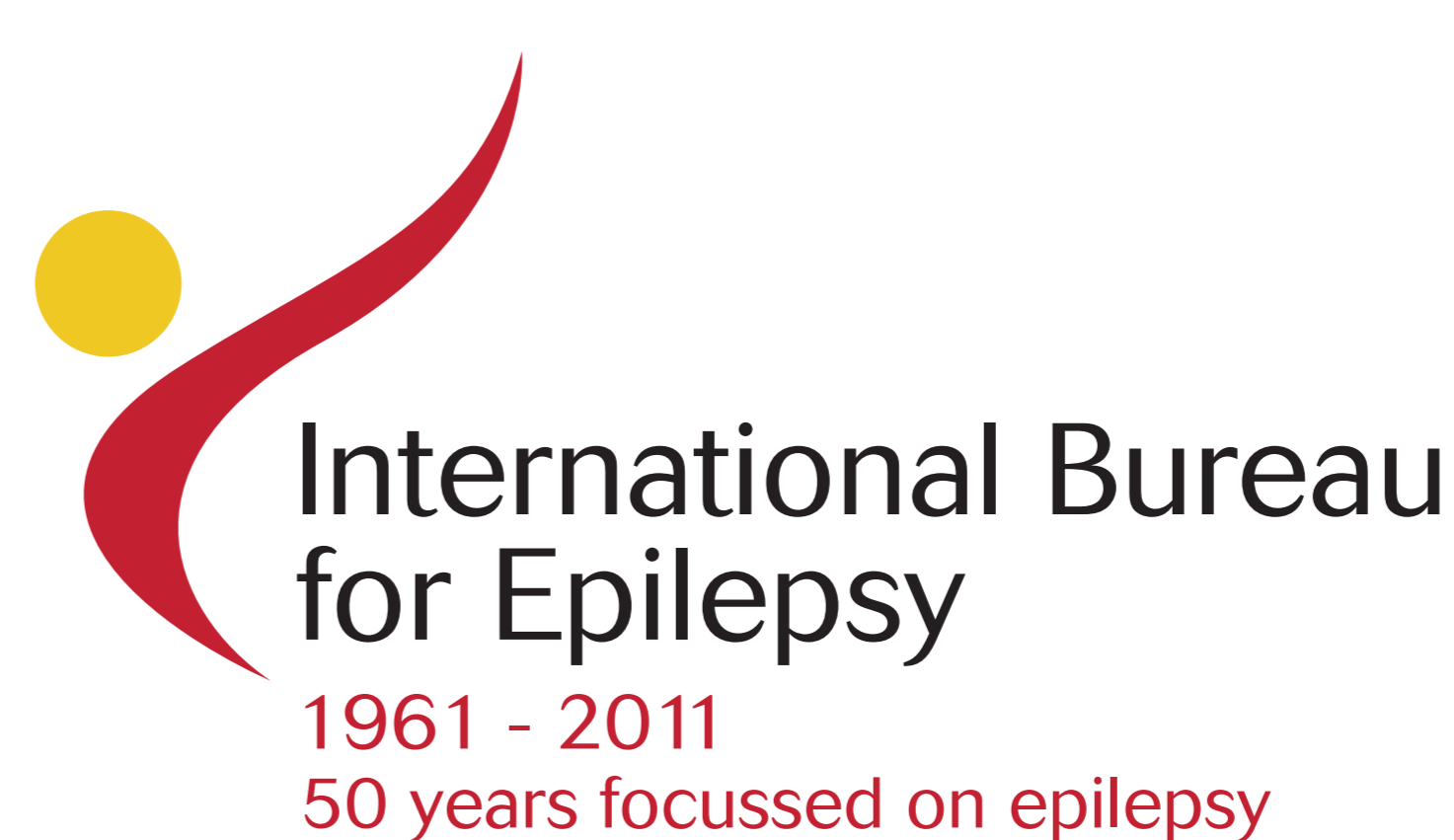
The most innovating project at this moment must be the 'online' project, with which we'll try to reach more young people through a website including FAQ, a forum and a chat room with the possibility of a one-on-one conversation with a social worker. The key word will be 'interactive' in a very enjoyable, fun way.

Also we created a leaflet to inform people about the financial consequences epilepsy can bring along, because it raises a lot of questions.



CONTACT DETAILS

Mrs Claudine Vandaele, social worker of the Flemish League against Epilepsy,
Bernard Spaelaan 141, 9000 Gent, Belgium
Tel: +32 9 222 04 04
Email: c.vandaele@cggeclips.be
Websites: www.epilepsieliga.be, www.ligueepilepsie.be



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ASSOCIATION FOR ASSISTANCE OF PATIENTS WITH EPILEPSY, BULGARIA



CAPITAL OF BULGARIA:

Sofia

POPULATION OF BULGARIA:

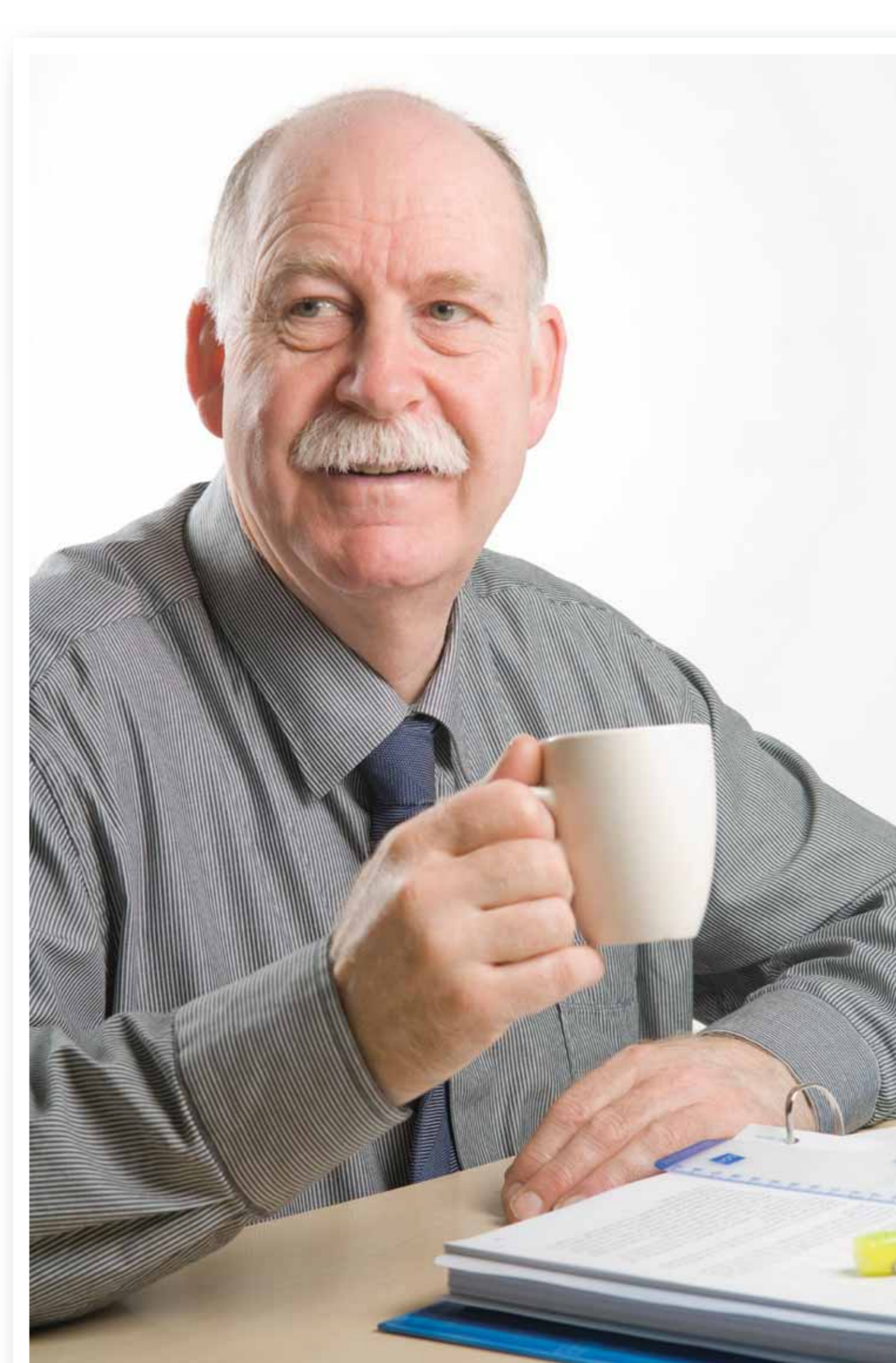
7,450,349 (July 2005 est.)

GEOGRAPHY AND PEOPLE:

Bulgaria shares a border with Turkey and Greece to the south, Macedonia and Serbia to the west, Romania to the north, and the Black Sea to the east. The capital, Sofia, lies in the western region of the country. Ethnic groups include Bulgarian, Turkish, Roma, and others. The official language is Bulgarian.

HEALTH:

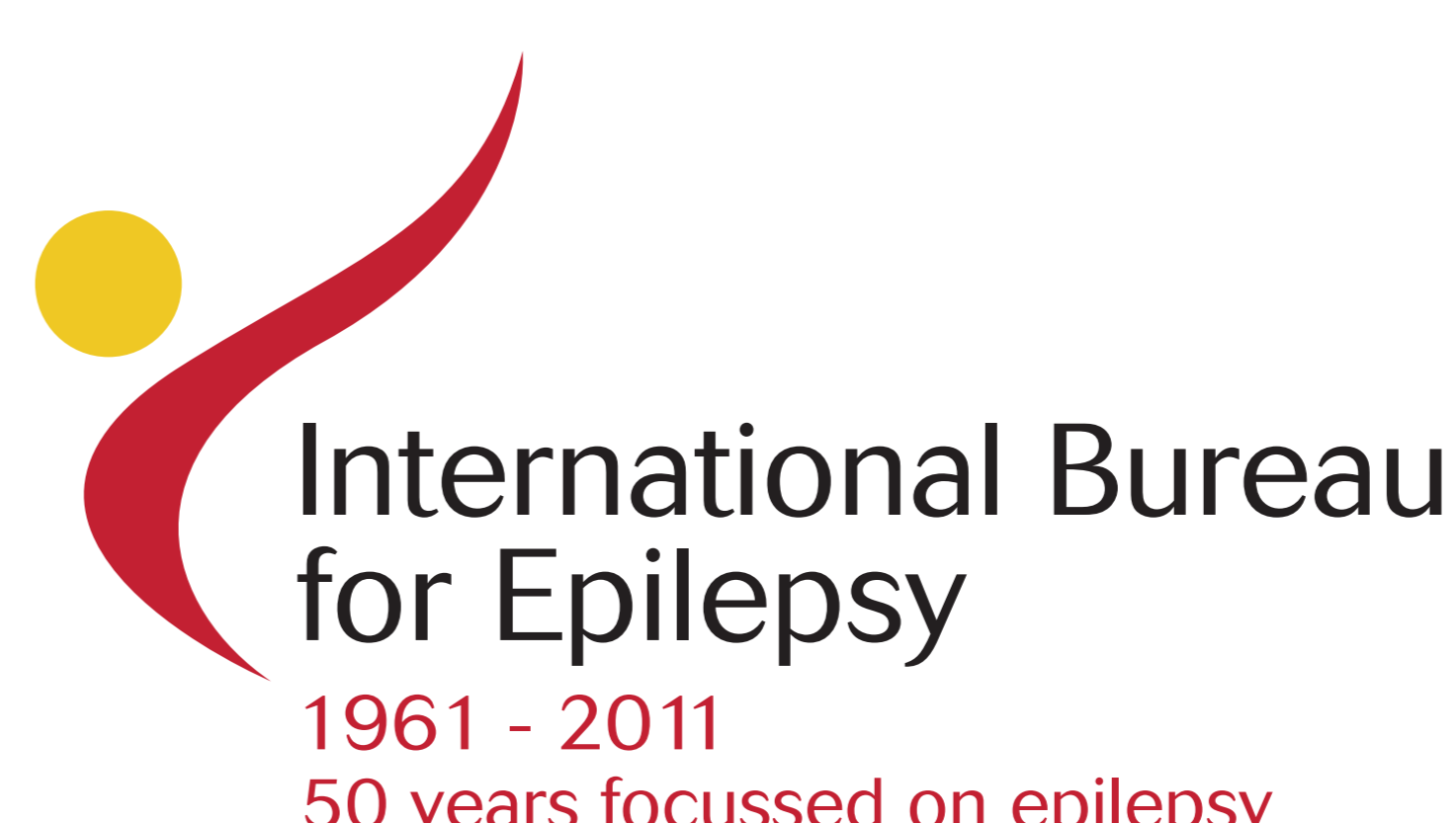
Bulgaria has a universal, mostly state-funded healthcare system. The National Health Insurance Fund (NHIF) pays a gradually increasing portion of the costs of primary healthcare. Employees and employers pay an increasing, mandatory percentage of salaries, with the goal of gradually reducing state support of health care. Between 2002 and 2004, health-care expenditures in the national budget increased from 3.8% to 4.3%, with the NHIF accounting for more than 60% of annual expenditures. In 2010, the healthcare budget amounts to 4.2% of GDP, or about 1.3 billion euro.



Bulgaria has 181 doctors per 100,000 people, which is above the EU average. Some of Bulgaria's largest medical facilities are the Pirogov Hospital and the Military Medical Academy of Sofia.

CONTACT DETAILS

Association for Assistance of Patients with Epilepsy,
20 Slavianska Str, 1000 Sofia,
Bulgaria
T/F: +359 29895341
aape_bulgaria@yahoo.com
Contact: Dr Marian Dimitrov



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

CROATIAN ASSOCIATION FOR EPILEPSY



TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1997

INITIAL AFFILIATION TO IBE

January, 2009

TYPE OF ORGANISATION

Individual membership

RANGE OF OPERATION

National

GOAL:

Promoting of all aspects of quality of life in people with epilepsy and members of their families.

REGULAR ANNUAL ACTIVITIES:

- Providing social care and medical education of people with epilepsy and members of their families
- Rising awareness of epilepsy in public: public presentations including TV and radio programmes, newspapers, website.
- Regular monthly meetings of our members with presentations of special interest, e.g. driving licence, neurosurgery of epilepsy, sport and leisure activities, new antiepileptic drugs, etc.

COUNSELING:

- Individually and by email
- Public awareness meeting on Croatian National Day of Epilepsy (14 February)

SPECIAL ACTIVITIES IN 2010:

Organizing the first Camp for children and adolescents with epilepsy in Croatia.

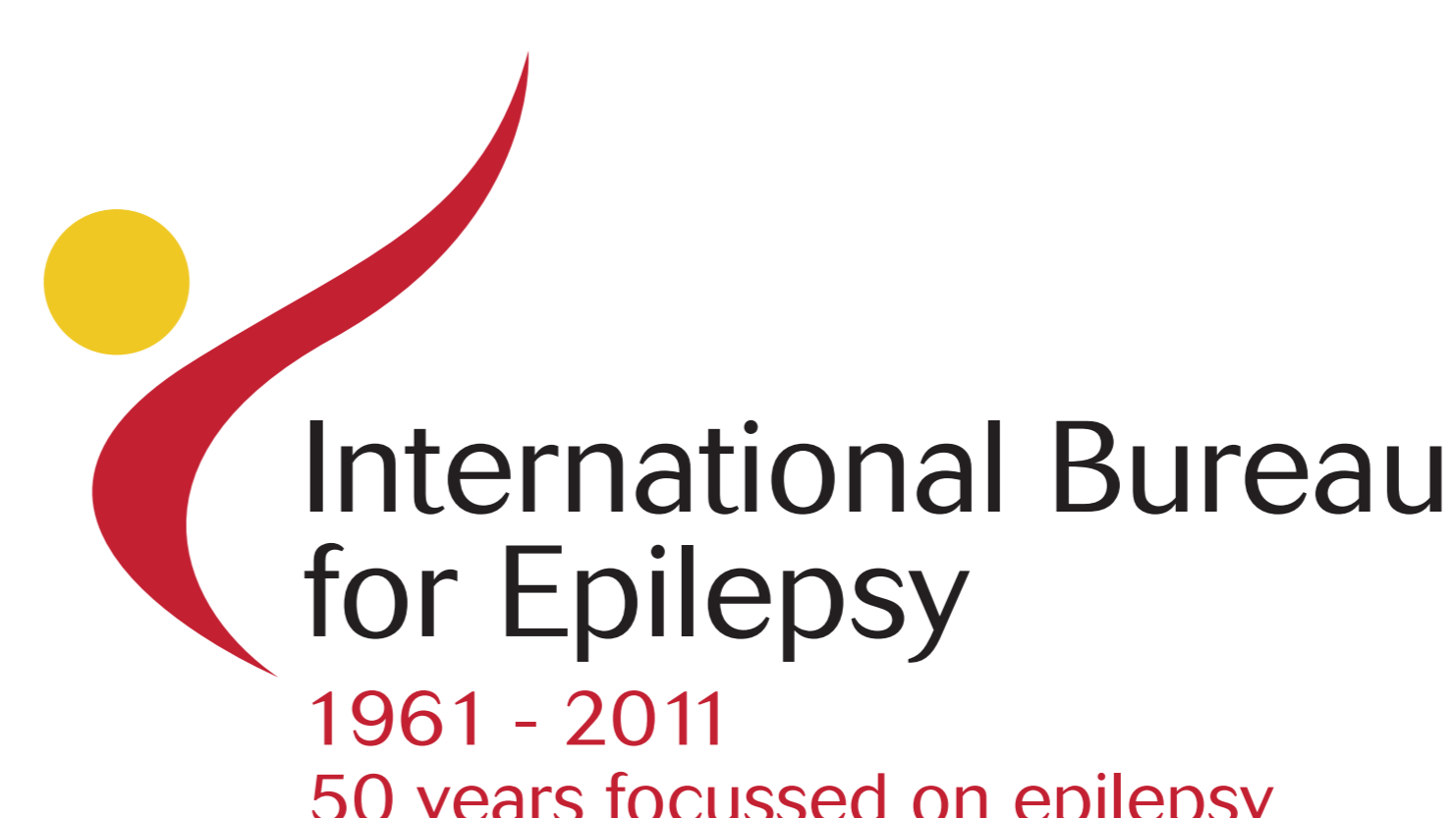


CONTACT DETAILS

Ivan Bielen, Sveti Duh 64, 10000 Zagreb, Croatia.

Email: info@epilepsija.hr

Website address: [http:// www.epilepsija.hr](http://www.epilepsija.hr)



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

CYPRUS ASSOCIATION OF SUPPORT FOR PEOPLE WITH EPILEPSY



Cyprus is a European Union member country located in the eastern Mediterranean Sea. It was a former British colony, which achieved independence only in 1960.

GEOGRAPHY:

Cyprus is the third largest island in the Mediterranean Sea, after the Italian islands of Sicily and Sardinia (both in terms of area and population). It is also the world's 81st largest by area and world's 49th largest by population. It measures 240 kilometres (149 mi) long from end to end and 100 kilometres (62 mi) wide at its widest point, with Turkey 75 kilometres (47 mi) to the north.

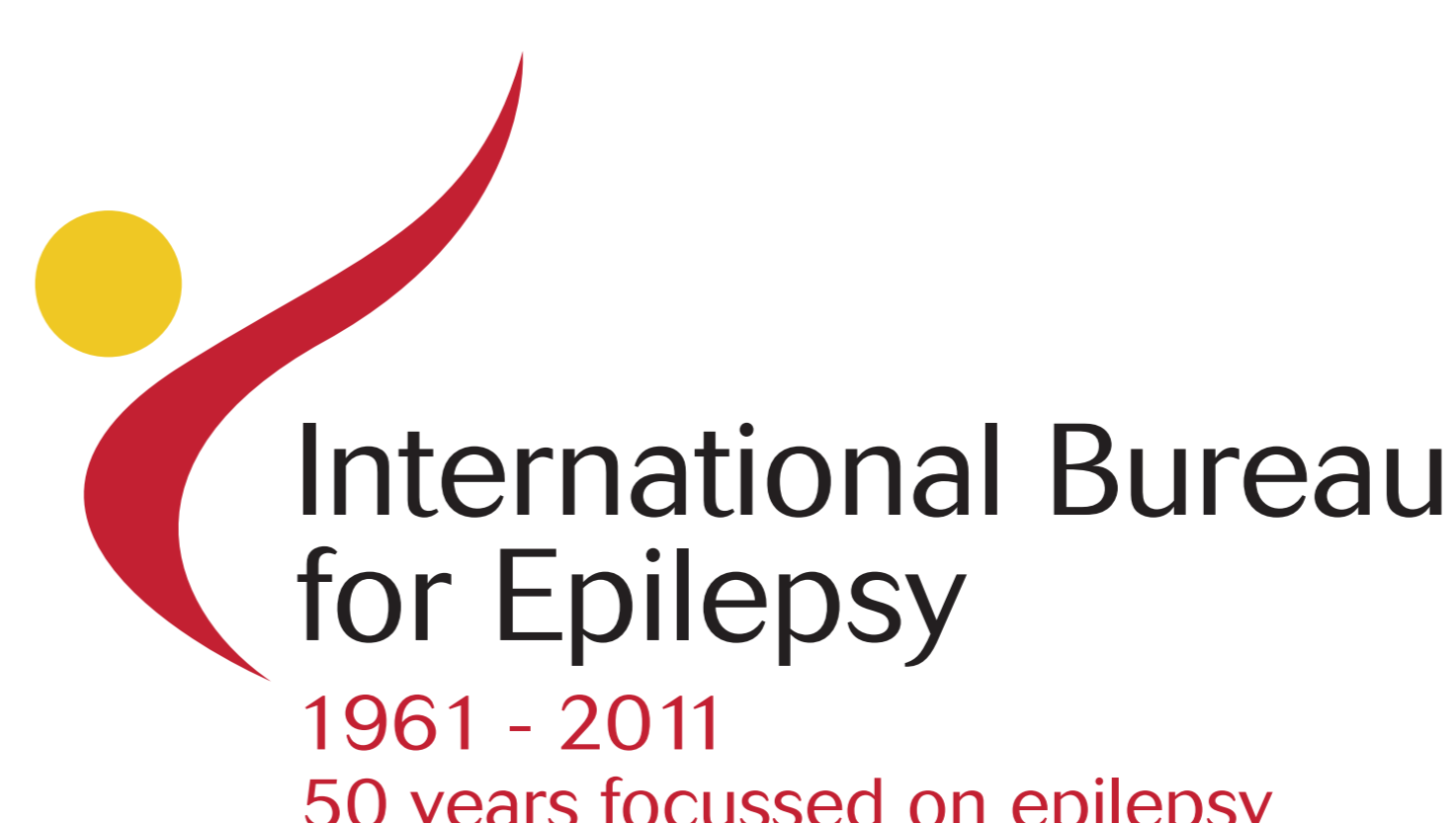
HEALTHCARE:

Cyprus health system is of good standards. Life Expectancy is high at 79 years for men and about 82 years for women. Infant mortality is low at 5 infant deaths per 1000 of the population. Further, crude death rate is at 6.9 persons per 1000 of the population.

Cyprus provides priority to its health care system and actively promotes preventive medicine. Many medical professionals are foreign trained particularly in the United Kingdom. Cyprus' health care system is being trusted not only by local residents but also by other foreign nationals who come to Cyprus for health reasons. Healthcare is inexpensive with State hospitals practically free and private health insurance is available at low cost. This is most especially important in emergency and accident situations with drug cost kept at a low minimum.

CONTACT DETAILS

8 Epidavrou Str., Platy 2114,
Nicosia, Cyprus.
T: +357 9941 2779
antigoni@cytanet.com.cy
Contact: Mrs A Kallimachou



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

DANISH EPILEPSY ASSOCIATION DENMARK



TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1962

INITIAL AFFILIATION TO IBE

2001

TYPE OF ORGANISATION

Individual membership

RANGE OF OPERATION

National

GOAL:

To secure the inclusion of people living with epilepsy into all aspects of society so that their conditions of life are not limited due to epilepsy.

The Danish Epilepsy Association conducted a major web-survey amongst +1200 members in the spring of 2011. The object of the survey was to clarify a number of health-related and social issues of special concern for people with epilepsy. The response to the survey was approximately 50% - equaling 634 members completing the web-based questionnaire.

The persons with epilepsy included in the survey range from 0 – 100 years of age (parents answering on behalf of children and adolescents (25% of the entire cohort)).

One issue of special concern to people with epilepsy in Denmark is dental health and dental damage caused by either epileptic seizures or as a negative side-effect to treatment with AEDs (or a combination of both).

The findings in the survey show a relatively high number of people with epilepsy who have dental damage related to epilepsy seizures and treatment with AEDs.

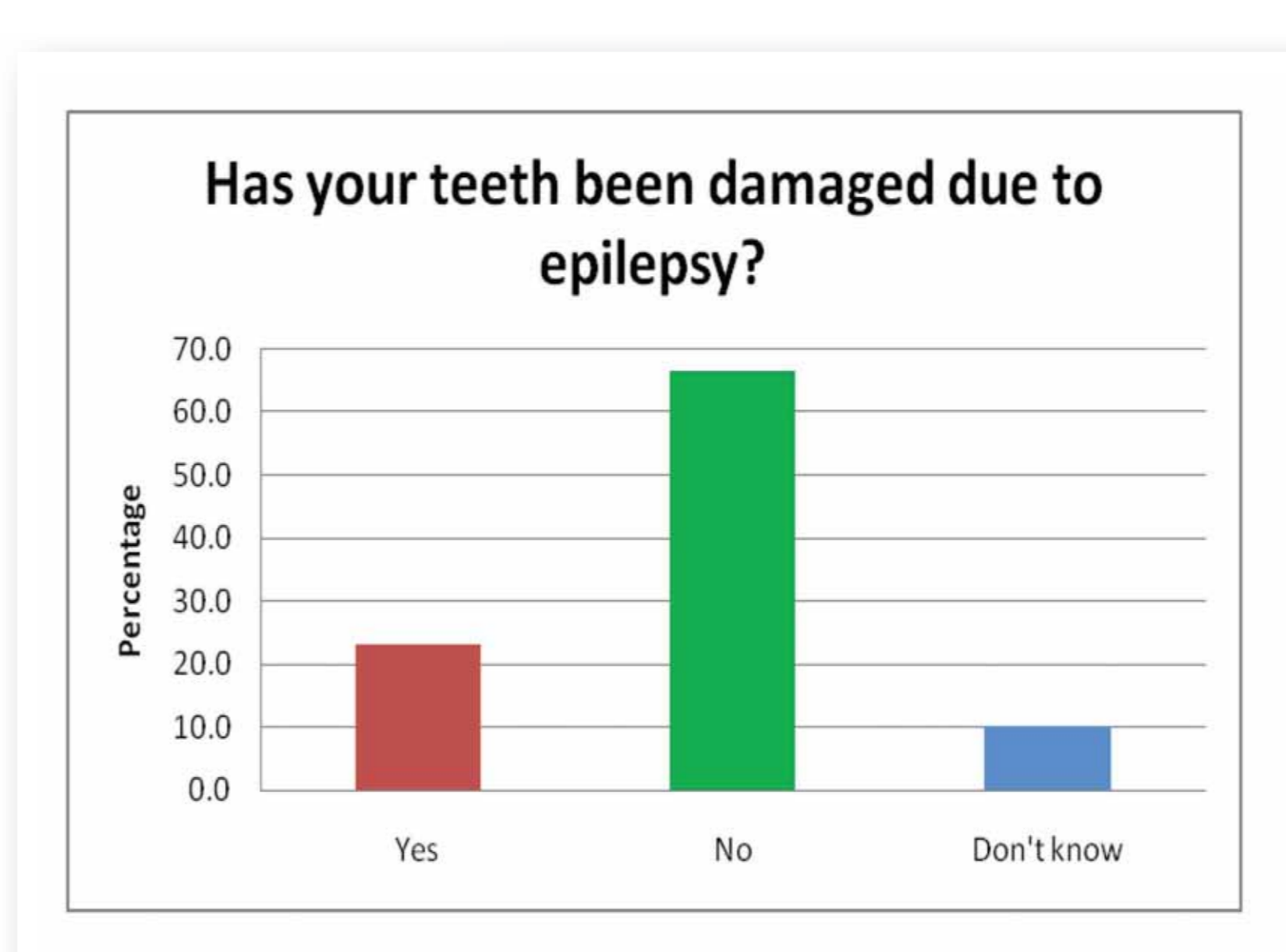


Figure 1: 23.2% of members answering the questionnaire reports to have suffered epilepsy related damage to their teeth.

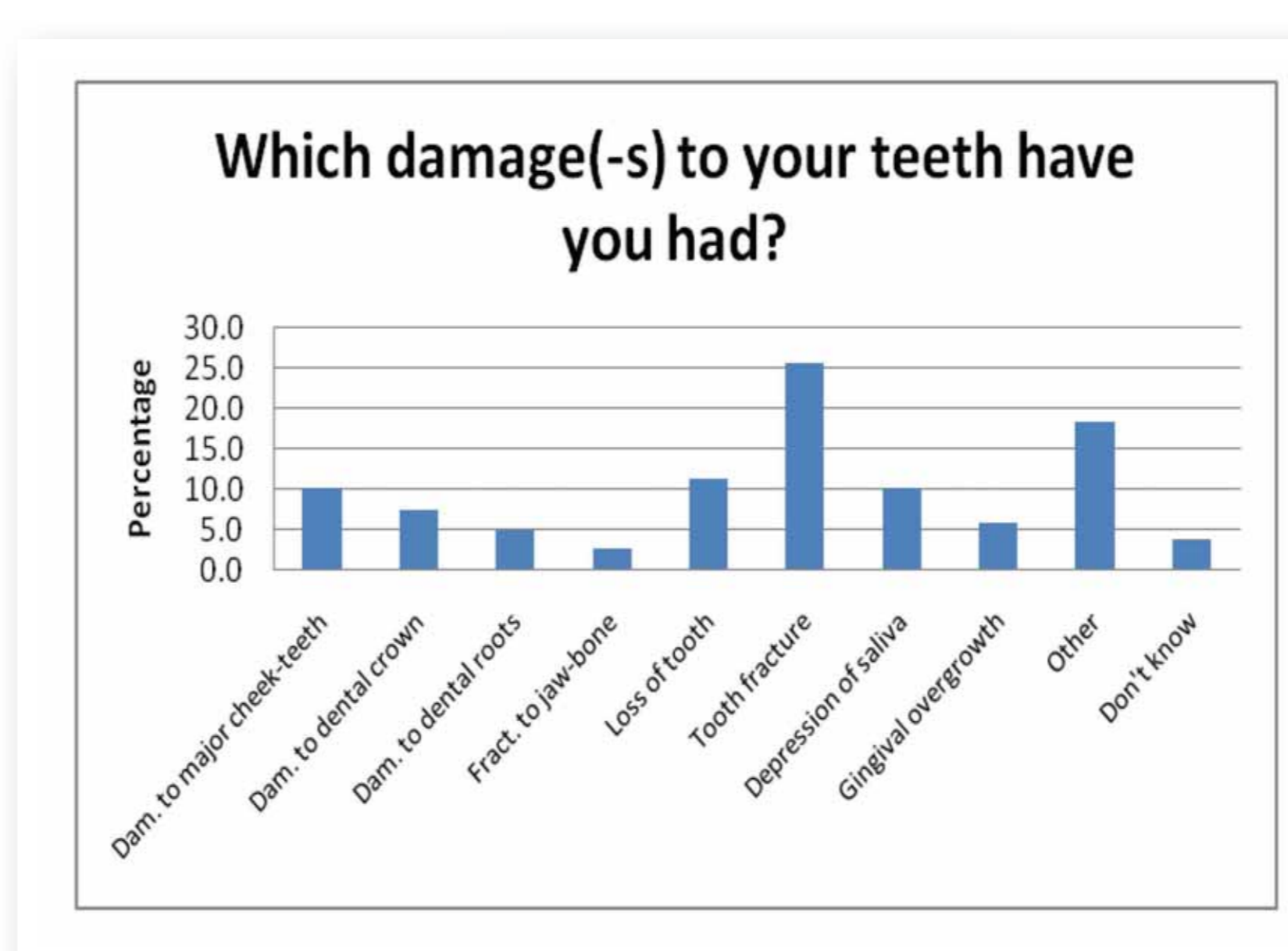


Figure 2: The sort of and frequency of damages caused by epileptic seizure and/or treatment with AEDs as reported by members (n. 129).

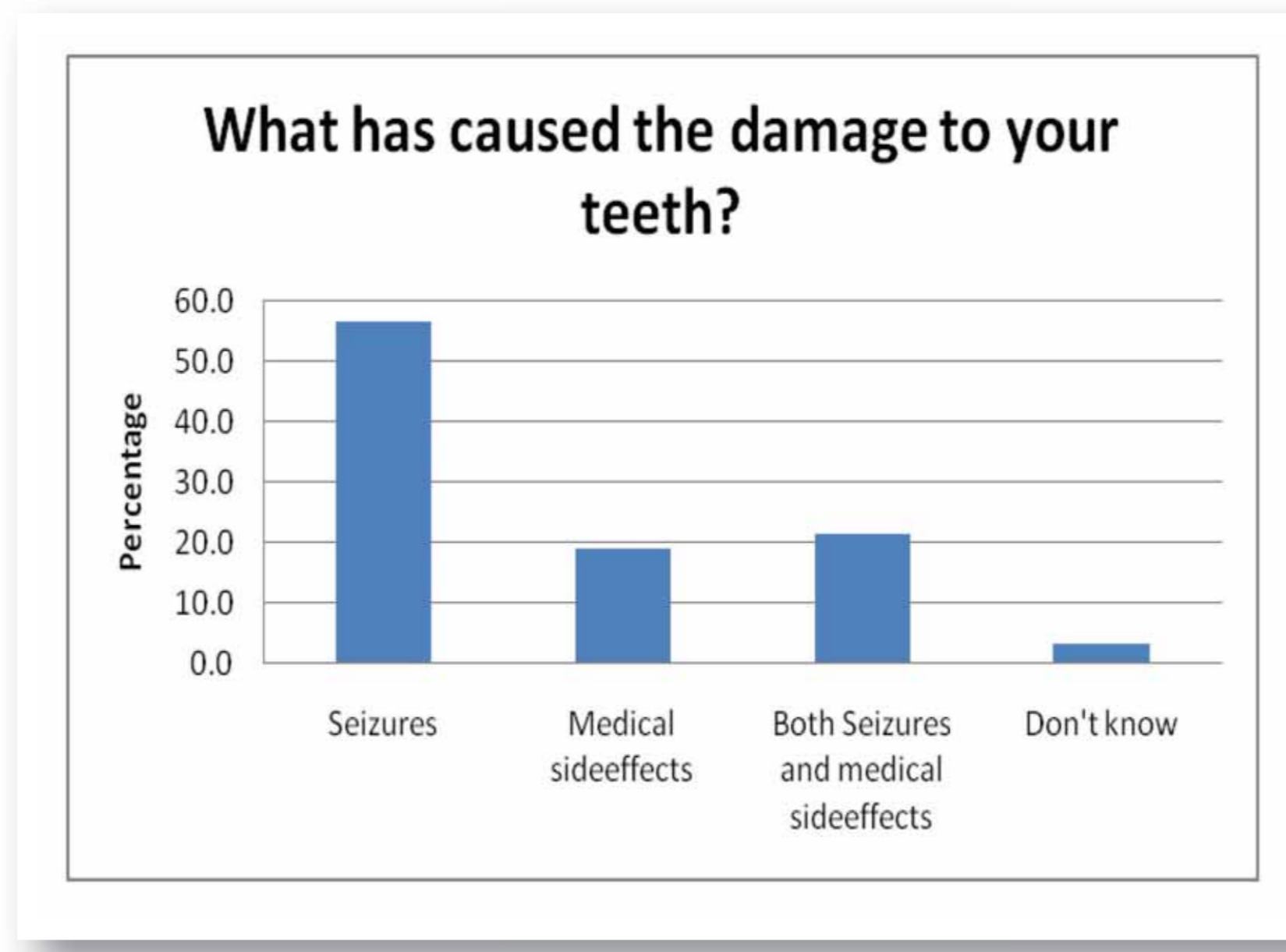


Figure 3: The reason to tooth-damage, as reported by members (n. 129).

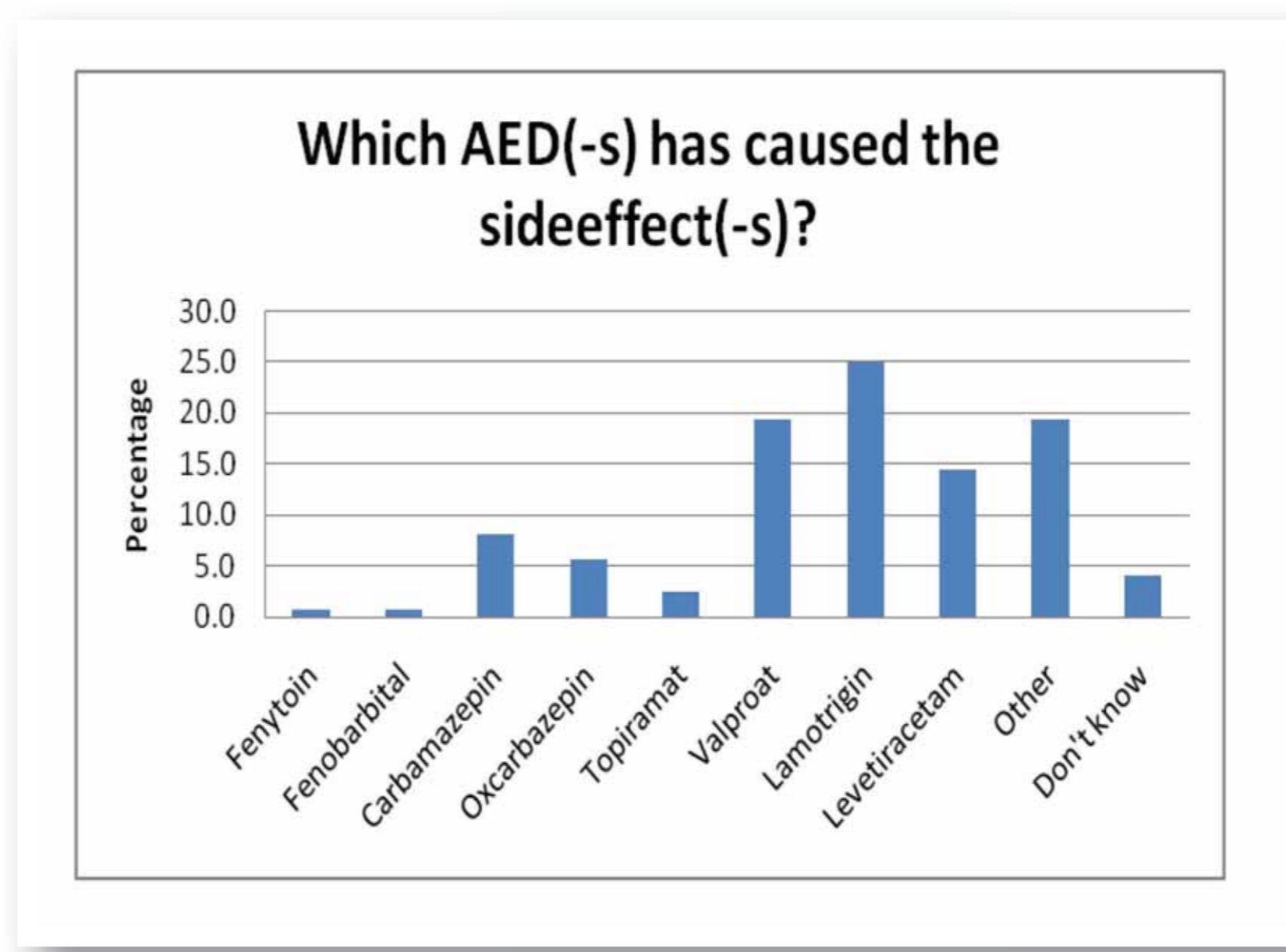
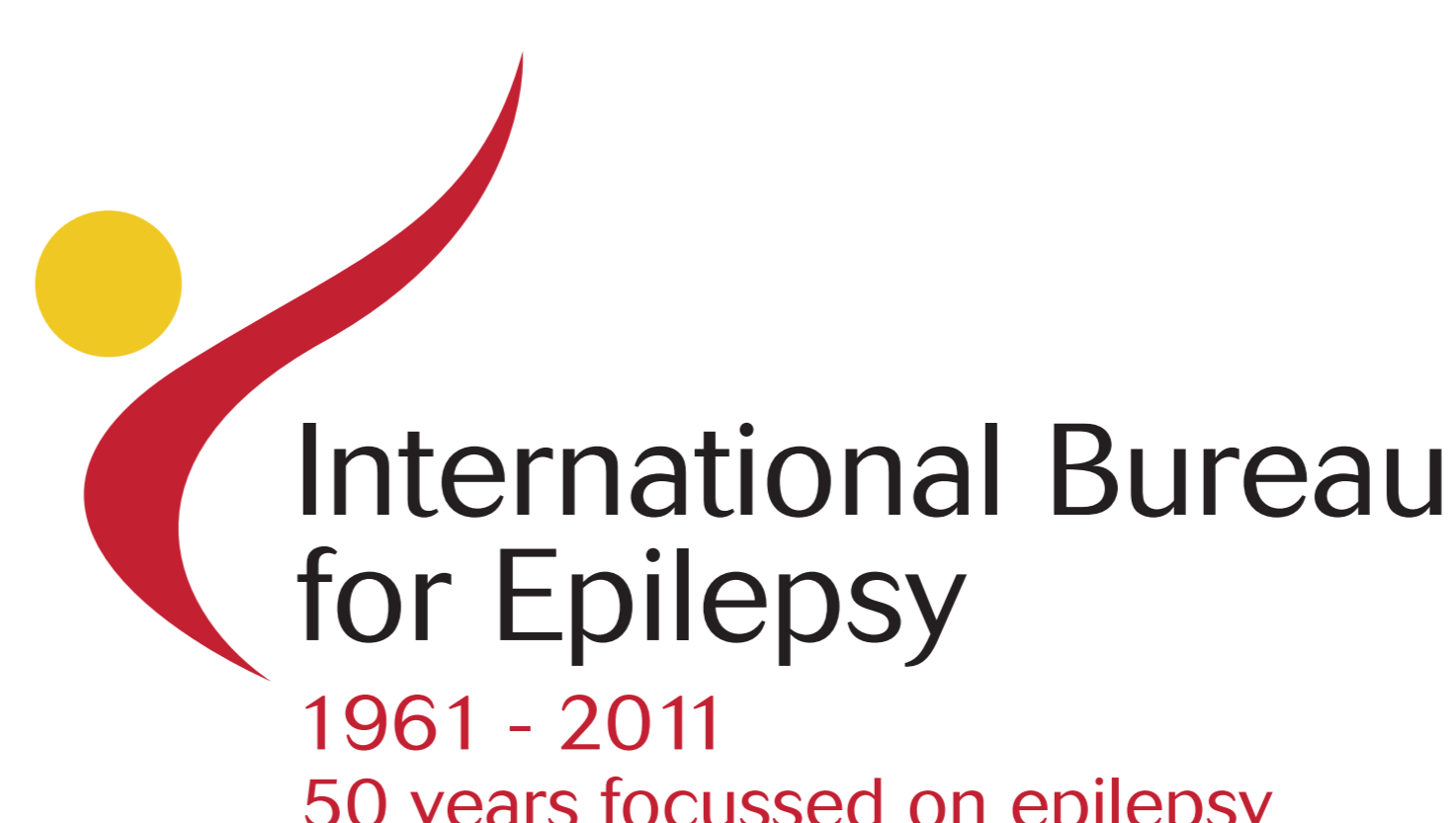


Figure 4: Type of AED related to tooth-damages, as reported by members (n. 129).

CONTACT DETAILS

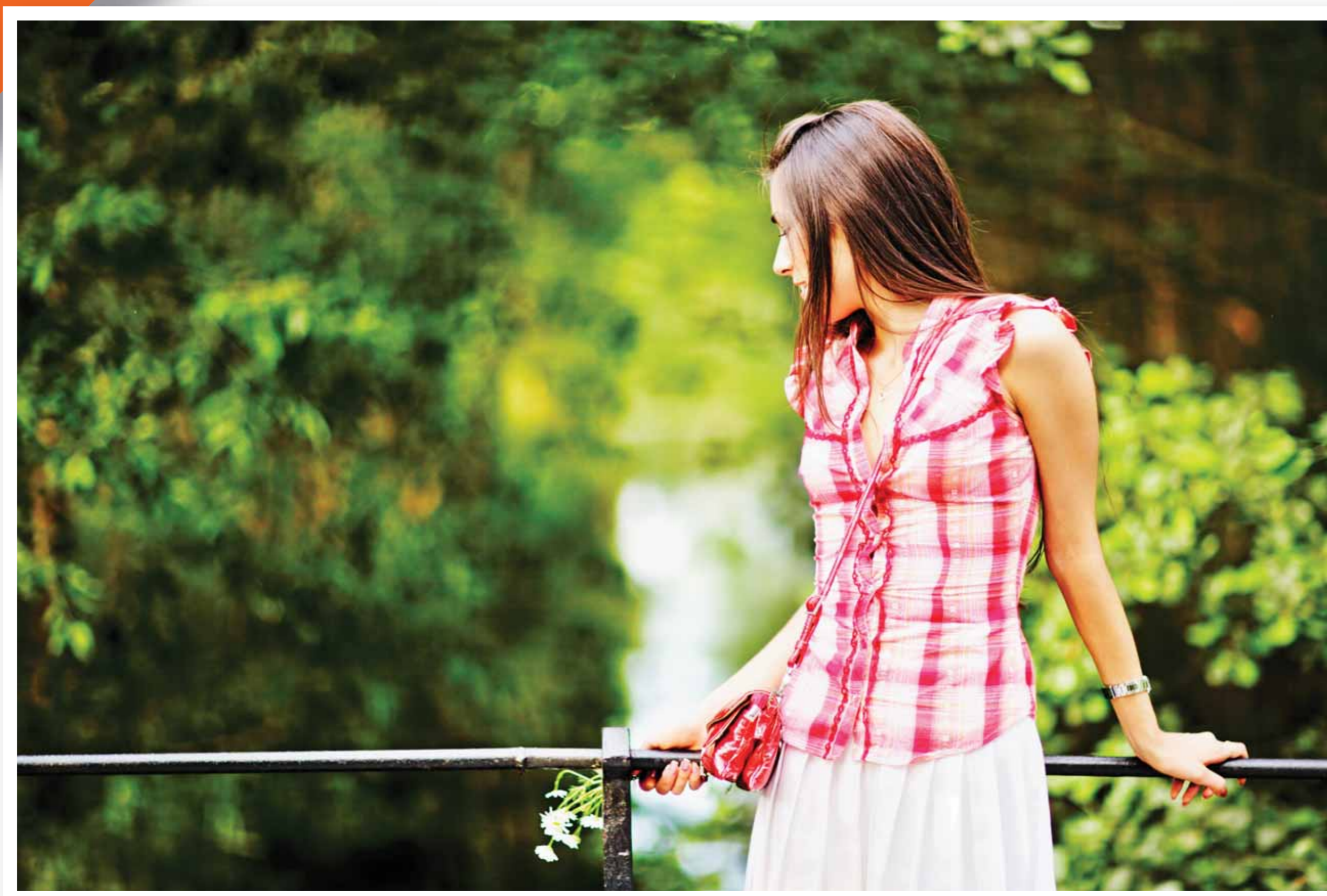
René Bøgh-Larsen, managing director, +45 30 60 89 96;
Email: rene@epilepsiforeningen.dk
Website: www.epilepsiforeningen.dk



International Bureau for Epilepsy

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

DANISH EPILEPSY CENTRE DENMARK



Denmark, with a mixed market capitalist economy and a large welfare state ranks as having the world's highest level of income equality.

POPULATION:
5,432,335 (July 2005 est.)

Denmark has been a member of the European Union since 1973, although it has not joined the Eurozone. Denmark is a founding member of NATO and the OECD. Denmark is also a member of the Organisation for Security and Cooperation in Europe (OSCE).

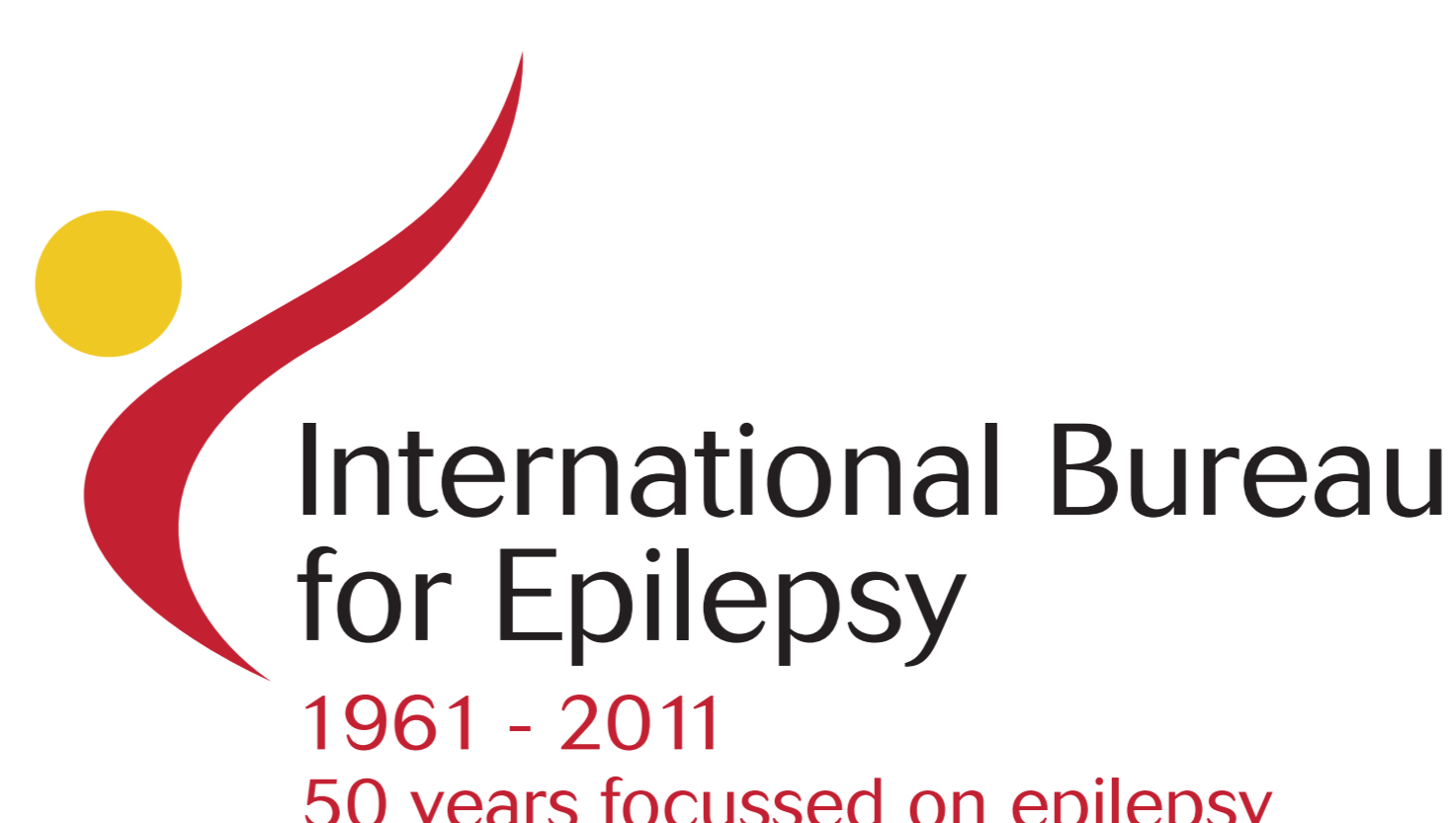
Health care in Denmark is largely financed through local (county and municipal) taxation with integrated funding and provision of health care at the local (county) level.

Most primary care is provided by general practitioners, who are paid on a combined capitation and fee-for-service basis. The counties control the number and location of general practitioners, and their fees and working conditions are negotiated centrally. The municipal health services provide health visitors, home nurses and school health care.



CONTACT DETAILS

Børneambulatoriet,
1 Epilepsihospitalet,
Dr Sells vej 23, 4293,
Dianalund,
Denmark.
F: +45 5827 1471
vst@filadelfia.dk
Contact: Mrs Vibeke Stubbings.



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EOLE, FRANCE



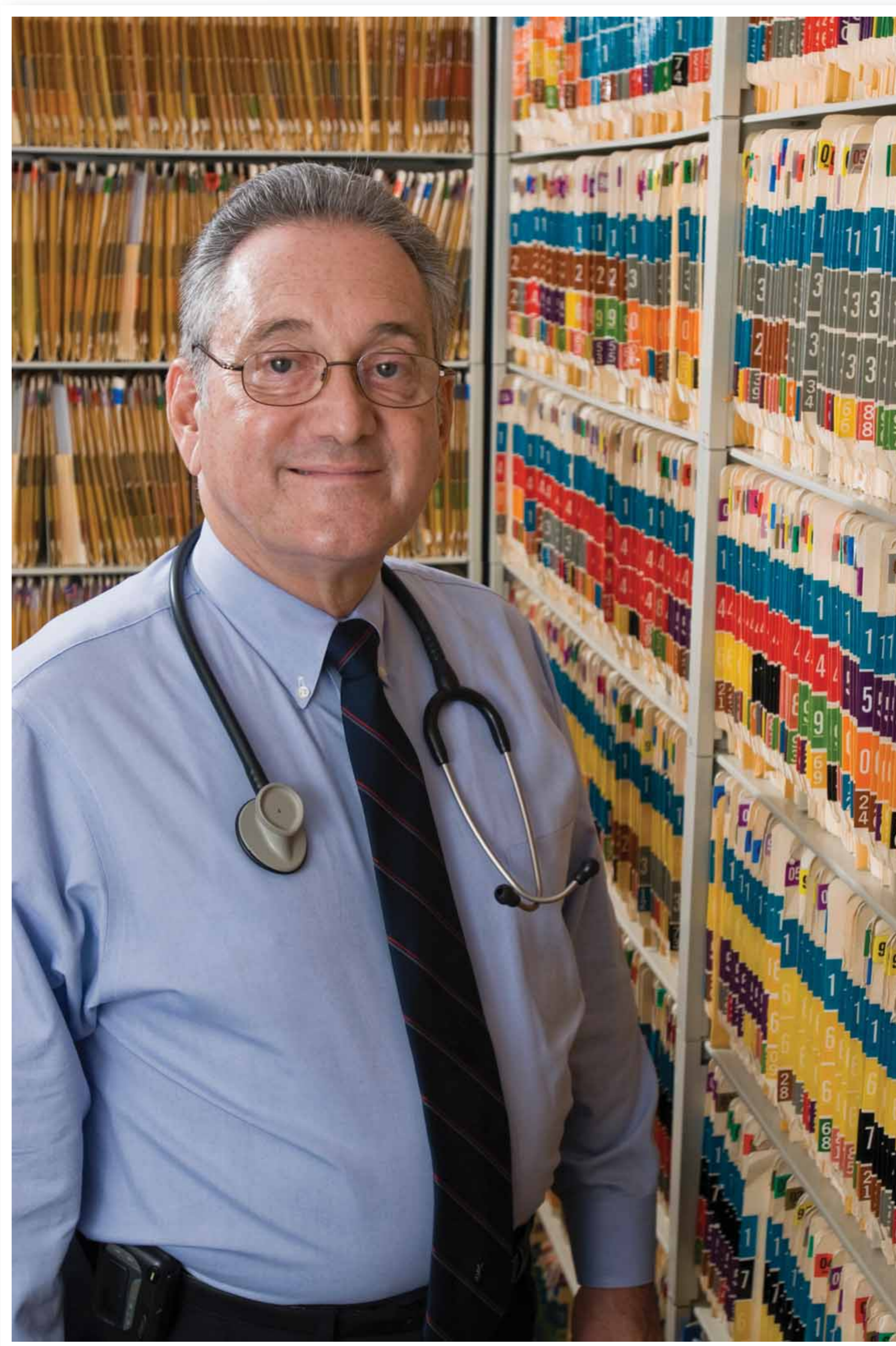
POPULATION:

60,656,178 (July 2005 est.)

CULTURE:

France has been a center of cultural creation for centuries. Many French artists have been among the most renowned of their time, and France is still recognized in the world for its rich cultural tradition.

The successive political regimes have always promoted artistic creation, and the creation of the Ministry of Culture in 1959 helped preserve the cultural heritage of the country and make it available to the public. The Ministry of Culture has been very active since its creation, granting subsidies to artists, promoting French culture in the world, supporting festivals and cultural events, protecting historical monuments. The French government also succeeded in maintaining a cultural exception to defend audiovisual products made in the country.

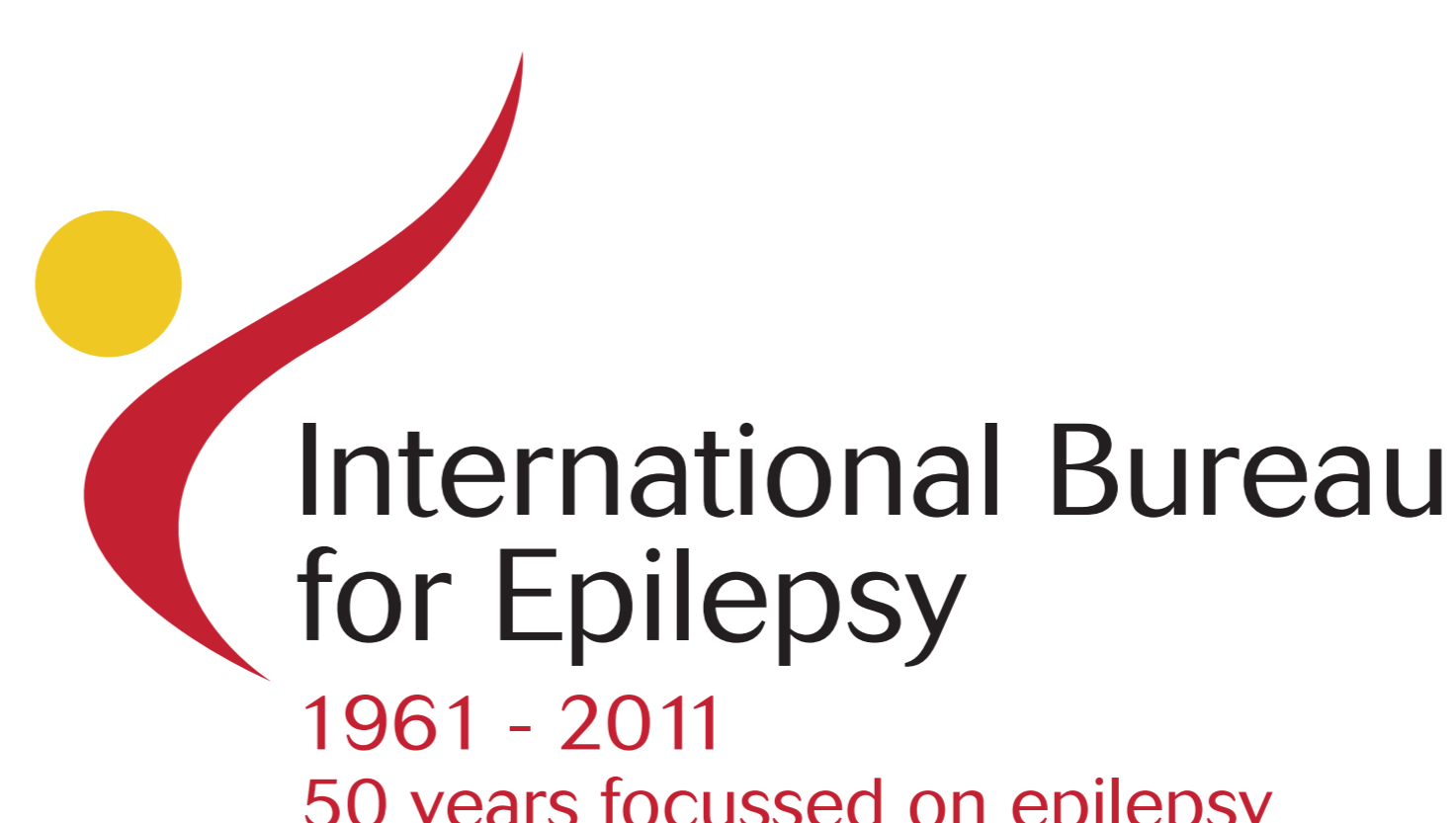


HEALTHCARE IN FRANCE:

The French healthcare system was ranked first worldwide by the World Health Organization in 1997 and then again in 2000. Care is generally free for people affected by chronic diseases (Affections de longues durées). Average life expectancy at birth is 77 years for men and 84 years for women, one of the highest of the European Union. There are 3.22 physicians for every 1000 inhabitants in France, whereas average health care spending per capita is US\$4,719 in 2008.

CONTACT DETAILS

EOLE, 240 Boulevard Voltaire,
75011, Paris, France.
T: +33 143 716 260
eole asso@wanadoo.fr
Contact: Dr Roger Salbreux



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPI-SUISSE



WHAT ARE OUR AIMS?

Epi-Suisse not only improves the standard of life but encourages the social integration of epileptic people in schools, advanced education, careers and hobbies. A well-founded and decent standard of life should and ought to be matter of fact for epilepsy sufferers, too.

Epi-Suisse looks behind the principal restrictions of everyday life for those inflicted with epilepsy, and goes on to examine these in a systematic manner. It is only the knowledge of such correlations that will enable possible action in the way of lobbying and the opening of «fair chance» channels as well as the encouraging of self responsibility in all aspects of life for epileptic people.

WHAT DO WE DO?

Epi-Suisse distributes information concerning epilepsy and its consequences in order to awake a better understanding of the illness and the problems of those inflicted. This is not only a practical activity, but one that is connected to scientific projects as well as the research of the psychosocial aspects of epilepsy.

With a multiple palette of specifically aimed services, the striving for comprehensive care of epileptic people and their relatives can be supported by the following:

- Regular circulation of a magazine
- Publications
- Self help groups- Information events
- Advice and dialog
- Leisure and hobby activities

Acting as a proxy on behalf of the patients towards employers, authorities, institutions, media and above all society as a whole, is additionally of major importance to Epi-Suisse.

CONTACT DETAILS

pi Suisse, Seefeldstrasse 84,
Postfach 313, CH 8034 Zurich,
Switzerland.
T: +41 434 886 880
Email: info@epi-suisse.ch

WHO ARE WE?

Epi-Suisse is an organisation throughout Switzerland that is occupied with the psychosocial issues of both those suffering with epilepsy and their relations. Epi-Suisse was founded on the second of July 2002 by various Swiss epilepsy organisations, and business was inaugurated on the first of January 2003.

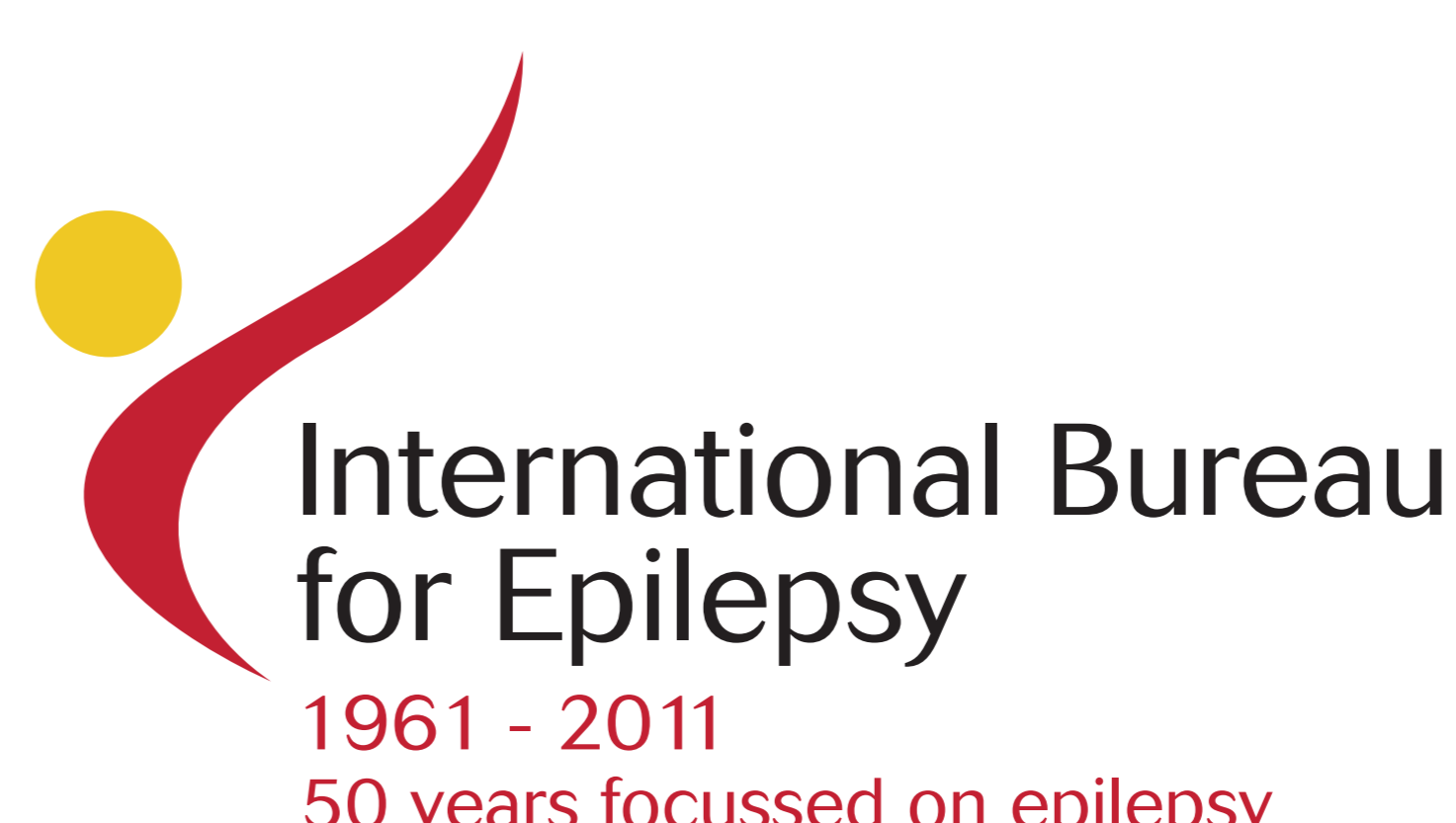
SELF - HELP

Meeting kindred spirits, exchanging thoughts, discussing problems and nurturing friendship: all these things as well as the possible acquaintance of a friend for life are offered by the various self-help groups for epileptic people.

Epi-Suisse also encourages the formation of new self-help groups throughout Switzerland and sup-ports those already established with their activities.

ADVICE

During a personal conversation or even on the telephone, many of the questions can be answered. With Epi-Suisse both epilepsy sufferers and their relations will always find an open ear. Requests will be handled in a careful and discreet manner. Spontaneous visits to the premises are also more than welcome.



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPILEPSIE EURO SERVICES, FRANCE



The association created in 1997 under the name of Epilepsy Euro Services and is an Associate Member of IBE

OUR MISSION SINCE 1998 HAS BEEN:

- To encourage awareness of the true facts about epilepsy
- To develop all available means to encourage the integration of the persons with epilepsy in the professional field
- To ensure the implementation of all necessary projects to achieve these objectives

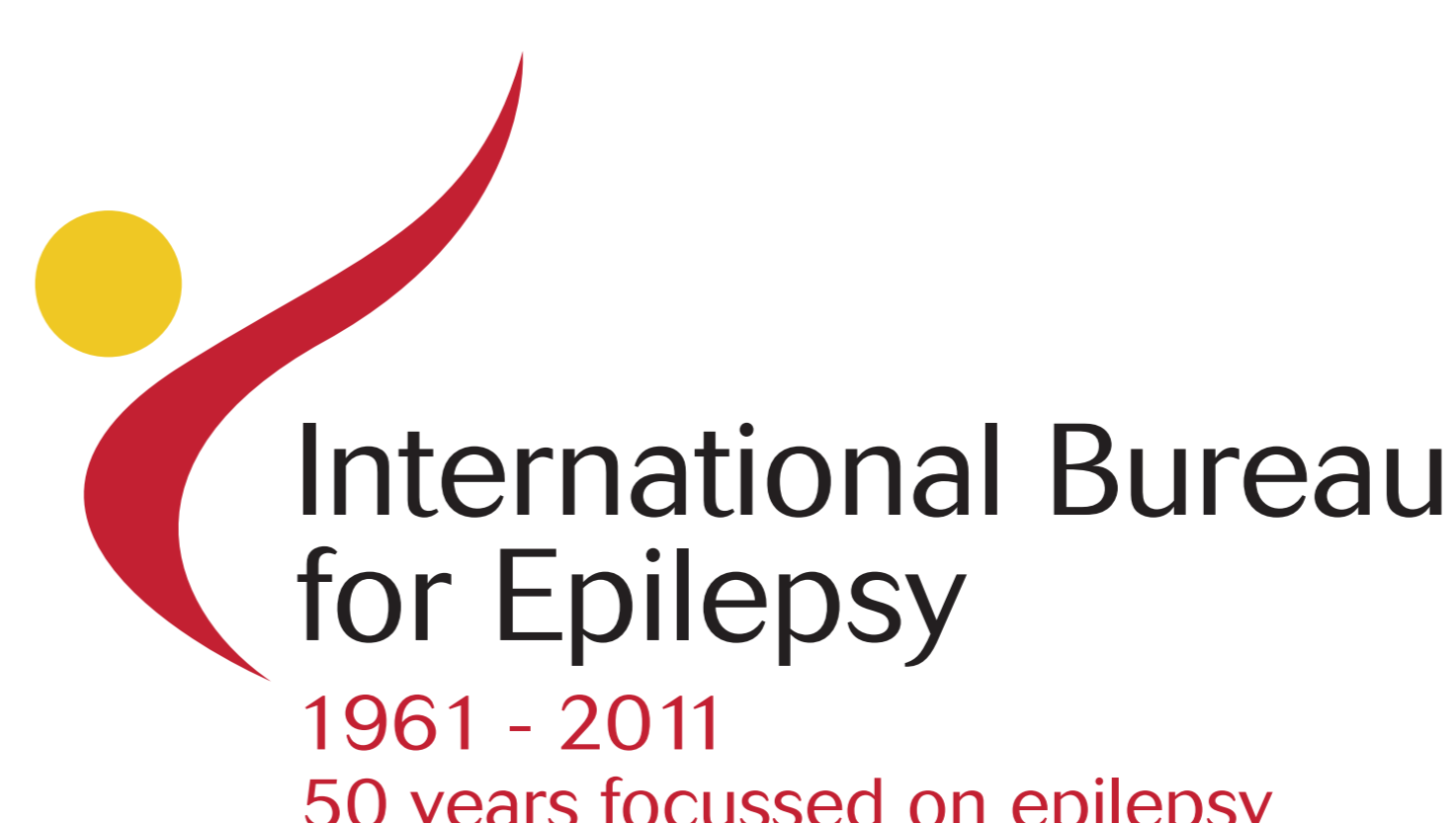
Our mission is the result of collaboration with organisations and group, public and private, as well as with enterprises, l'Agefiph, government departments, regional councils, municipalities, and those involved in professional integration (Cap Emploi, PDITH), educational departments and the MDPH

OUR SUCCESS:

Our knowledge and know-how, a result of our expertise in the field of epilepsy was transferred to those suffering chronic illness or disability.

CONTACT DETAILS

Epilepsie Euro Services,
115 rue de l'Abbé Groult,
75015 Paris, France.
T: +33 156 801 060
epieuros@club internet.fr



International Bureau for Epilepsy

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

ÉPILEPSIE-FRANCE



TYPE OF IBE MEMBER

Associate member

Épilepsie-France is a national association regulated by the law; it was established on 4th November 2004 as a result of the fusion of two pre-existing associations – l'Association pour la Recherche, Pour l'Éducation et l'Insertion des Jeunes Épileptiques (ARPEIJE), created in 1998 and the le Bureau Français de l'Épilepsie (BFE), created in 1991. The fusion into the new association Épilepsie-France came into being on 1st January 2006. The association brings together persons with epilepsy and those close to the, benevolent professionals and other associations.

Épilepsie-France works exclusively for the benefit of persons with epilepsy and their families and carers, in order to improve their quality of life. To do so, the association brings together other persons with epilepsy and their families, medical professionals and other organisations interested in epilepsy.

Épilepsie-France is managed by an administrative council elected by its members.

The association is at the same time a movement for action and an association providing services to its members in line with its charter.

Épilepsie-France is a member of CISS, with comprises a group of 32 associations involved in the health field, in order to provide a complementary approach for the chronically ill, the disabled, their carers and families.

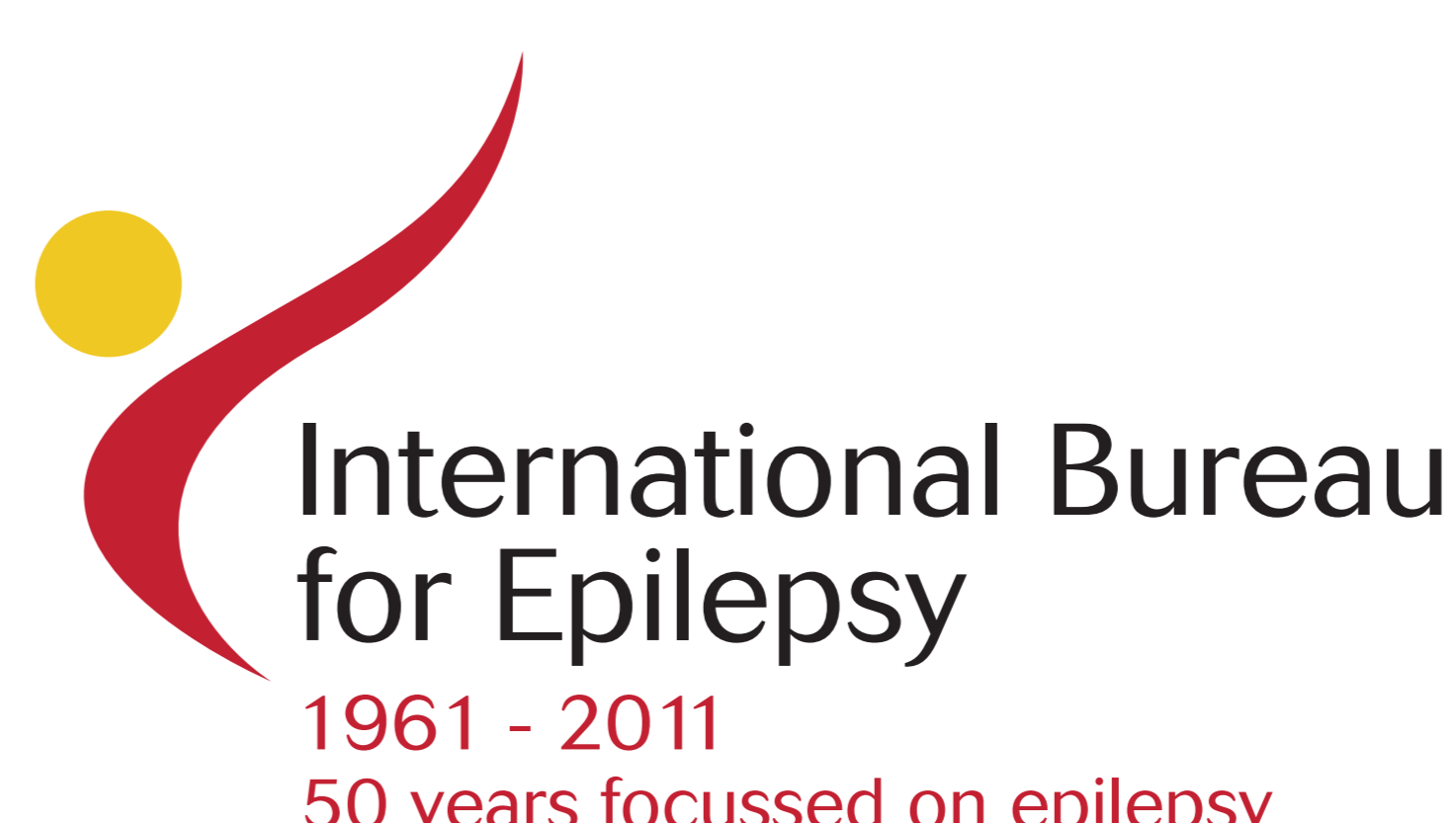
SERVICES DEVELOPED BY PAR ÉPILEPSIE-FRANCE INCLUDE THE FOLLOWING:

- Daily telephone helpline, allowing anyone with a query to seek information
- Response to all requests sent by regular post or by email
- Permanent office where people can be welcomed
- Regular meetings for members, to exchange views, establish relations and become informed
- Organisation of an annual national one day meeting, alternating between Paris and the provinces, in the course of which we have information booths, workshops and round table discussions
- General assembly meetings
- Comprehensive publications on all aspects of living with epilepsy. These publications are made available on request and are also available at meetings and other gatherings
- Quarterly newsletter giving diverse information and news

Épilepsie-France is a member of the Comité National pour l'Épilepsie with the French League Against Epilepsy, the French Foundation for Epilepsy Research, AISPACE, and EOLE.

CONTACT DETAILS

Épilepsie-France
133, rue Falguière
75015 PARIS
Téléphone : 01 53 80 66 64
siege@epilepsie-france.fr



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

NATIONAL EPILEPSY FOUNDATION (NEF) NETHERLANDS

TYPE OF IBE MEMBER

Associate member

FOUNDING DATE

1893

TYPE OF ORGANISATION

Donors (55,000) and volunteers (35,000); staff (20); no members

RANGE OF OPERATION

mainly local

The NEF is committed to the battle against epilepsy and its consequences by:

- Contributing to more knowledge and better treatment of epilepsy
- Helping people with epilepsy to achieve an optimal quality of life

The NEF therefore

- Subsidizes epilepsy research, holds a professorial chair in epilepsy and stimulates education of professionals in the field of epilepsy
- Provides information on epilepsy: for people with epilepsy, epilepsy care professionals and general public
- Provides services: special holidays for people with severe epilepsy, grants for other epilepsy organizations and lobby

WEBSITES:

www.epilepie.nl

www.epilepsiefonds.nl

www.detegenaanval.nl

NATIONAL EPILEPSY SYMPOSIUM 2010



Dr. Erwin van Vliet receives the First Harry Meinardi award for the best thesis in epilepsy research from Prof. Jaap Troost, chair of the Scientific Advisory Board of the NEF.

CONTACT DETAILS

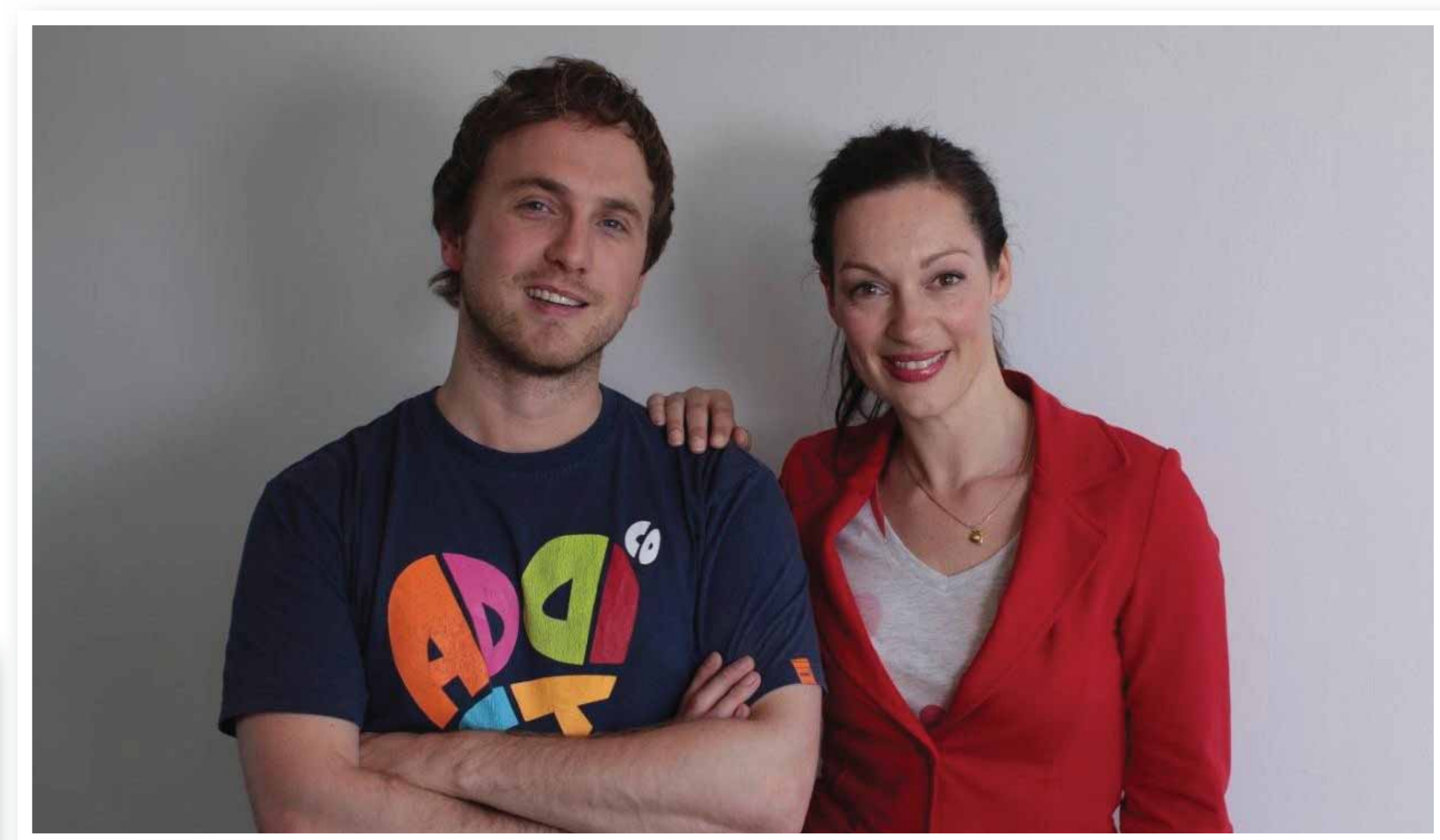
National Epilepsie Fonds/De Macht van het Kleine,
Postbus 270, 3990 GB
Houten, Netherlands.
T: +31 306 344 063,
info@epilepsiefonds.nl

PETITION IN DUTCH PARLIAMENT



NEF supported the political lobby to skip the budget cuts for the special epilepsy schools and their national support organization for children with epilepsy in primary schools. The government has delayed the plans.

EPILEPSY CAMPAIGN



Rick (boy above left) plays the leading part in the new campaign 'With epilepsy you never know' that focuses on the unpredictability of epilepsy. Miryanna is a Dutch actress who supports Rick in talking about his epilepsy with his friends (communication instruments: TV commercial, ads in national newspaper, TV talk show).

COUNTERATTACK AGAINST EPILEPSY

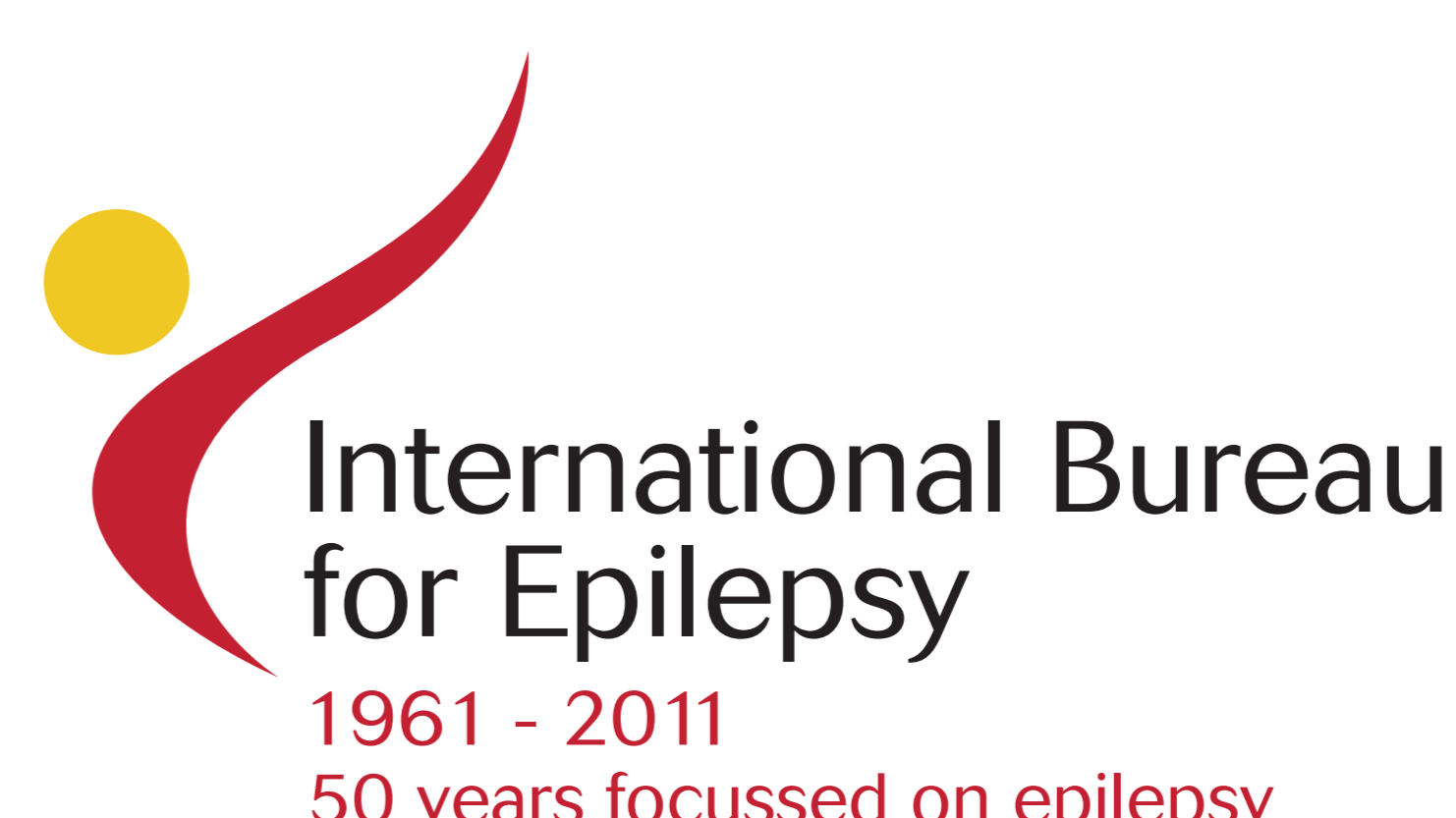
FIT TO FINISH
Vele sporters komen tijdens Fit to Finish in actie voor De Tegenaanval. Dit unieke evenement, waar tijdens de grote finalereden vier sporten bij elkaar komen, vindt plaats in het historische gebied van de Geuzen Parken nabij Eindhoven.

MEER INFO?
Het Nationaal Epilepsie Fonds zet zich al meer dan honderd jaar in voor mensen met epilepsie.

WIL JE MET MIJ?
in de aanval tegen epilepsie

DE TEGEN AANVAL

New fundraising program aimed at individuals to organize their own fundraising event. Goal: 250 fundraising events in 2011.



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPILEPSY SCOTLAND, UK



Epilepsy Scotland – striving for a better deal for people with epilepsy

We represent more than 40,000 people with epilepsy in Scotland to ensure their voice is heard. We have been working hard on a number of issues to make life better, fairer and safer for people with epilepsy, their families and carers.

Established in 1954, Epilepsy Scotland is a full and founder member of IBE. Our membership includes hundreds of individuals, organisations and professionals involved in epilepsy care. Their support and help ensures epilepsy has a powerful voice.

WE OFFER A RANGE OF SERVICES AND SUPPORT

- Helpline: 0808 800 2 200 which includes a translation line for different languages and a type talk service for people with hearing impairments.
- Web site: www.epilepsyscotland.org.uk
- Text service: 07786 209 501
- Information guides and fact sheets
- Facebook, Blog and Twitter
- Training courses and forums
- One-to-one support and activity days
- Newsletters and policy briefings
- Public awareness campaigns and information events
- Support for the Scottish Parliament's Cross-Party Group on Epilepsy

WE PARTNER WITH OTHERS TO BRING CHANGE FOR PEOPLE WITH EPILEPSY:

- Scottish Ambulance Service has created new ways to give emergency care
- Politicians (MSPs) have supported our efforts to protect specialist nurse posts
- The NHS has accepted our recommendations for a new set of clinical standards
- Nurseries and primary schools can use our illustrated epilepsy booklets for children
- Probationer police officers now have epilepsy-awareness training from us
- The Crown Office will consider epilepsy-related factors for cases going to court
- Taxi drivers have a handy epilepsy first card in case a passenger has a seizure

CONTACT DETAILS

Helpline: 0808 800 2200
www.epilepsyscotland.org.uk
Email: enquiries@epilepsyscotland.org.uk
Text: 07786 209 501
Tel: + 44 (0)141 427 4911
Fax: +44 (0)141 419 1709
Joint Epilepsy Council of the UK and Ireland member

Among many of the successful partnerships projects this year, we developed the United Kingdom's first Epilepsy and Occupational Health guide:

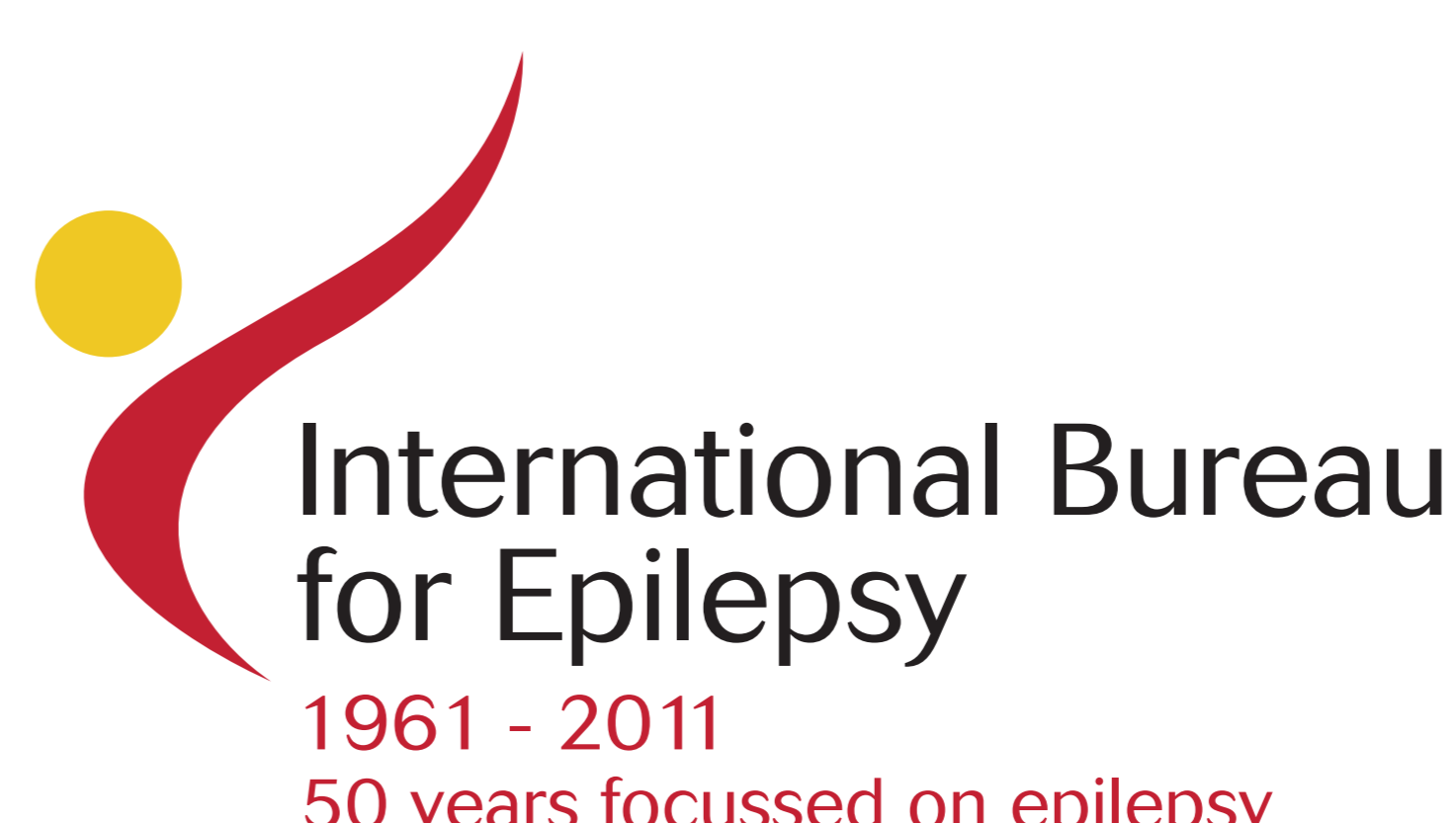
- Created by a working group of experts in the public, private and voluntary sectors
- Launched by the Deputy First Minister in the Scottish Parliament
- This pdf resource is available on our website: www.epilepsyscotland.org.uk

We also have two new champions for epilepsy:

- Teen model Rosie Gilmour, who has epilepsy herself
- Scotland/ Glasgow Warriors rugby player, Graeme Morrison whose brother has epilepsy

OVER THE NEXT 12 MONTHS WE HOPE TO:

- Establish a new epilepsy and the law working group to develop a legal guide
- Make epilepsy awareness part of the training curriculum for student teachers



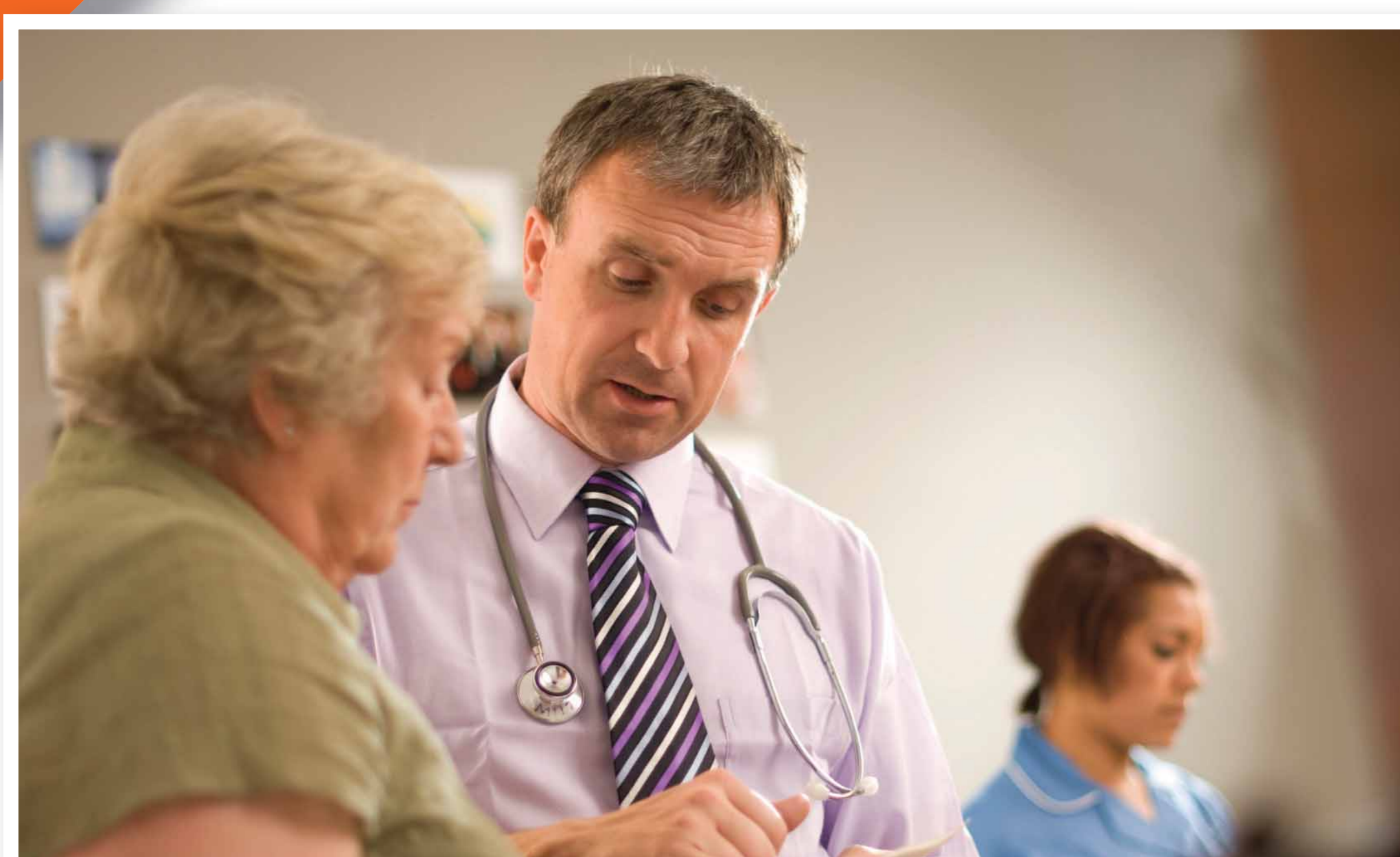
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPILEPSY SOCIETY (FORMER NATIONAL SOCIETY FOR EPILEPSY), UK



Our vision is a full life for everyone affected by epilepsy, by promoting research, education and public awareness and by delivering specialist medical care and support services.

The Epilepsy Society's ambitious programme of fundraising and campaigning seeks to raise awareness and understanding of epilepsy, whilst securing vital funds to underpin all aspects of our work.

2011 - EPILEPSY SOCIETY

On 1 January 2011, we took on our new working name, Epilepsy Society.

By shortening and simplifying our name, we hope to reach out to more people affected by epilepsy and, together, help fulfil our vision of 'a full life for everyone affected by epilepsy'. We changed the way we look from NSE orange to Epilepsy Society.

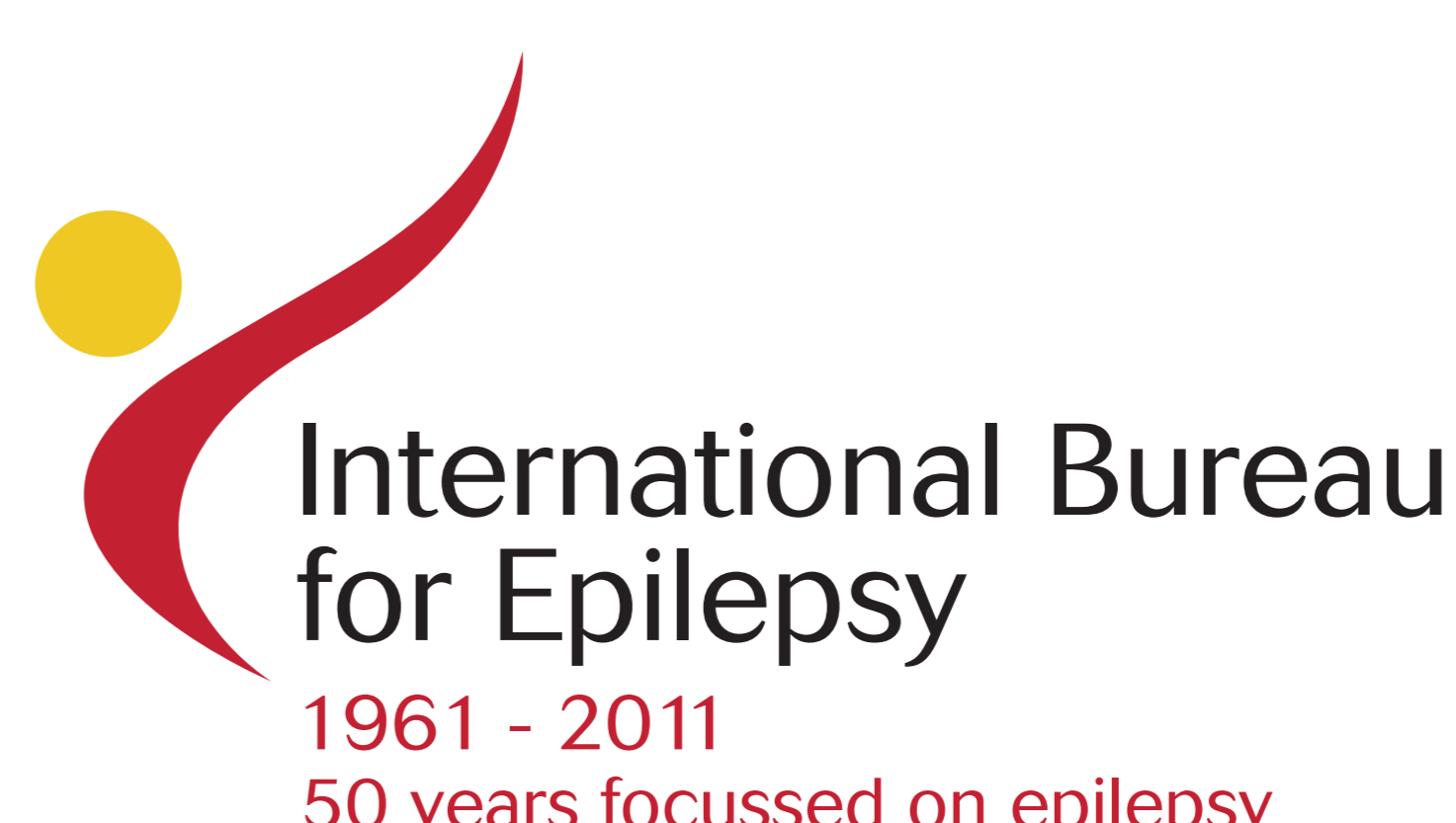
We remain the only UK epilepsy charity to deliver a full programme of medical research in epilepsy. And we continue to provide expert medical care, residential care and information services including our leaflets and videos, helpline and information clinics in NHS hospitals.

Now we want to work together with people affected by epilepsy on campaigns and awareness raising to influence society, government and the media. People affected by epilepsy still face too many challenges to living a full life, and we want to work with you to make that difference.



CONTACT DETAILS

National Society for Epilepsy
Chesham Lane, Chalfont St
Peter, Buckinghamshire
SL9 0RJ, UK.
T: +44 149 460 1300
www.epilepsysociety.org.uk



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ESTONIAN EPILEPSY ASSOCIATION



POPULATION:

1,332,893 (July 2005 est.)

TYPE OF IBE MEMBER

Full member

Officially the Republic of Estonia is a state in the Baltic region of Northern Europe. It is bordered to the north by the Gulf of Finland, to the west by the Baltic Sea, to the south by Latvia (343 km), and to the east by the Lake Peipsi and the Russian Federation (338.6 km). Across the Baltic Sea lies Sweden in the west and Finland in the north. The territory of Estonia covers 45,227 km² (17,462 sq mi), and is influenced by a temperate seasonal climate.

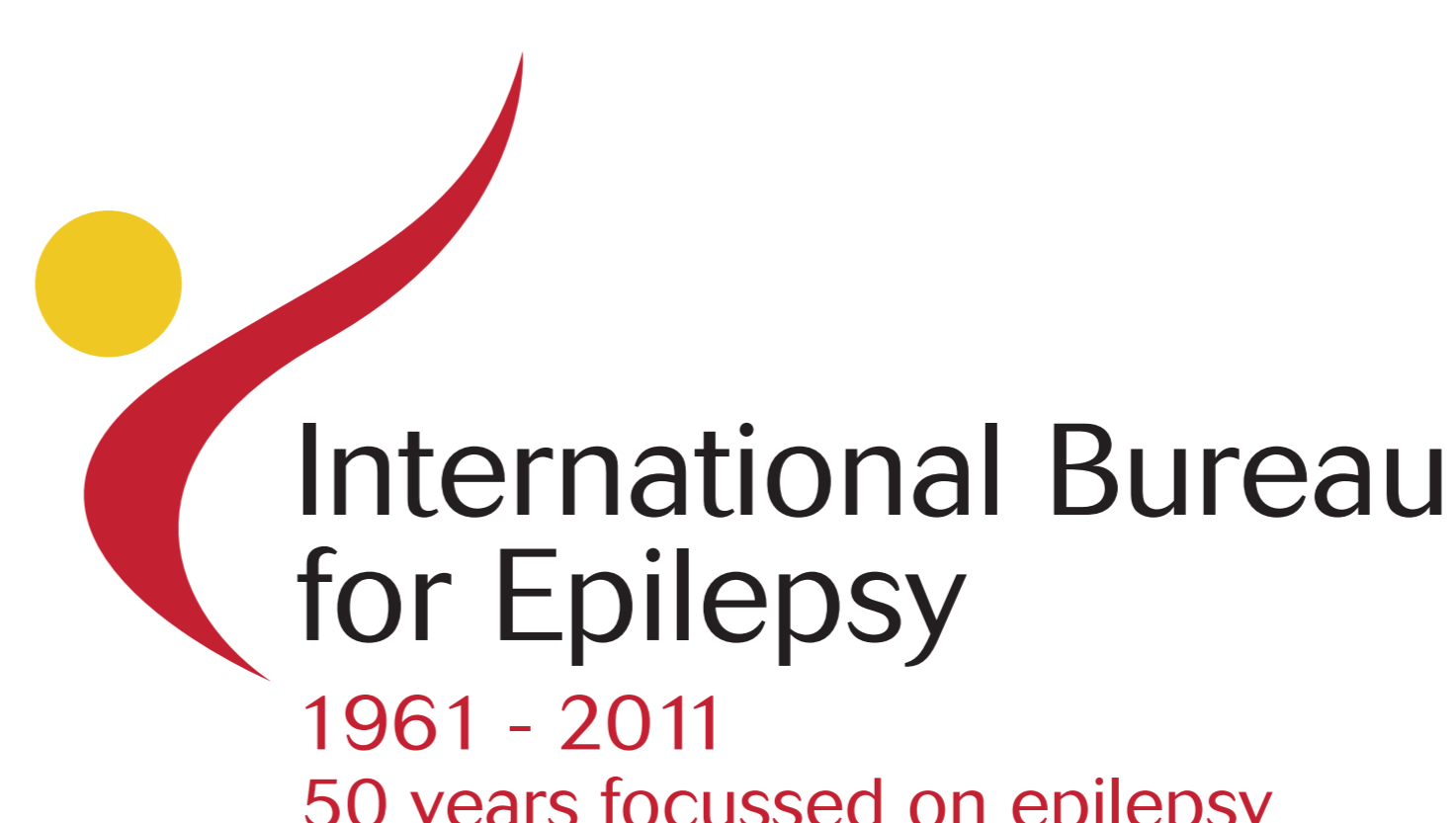
Estonia is a democratic parliamentary republic and is divided into 15 counties. The capital and largest city is Tallinn. With a population of 1.34 million, Estonia is one of the least-populous members of the European Union, Eurozone and NATO. Today, Estonia has the highest GDP per person of any country that used to be part of the Soviet Union. Estonia is listed as a High-Income Economy by the World Bank and a High-income OECD member. The United Nations lists Estonia as a developed country with a Human Development Index of "Very High". The country is also ranked highly for press freedom, economic freedom, democracy and political freedom and education.

Healthcare in Estonia is supervised by the Ministry of Social Affairs and funded by general taxation through the National Health Service.



CONTACT DETAILS

Estonian Epilepsy Association
Puusepp St 2,
51014 Tartu, Estonia.
T: +372 731 8515
epilepsialiit@hotmail.ee
Contact: Dr Andreas Oun



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

DEUTSCHE EPILEPSIEVEREINIGUNG E.V. – GERMANY



COUNTRY OF OPERATION

Germany

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1988

TYPE OF ORGANISATION

Individual Membership, about 1,000 members

RANGE OF OPERATION

National

MISSION:

German Epilepsy Association (DE) is a national non-profit and non-government organisation, whose aim is to enhance the quality of life of persons affected by epilepsy through means of information, education and awareness initiatives that build understanding and acceptance of epilepsy. Our mission is to counteract stigma and discrimination of people with epilepsy and their families as well as to strengthen people with epilepsy by encouraging them to deal epilepsy as self-confidently and as self-consciously as possible.

GOALS:

- To increase public awareness of epilepsy as a brain disorder most frequent in the world. In Germany about 600,000 persons are affected by epilepsy.
- To promote public and professional education about epilepsy.
- To identify the needs and special needs of people with epilepsy and their family members.
- To achieve equal rights for people with epilepsy in all aspects of life
- To encourage governments of health to address the needs of treatment, including awareness, education, diagnosis, treatment care, services and prevention.
- To encourage governments of communities to support people with epilepsy of every age and their families at all social aspects.

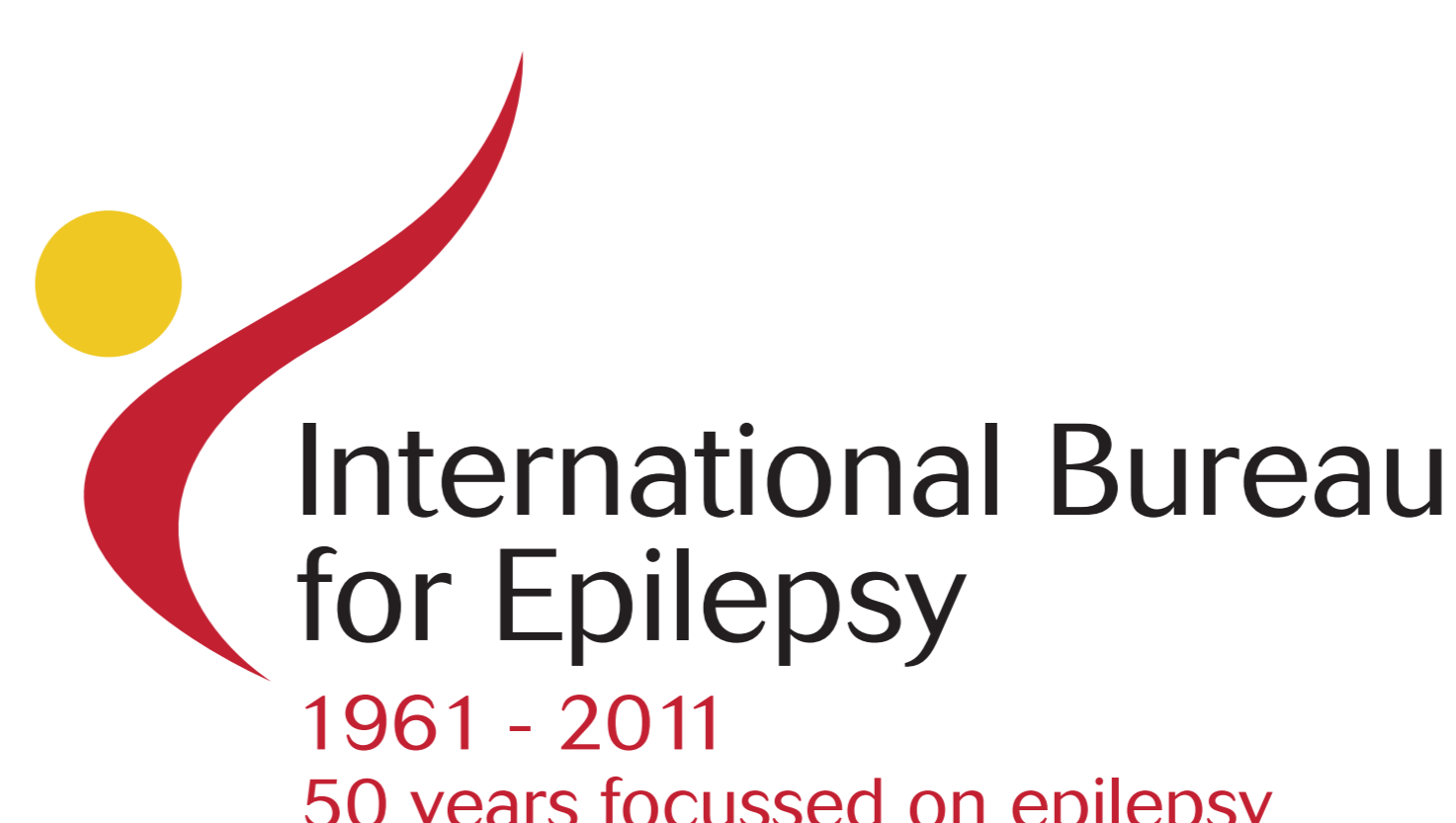
REGULAR ANNUAL ACTIVITIES:

- We give free information and advice to everyone, also by special phone hotline
- We give expert advice and connect people in the whole country in epilepsy matters
- We gather information and experience in all epilepsy matters
- We offer seminars and work-shops on self-control, we organise work shops for parents of children with epilepsy, for leaders of self-help groups as well as on various and important subjects for affected and differently concerned people.
- We hold our annual conference to inform our members and delegates from self-help groups on special topics and to promote exchange of experience
- We produce our journal *einfälle* (4/12) including actual information on epilepsy treatment in Germany, interesting topics and news and activities throughout German epilepsy self-help initiatives. By means of our journal *einfälle* we are able to support and give information on research.

Since 1996 we organise the German Epilepsy Day in collaboration with many self help groups in Germany. Together we perform various activities throughout Germany. Every year we perform a concerted event in cooperation with the German Section of the International League against Epilepsy and with Stiftung Michael (Foundation) to raise good awareness.

CONTACT DETAILS

Annemarie Söhnel, Zillestr. 102,
Phone 0049-30-342 44 14,
Fax -342 44 66,
anne.soehnel@epilepsie.sh
www.epilepsie.sh



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

GRAVESEND EPILEPSY NETWORK, UK



Gravesend Epilepsy Network (GEN) is an independently registered charity, established 30 years ago to give direct help, information and support to people with epilepsy and their families. All work is carried out by unpaid volunteers dedicated to helping those affected by the condition.

GEN is recognised as one of the leading epilepsy support groups in the UK. We are members of the Joint Epilepsy Council, the International Bureau for Epilepsy and the International League Against Epilepsy. We have been involved in many conferences around Europe. Members of the group have also given presentations to several UK conferences, also to local organisations including Social Services, local hospitals and the emergency services.

On 2 separate occasions GEN have compiled, printed and distributed free 'Information Packs' about epilepsy and sent them to all schools, GP's and medical Practices throughout Northwest Kent.

The charity meets regularly for coffee mornings and more formal monthly meetings, where we invite speakers along to talk on many epilepsy related topics both medical and social. We have social evenings of quizzes, picnics, meals out, and chats to 'air views'. We have taken members away on long weekend breaks and provided a safe, supportive environment where people with epilepsy and their carers have been able to relax and enjoy themselves, many for the first time in their lives. We have donated over £100,000 to recognised epilepsy research projects over the years. Members have participated in research programmes, the making of television programmes and education & training videos. Some have also been chosen to represent the UK at a number of European conferences in the past.

Members gave evidence to an All Party Parliamentary Group investigation at the House of Lords in 2007, which resulted in a Parliamentary report entitled 'Wasted Money, Wasted Lives' highlighting the cost of badly resourced epilepsy services in the community. Several quotes from our

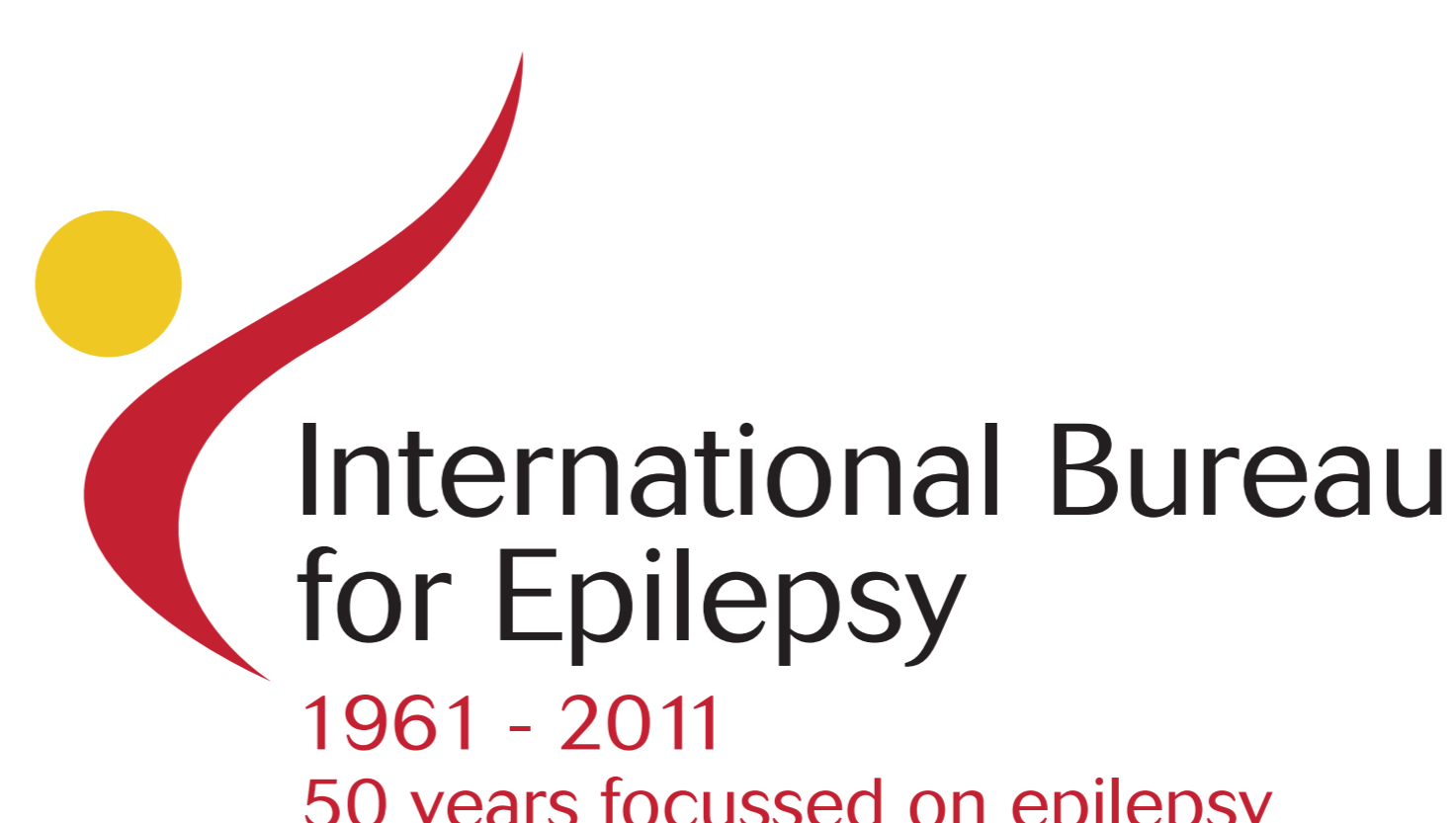
evidence were reproduced in the report.

Also, thanks to our association with IBE, we were the only English Epilepsy charity in attendance at Strasbourg on 14/15 February 2011 for the Launch of European Epilepsy Day. Although we sent a personalised email to all 72 English MEP's, inviting them to attend the launch, we were only able to personally meet 3 on the day. However, these 3 have proven to be very positive contacts. Glenis Willmott who is the leader of the UK Labour party in Europe promised us that Epilepsy would be the next major medical condition that the EU would take as its next project. Peter Skinner has been elected as Vice Chair of the European Advocates for Epilepsy Group.

When epilepsy is first diagnosed it is quite shattering, not only to the individual, but to the whole family. A driving licence is often forfeited immediately, and some leisure activities have to be curtailed. Doctors, so busy, often do not have the time to sit and explain, and this is where our trained Counsellor is available to help. She can give information regarding side effects of drugs, help by indicating what benefits may be applied for, and by just being there for people to talk to. She helped to set up a patients help desk at the National Hospital for Neurology in London and 2 others in North West Kent.

CONTACT DETAILS

Gravesend Epilepsy Network
13 St George's Crescent
Gravesend DA12 4AR, UK.
T/F: +44 147 435 1673
gravesendepilepsy@supanet.com
Contact persons: Fred and Lynn Savill



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ASSOCIATION OF HUNGARIAN PEOPLE LIVING WITH EPILEPSY



The Magyar Epilepsziás Betegek J v jéért Egyesület (Association of Hungarian People Living with Epilepsy) was founded in November 2004, and has been working as a registered public association since 23. 03. 2005.

On the 24th of February 2010 we launched our new and improved website. Its main purpose is to give up-to-date information and assistance to people living with epilepsy and their families. The website has a "Doctor's answer" column where patients can get their medical questions answered, but assistance is also provided to those who seek legal or moral advice – all this in full privacy.

For the last couple of months we have been working on a small informative publication entitled "Epilepsy my secret companion". Our purpose with it would be to properly inform people about this condition, and to dissolve any misbeliefs people have concerning epilepsy. Unfortunately due to lack of funds we have not yet been able to publish the print ready publication.

We believe that not only adults but also children need to be properly informed about epilepsy. As a result with the help of specialist, we have been holding informative classes about epilepsy in grade-schools. We hope this way the students will be more open towards both epilepsy affected children and adults.

All though we have come a long way since the beginning, we are still facing major difficulties such as the lack of a head office due to the shortage of funds. We also have difficulties due to the fact that the work done in our association is being done voluntarily. The lack of a stable financial background and a head office makes the recruitment very hard, and thus with less volunteers we have, the less work we can do. But the biggest difficulty we face is the never fading discrimination. People living with epilepsy are forced to lie about their condition in order to keep their jobs. There are many celebrities living with epilepsy who are hiding in shadows because of this fear, and who are unwilling to step up and show that even those who live with this condition are capable of living a happy and full life.

Over the years we have held several artistic competitions mainly in literature and graphic art, in hope of boosting not only the self confidence but also the creativity of people living with epilepsy throughout Hungary. This way we were able to give a chance of publishing these artists' artwork and also give them small symbolical prizes for their beautiful works.

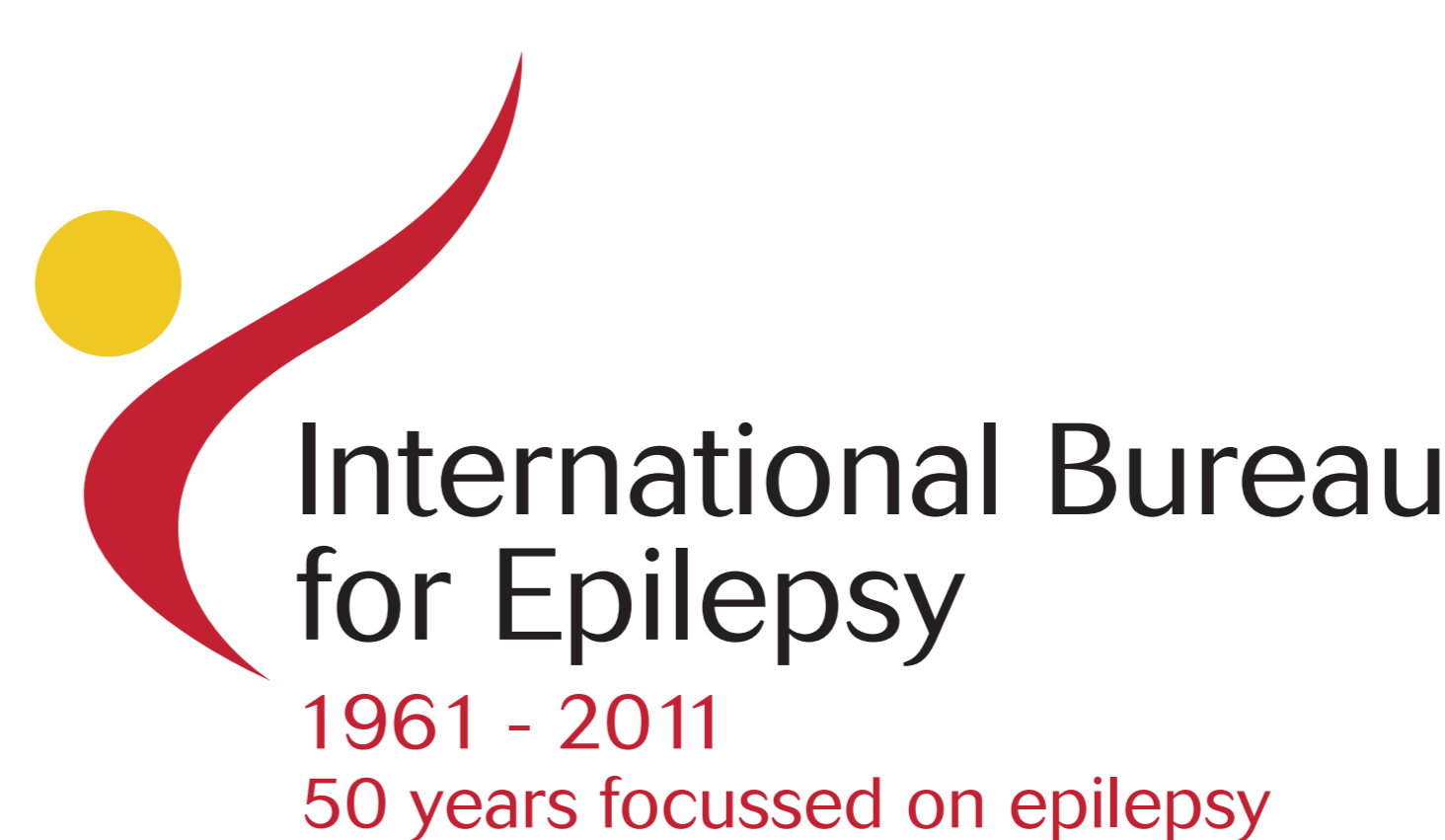
The year 2011 has been a very prosperous year so far. We had the chance to participate in the European Epilepsy Day in Strasbourg, during which we presented our association, its work, its purposes and the difficulties we face.

After this major event we organized and hosted the 16th National Epilepsy Day held in Budapest. The event was a great success.



CONTACT DETAILS

Association for Future of People with Epilepsy in Hungary, Lenkey u.7,
Budapest H 1184,
Hungary
solesz65@gmail.com
Contact person: Mr Zsolt Szabó



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

LAUF, THE ICELANDIC EPILEPSY ASSOCIATION



POPULATION:

Iceland has a population of circa 320,000.

TYPE OF IBE MEMBER

Full member

Iceland is a volcanic island in the North Atlantic Ocean east of Greenland and immediately south of the Arctic Circle. About 79% of Iceland's land area, which is of recent volcanic origin, consists of glaciers, lakes, a mountainous lava desert (highest elevation 2,000 meters--6,590 ft.-above sea level), and other wasteland. The inhabited areas are on the coast, particularly in the southwest where about 60% of the population lives. Because of the Gulf Stream's moderating influence, the climate is characterized by damp, cool summers and relatively mild but windy winters.

ABOUT ICELANDIC SURNAMES!

Most Icelanders are descendants of Norwegian settlers and Celts from the British Isles. According to Icelandic Government statistics, 94% of the nation's inhabitants live in urban areas (localities with populations greater than 200) and about 63% live in the Reykjavik metropolitan area.

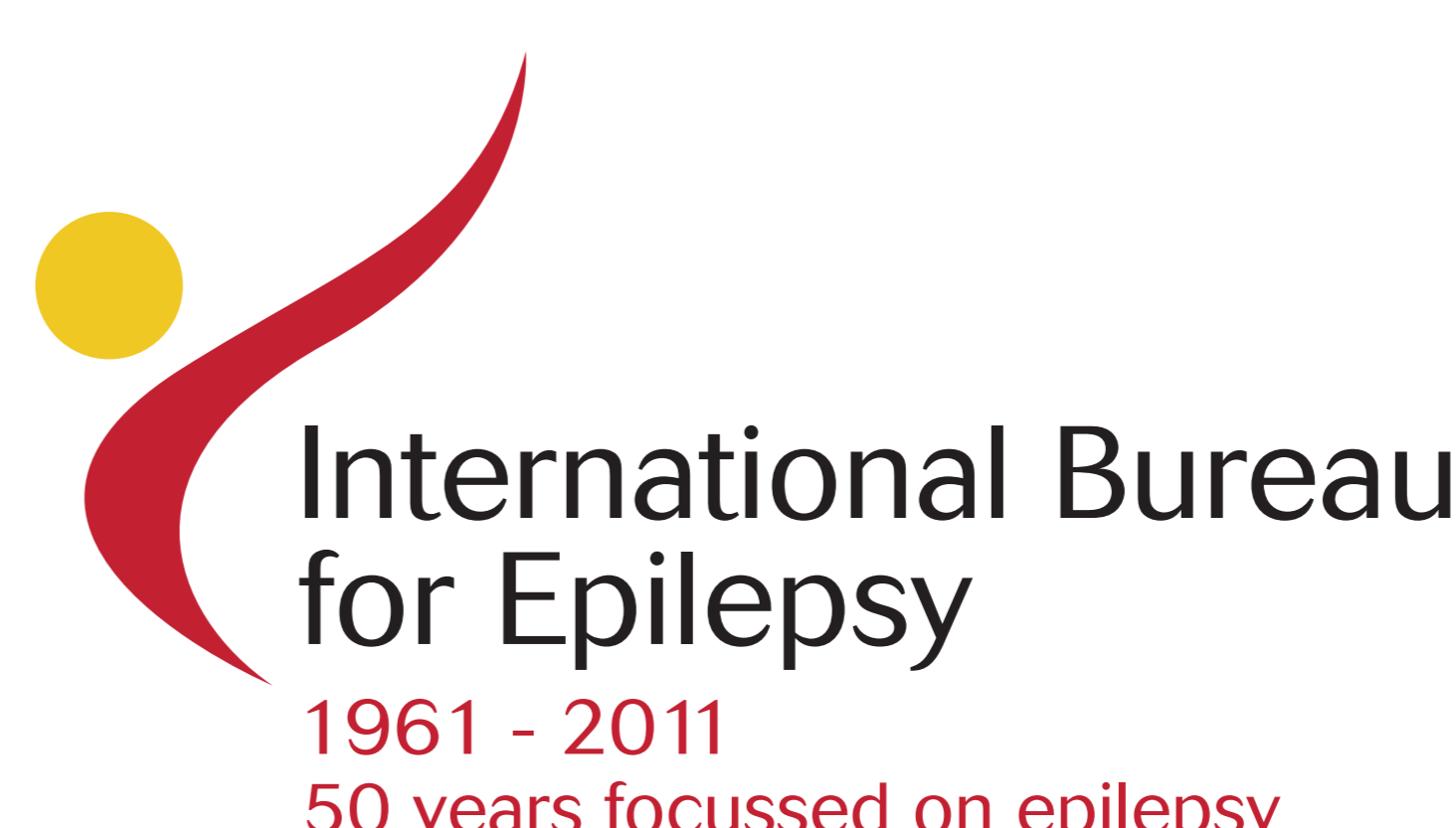
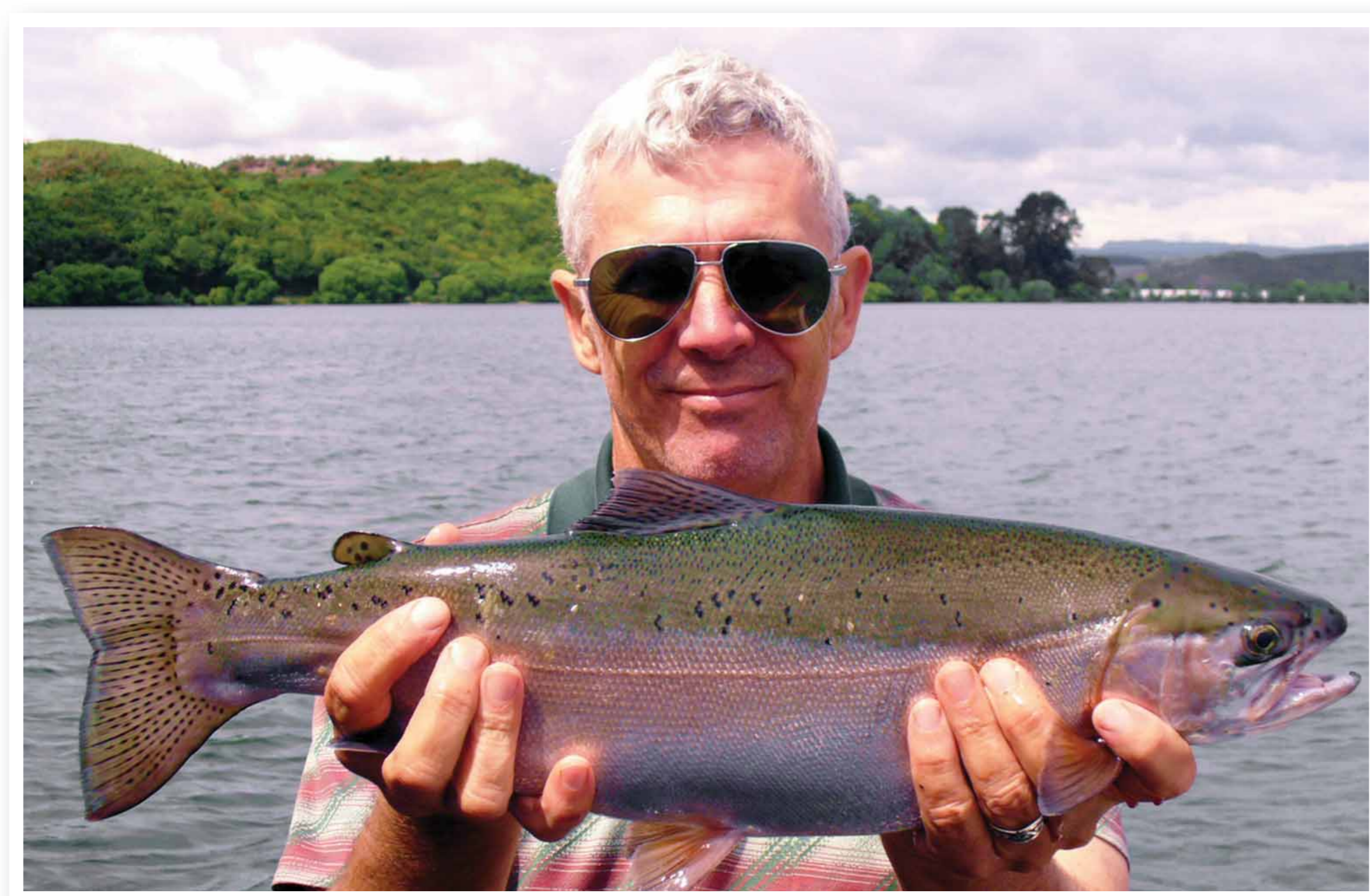
Most Icelandic surnames are based on patronymy, or the adoption of the father's first given name. For example, Magnus and Anna, children of a man named Petur, would hold the surname Petursson and Petursdottir, respectively. Magnus' children, in turn, would inherit the surname Magnusson or Magnusdottir, while Anna's children would claim their father's first given name as their surname. Women normally maintain their original surnames after marriage. This system of surnames is required by law, except for the descendants of those who had acquired family names before 1913. Because of its small size and relative homogeneity, Iceland holds all the characteristics of a very close-knit society.

CONTACT DETAILS

LAUF, The Icelandic Epilepsy Association,
Hatun 10b, 105,
Reykjavik, Iceland.
T: +354 551 4570
lauf@vortex.is
Contact: Ms Margret Njalsdottir

HEALTHCARE IN ICELAND

Iceland has universal health care. The health care system is largely paid for by taxes (85%) and to some extent by service fees (15%) and is administrated by The Ministry of Health. A considerable portion of government spending is assigned to healthcare. The country is divided into 7 health care regions. There is almost no private health insurance in Iceland, and no private hospitals.



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EYAL – ISRAEL EPILEPSY ASSOCIATION



EYAL is a non-profit organization founded in 1985 by a group of parents with the support of doctors, educators and other professionals for the purpose of improving services for the welfare of adults and children with epilepsy.

EYAL's board (volunteer) consists of people directly or indirectly affected by epilepsy who wish to help children and adults with epilepsy to overcome the obstacles and participate successfully in all walks of life.

EYAL's chairwoman is Tamar Vital, a public relations expert and a person with epilepsy from a young age.

EYAL is a member of the International Bureau of Epilepsy (IBE) and is in touch with various epilepsy support organizations throughout the world. EYAL concentrates its efforts on identifying the needs of people with epilepsy and fulfilling these needs. Therefore, we work on the individual, community and national levels.

In our capacity as the only Israeli epilepsy association, we act as a lobbying group that must work to influence the country's decision-makers in order to fulfill the needs of people living with epilepsy.

EYAL relies for its support on private donations and foundation grants, as well as on the symbolic annual membership fee of 200 NIS per family. The membership fee is a small amount for each of us to contribute, but is substantial for EYAL.

EYAL OFFERS:

- Updated and accurate information about epilepsy
- Hotline
- Guidance
- Specific and family treatment and professional advice
- Support groups
- Lectures and conferences to the general public
- Workshops

TARGET AUDIENCE:

People with epilepsy and their families

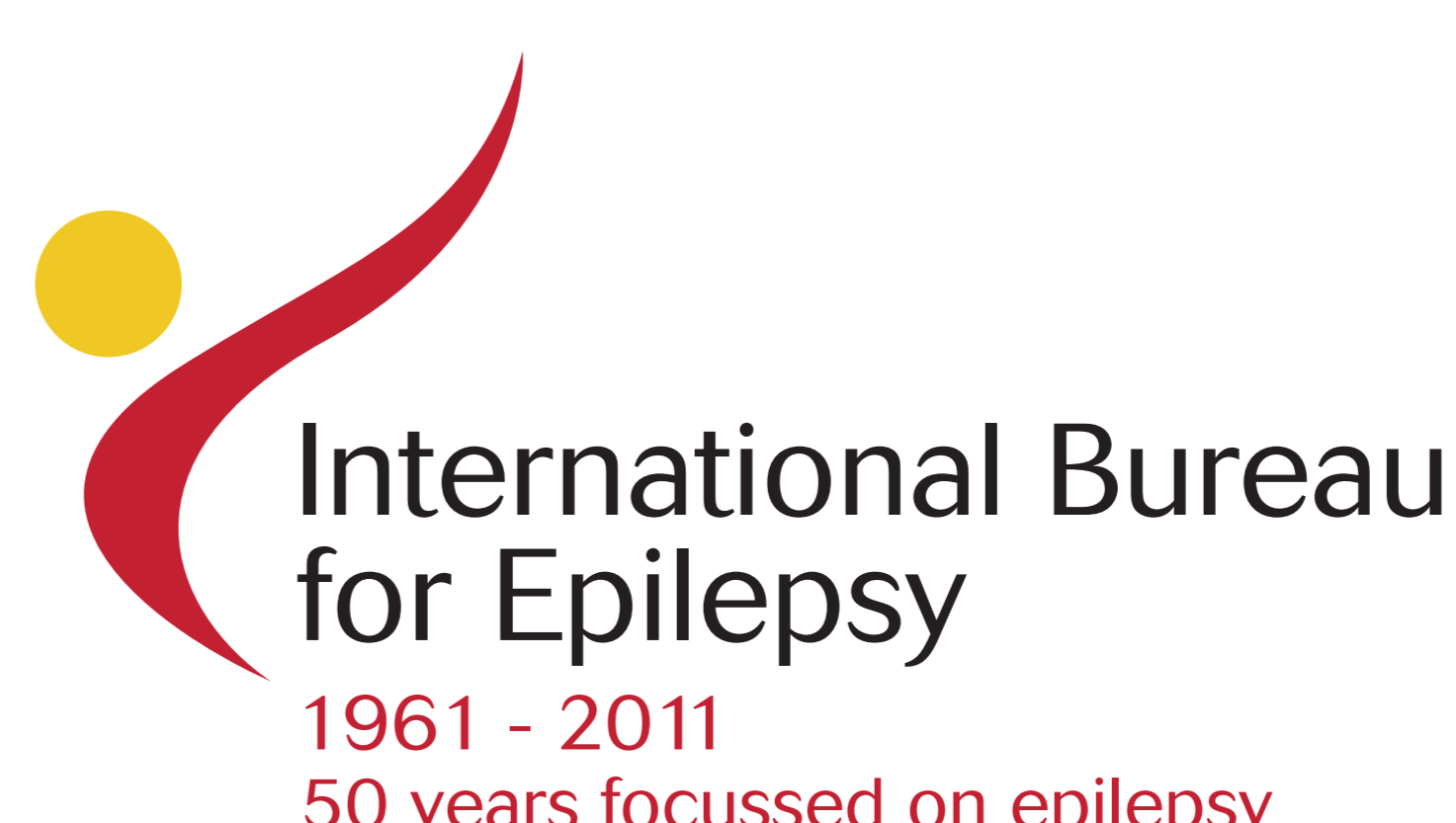
LANGUAGES:

Hebrew, Russian, English



CONTACT DETAILS

Israel Epilepsy Association
4 Avodat Yisrael, PO Box 1598,
Jerusalem 91014,
Israel.
T: +972 5000 283
E-mail: Epilepsy.il@gmail.com
Website: <http://www.epilepsy.org.il>



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ITALIAN ASSOCIATION AGAINST EPILEPSY AICE



TYPE OF IBE MEMBER

Full member

TYPE OF ORGANISATION

Organisational Membership & Individual

RANGE OF OPERATION

National

GOALS AND OBJECTIVES:

- promote the status of people with epilepsy by improving their self-sufficiency, autonomy and self-esteem thanks to better quality of services and the ending of discriminatory factors;
- support individual projects, combining medical with social aspects;
- encourage, in the equal dignity, the relationship between the doctor and the patient;
- develop appropriate financial foundation to support research on drug resistance;

The association consists of organizational regional membership (17) each with its individual membership (total of 2334). All those involved with the association work on a voluntary basis.

The main educational publication is the Notiziario AICE which is published quarterly and sent to AICE members and to other social and individual entities.

AICE's main commitment is to offer support to people with epilepsy.

AICE also holds public meetings three times a year: in February, May and October.

Finally – we welcome to all to Italy and to Rome to celebrate the 29th International Epilepsy Congress 2011!



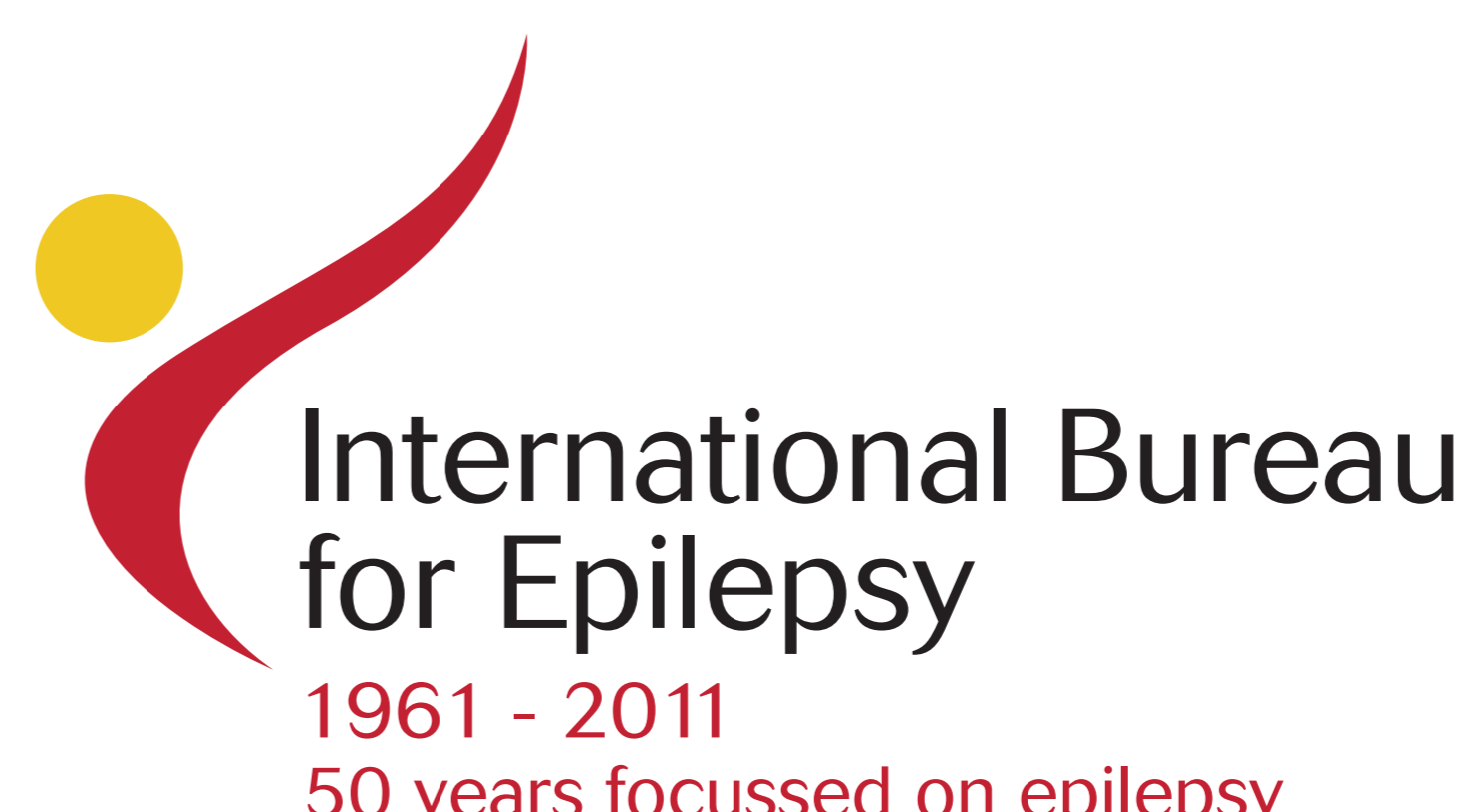
CONTACT DETAILS

Associazione Italiana contro l'Epilessia (AICE),
Via T Marino 7, 20121 Milan,
Italy.

T: +39 028 09 299

assaice@iperbole.bologna.it

Contact: Mr Giovanni Pesce



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPILEPSIJA AURA, FYR MACEDONIA



TYPE OF IBE MEMBER

Full member

FYR Macedonia, officially the Republic of Macedonia (transliterated: Republika Makedonija), is a country located in the central Balkan peninsula in Southeast Europe. It is one of the successor states of the former Yugoslavia, from which it declared independence in 1991.

A landlocked country, the Republic of Macedonia is bordered by Kosovo to the northwest, Serbia to the north, Bulgaria to the east, Greece to the south and Albania to the west. The country's capital is Skopje, with 506,926 inhabitants according to a 2002 census. Other cities include Bitola, Kumanovo, Prilep, Tetovo, Ohrid, Veles, Štip, Koani, Gostivar and Strumica. It has more than 50 lakes and sixteen mountains higher than 2,000 m (6,562 ft). Macedonia is a member of the UN and the Council of Europe. Since December 2005 it has also been a candidate for joining the European Union and has applied for NATO membership.

ECONOMY:

Recently ranked as the fourth 'best reformatory state' out of 178 countries ranked by the World Bank, Macedonia has undergone considerable economic reform since independence. The country has developed an open economy with trade accounting for more than 90% of GDP in recent years. Since 1996, Macedonia has witnessed steady, though slow, economic growth with GDP growing by 3.1% in 2005.

HEALTHCARE IN FYR MACEDONIA:

Some fifty years ago, the average life expectancy in Macedonia was 50 years. Today the average life expectancy is 72. The infant mortality rate has been constantly decreasing and is now 2.76%.

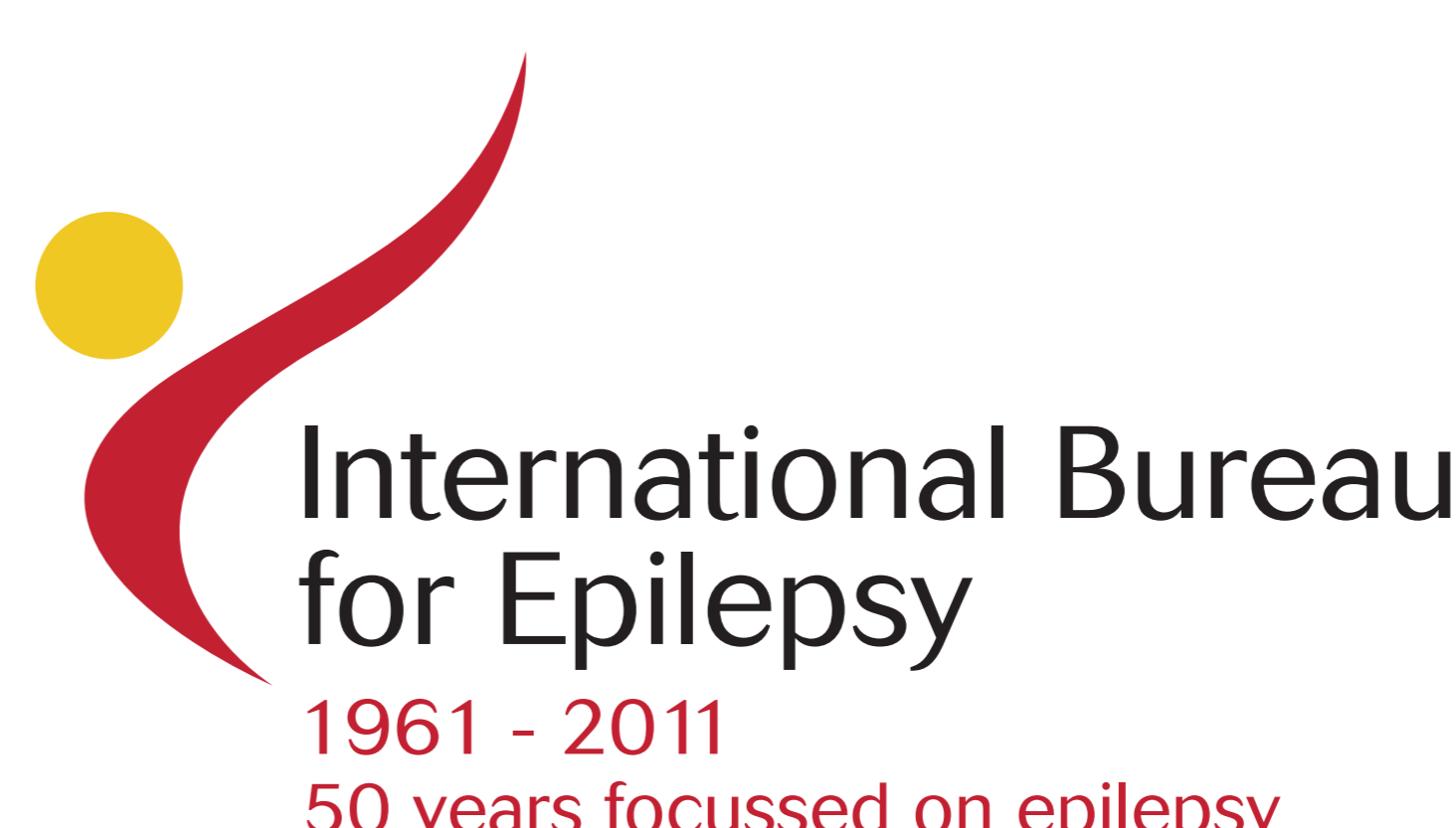
The citizens of Macedonia contribute part of their income to health and medical care. This has made it possible for the health service to be free and accessible to every citizen. The health service is provided through a widespread network of medical institutions.

The health care of the population of the Republic of Macedonia is provided in 17 health care institutions, and 16 medical centers with a big number of working units, clinics and offices distributed in the cities and around 300 medical units in the villages, one individual health station, one General City Hospital, 6 specialized hospitals, 9 institutions, 3 centers for special kinds of diseases, 3 natural clinics, one Clinical Center and one Dentistry Clinical Center, as well as 818 private health organizations.



CONTACT DETAILS

Epilepsija Aura, Ohridska 2,
Bitola, 7000, FYR Macedonia.
T/F: +389 472 55520
epilepsija_aura@yahoo.com
Contact: Mrs Ana Doneva



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

NORWEGIAN EPILEPSY ASSOCIATION (NEF) NORWAY



COUNTRY OF OPERATION

Norway

TYPE OF IBE MEMBER

Full member

FOUNDING DATE

1974

TYPE OF ORGANISATION

Individual membership

RANGE OF OPERATION

National

THE GOAL OF OUR ORGANISATION:

The Norwegian Epilepsy Association is based on three core values: Knowledge, Empowerment and Quality of life.

Our work for people with epilepsy and their next of kin includes a broad spectre of efforts targeting public awareness, politicians and regulators as well as people with epilepsy.

ESTIMATED NUMBER OF PEOPLE WITH EPILEPSY IN NORWAY:

1% of the population. Approximately 45000 people.

NUMBER OF MEMBERS:

About 5500 members

Special Activities 2011

SUMMER CAMP AND COURSES:

Every year we arrange summer camps for young people with epilepsy as well as one for families affected by epilepsy. We also arranged a series of courses for different target groups.

INFORMATION PROJECT FOR NEWLY DIAGNOSED:

In one of our biggest information projects, we signed cooperation agreements regarding information brochures, with all the hospitals/neurological departments in Norway. The hospitals now gets free brochures but are engaged to deliver information to all newly diagnosed people with epilepsy.

CONTACT DETAILS

Name: Secretary general, Stine Jakobsson Strømsø
Address: Karl Johans gate 7, 0154 Oslo, Norway
E-mail: nef@epilepsi.no stine@epilepsi.no
Website address: www.epilepsi.no

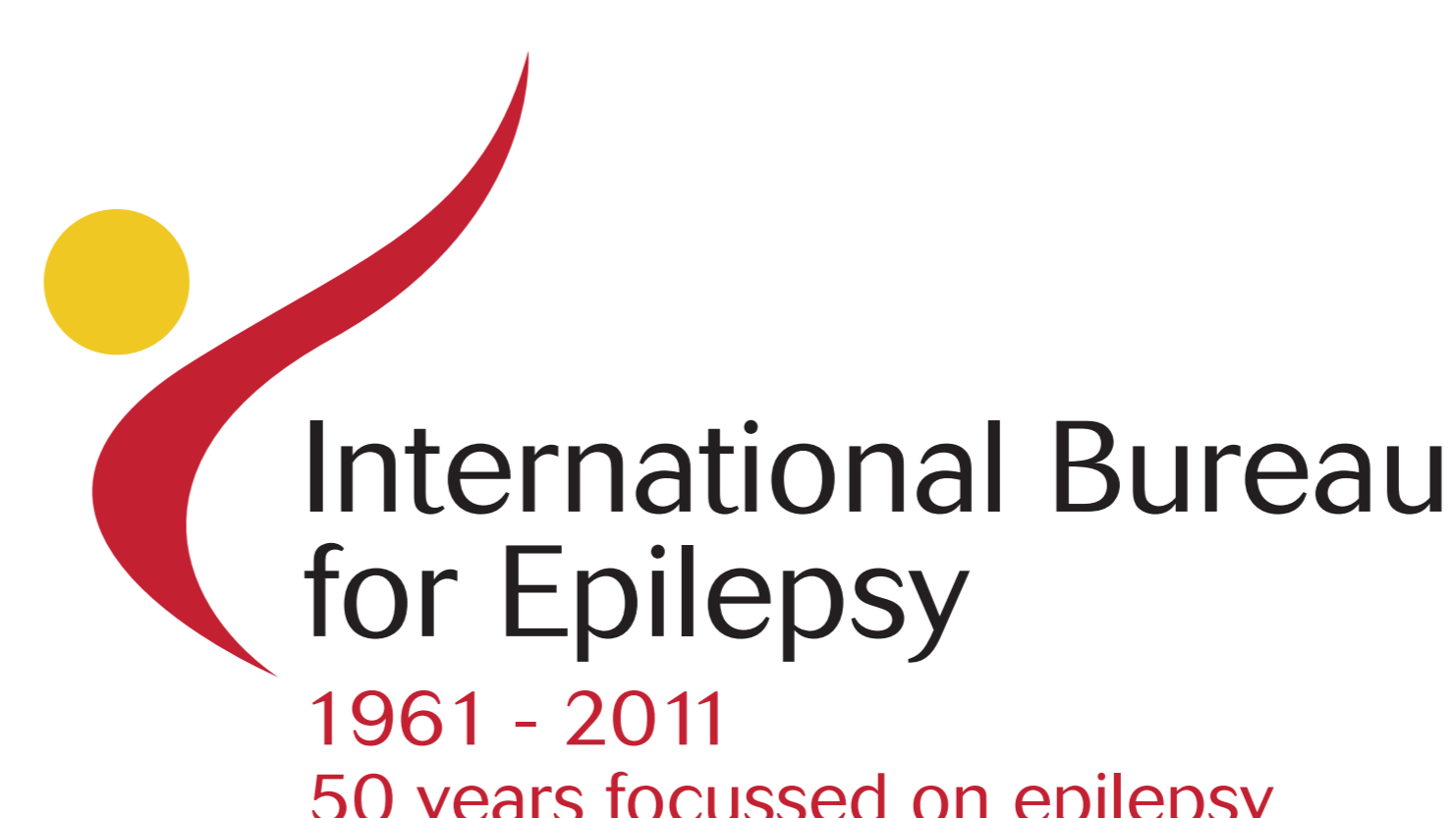
EPILEPSY STUNT:

In autumn 2011 the association will conduct a series of epilepsy stunts in the five largest cities in Norway. The stunt will include actors demonstrating epileptic seizures as well as information talks for people with epilepsy and others who are interested in the topic. The project is built on a similar activity from 2009 (see picture).



INFORMING THE POLICE:

Police officers are sometimes called instead of medical professionals in a seizure situation. Every year some people with epilepsy experiencing waking up in a cell after a seizure. This is not right! The Norwegian Epilepsy association therefore conducts a project with the intention of informing the police about seizures and first aid.



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

PAREPI, SWITZERLAND



EPILEPSY IN CHILDHOOD – A BIG CHALLENGE FOR PARENTS!

ParEpi is the Swiss Association for Parents of Children with Epilepsy.

Our goal is an optimal quality of life for the afflicted child and its parents:

- We counsel and impart information about the disease epilepsy.
- We arrange contacts between parents for the exchange of information.
- We organize events for parents and their relations.
- We arrange holiday camps for afflicted children.
- We work along the principle of empowerment.

ParEpi informs the public to increase the consideration for the afflicted people.

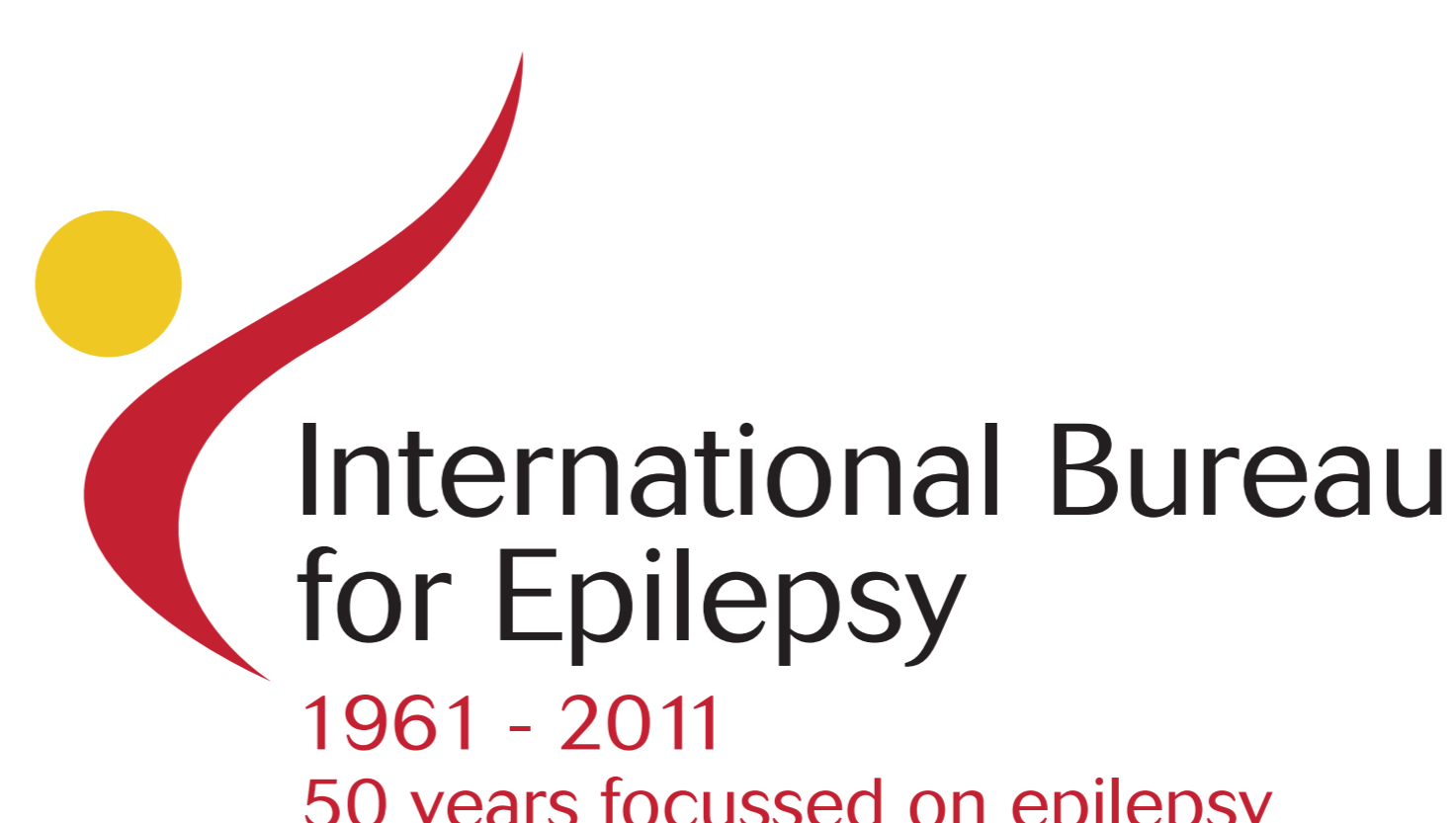
ParEpi is a union which was founded in 1970 and now counts almost 1,000 members. It finances itself through membership fees as well as through donations and it has a contract with the Swiss Federal Insurance Office (FSIO). It is licensed by ZEWO.

The main office of ParEpi is operatively led by Epi-Suisse, the Swiss Epilepsy Association.



CONTACT DETAILS

ParEpi
Seefeldstr. 84
CH-8008 Zürich
T +41 43 488 65 60
parepi@bluewin.ch



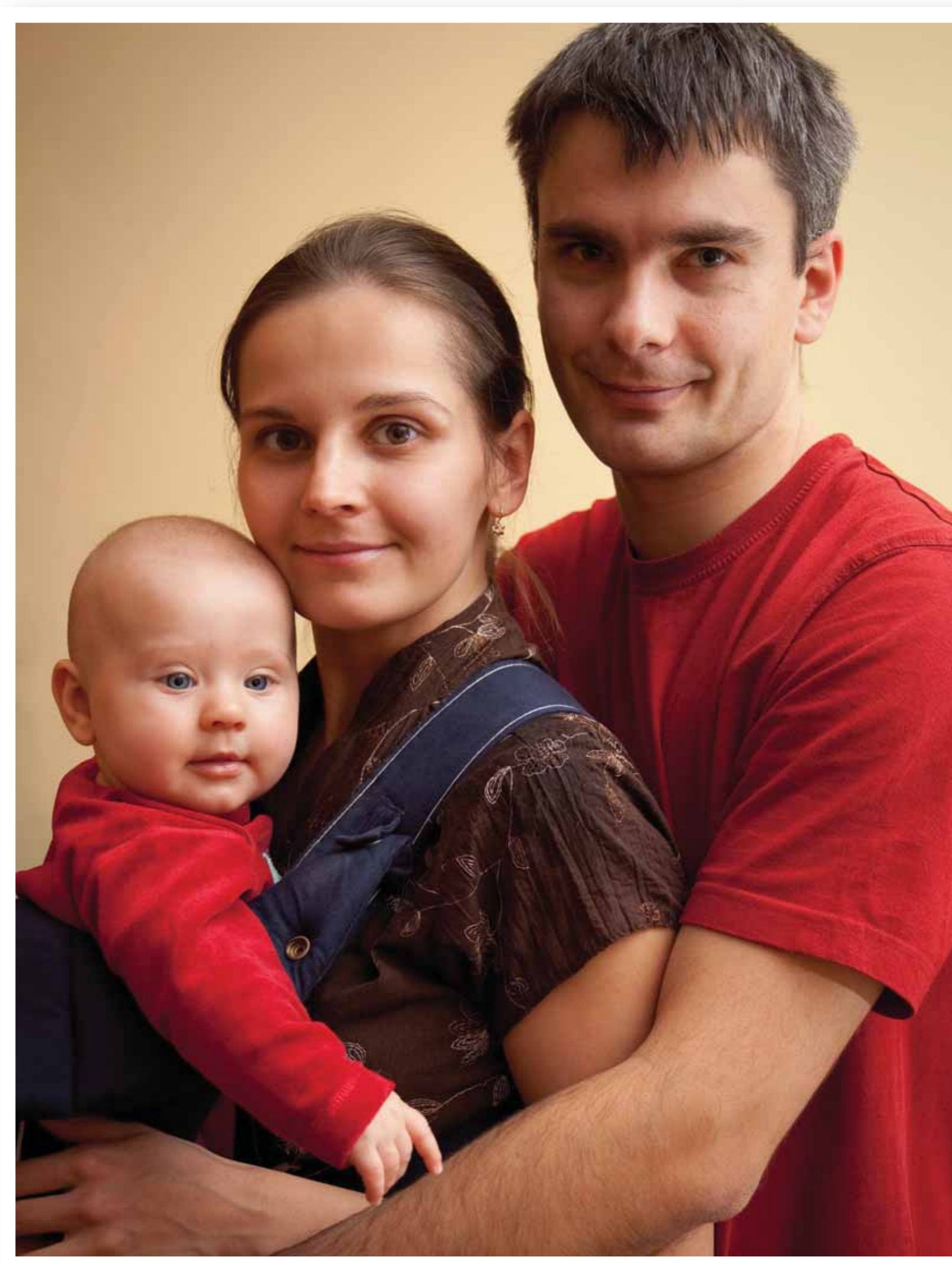
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

POLISH ASSOCIATION FOR PEOPLE SUFFERING FROM EPILEPSY



Polish Association for People Suffering from Epilepsy was founded in 1985 under different political and legal conditions (communist system) thanks to a group of people suffering from epilepsy that was headed by Mr. Tadeusz Zarebski. This group had to overcome a lot of barriers and bureaucratic difficulties.

In 1985 the Polish Association for People Suffering from Epilepsy obtained legal entity to work for people suffering from epilepsy in Poland, which counts for over 400 thousand persons.

Following legal recognition, the Polish Association for People Suffering from Epilepsy began creating regional branches and clubs for people with epilepsy. They took active part in legislative consultations: in 1991 a pioneering law on employment and rehabilitation of disabled persons was resolved. This law promotes employment of people suffering from epilepsy.

This association has been active for 26 years. The Polish Presidents: Lech Walesa and Aleksander Kwasniewski decorated the leaders of association with high state medals and Gold/Silver and Bronze Merit Crosses. Mr. Tadeusz Zarebski and Ms. Stanislawia Siedlecka obtained (the cross) Krzyz Kawalerski Orderu Odrodzenia Polski.

During 26 years of service the Association has conducted and conducts the following programs:

Program of rehabilitation coordinated by Mrs. Stanislawia Siedlecka, Secretary General. Over 100 rehabilitation periods were carried out with the participation of thousands of people with epilepsy and their families. The rehabilitation period lasts 14 days and is very popular as a form of integration, rehabilitation and exchange of experiences.

Program "APARAT EEG" (APPARATUS EEG) – serving as a support of medical units treating epilepsy. The association has bought 24 EEG machines, 2 videometry machines and other medical equipment. This equipment was delivered to hospitals, clinics and dispensaries in twenty cities throughout Poland.

Program of direct help to the poorest people suffering from epilepsy and their families whose only source of income is a nominal pension of \$250-300 monthly. A serious problem is unemployment for people with epilepsy and a reluctance of employers to employ them.

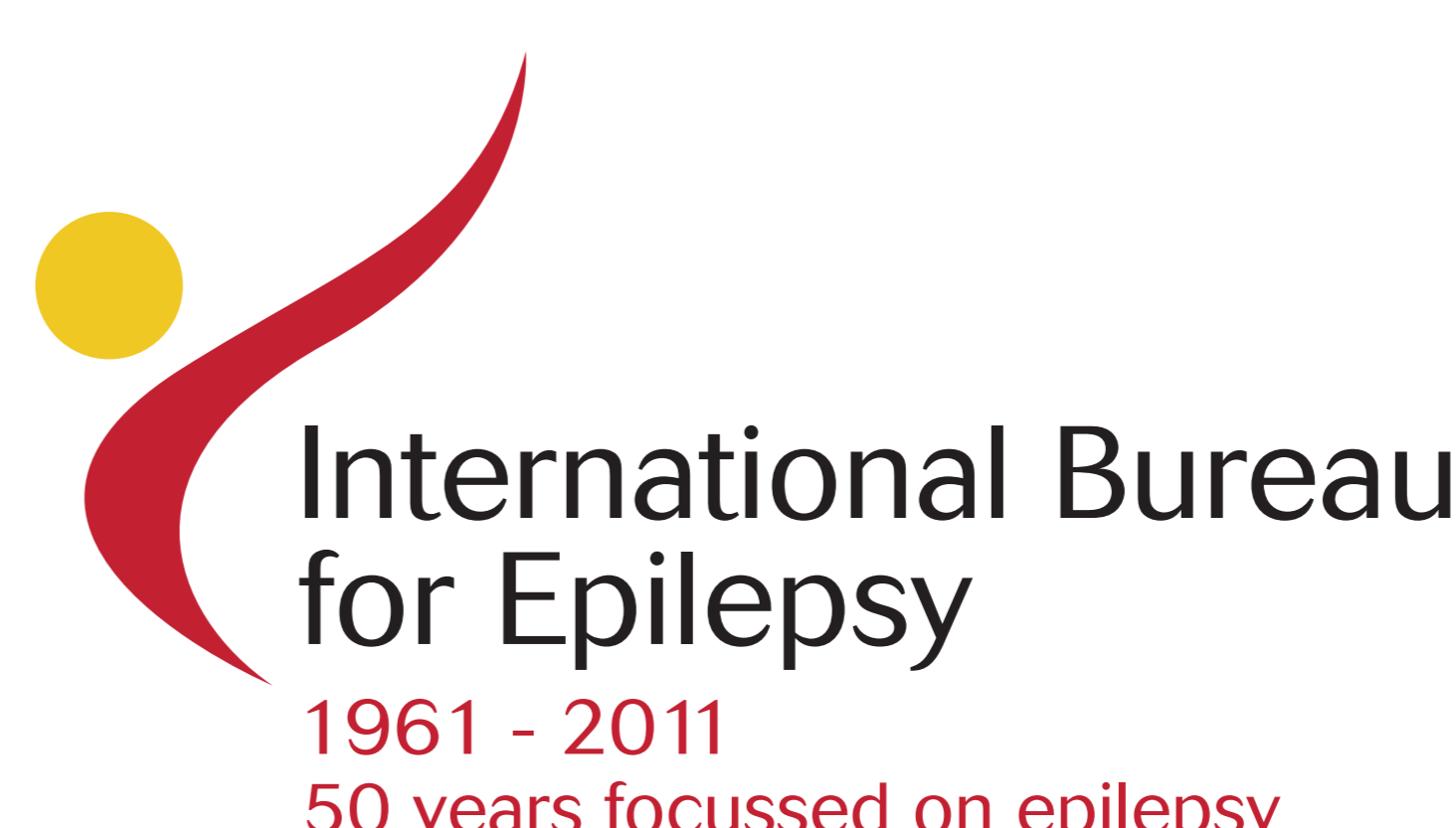
Program of health education in epilepsy – 2 guide books were published to change the image of epilepsy. The association organizes different integration events, conferences, seminars. For some years a Workshop for Occupational Therapy in Ozorkow has existed and every year an the action called "Zauwa Mnie" (See Me) is also organised.

In 1991 and 1993 the Polish Association for People Suffering from Epilepsy had an exchange programme for people with epilepsy with "IKAROS" in Belgium – Gent which was headed by Karel and Rosanne Blomme-Dorme.

In 2011 and in the future Polish Association for People Suffering from Epilepsy will try to continue the present programs if financially possible.

CONTACT DETAILS

Polish Association for People Suffering from Epilepsy,
Ul Fabryczna 57,
15 482 Bialystok, Poland.
T/F: +48 856 754 420



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EPI APFAPE (EPI), PORTUGAL



- EPI – Portuguese Association of Family, Friends and People with Epilepsy
- EPI was created on January's 2006 and is a Full Member of IBE, since November's 2007.
- EPI has a total of 798 associates; everyone can be an EPI's associate as an individual membership.
- EPI has a national range of operation, in three distinct zones: Oporto, Coimbra and Lisbon.

EPILEPSY NATIONAL DAY – 11 MARCH

The celebration of the Epilepsy's National Day – 11th March (date of the 1st meeting of general assembly) has promoted social dialogue and awareness of the general population for this disease that affects about 70,000 people in Portugal, eradicating discriminatory attitudes, through awareness campaigns and information.

ACTIVITIES

“Epilepsy TOUR: 12 hrs on the rails”

The Epilepsy TOUR consisted of a train trip that went to the cities of Lisbon, Coimbra and Porto. The aim was to promote conferences on train with guests as doctors, people with epilepsy and their families, partners and journalists seeking to demystify the disease and trying to capture the attention of the media for this day.

NATIONAL JOURNALISM PRIZE FOR EPILEPSY

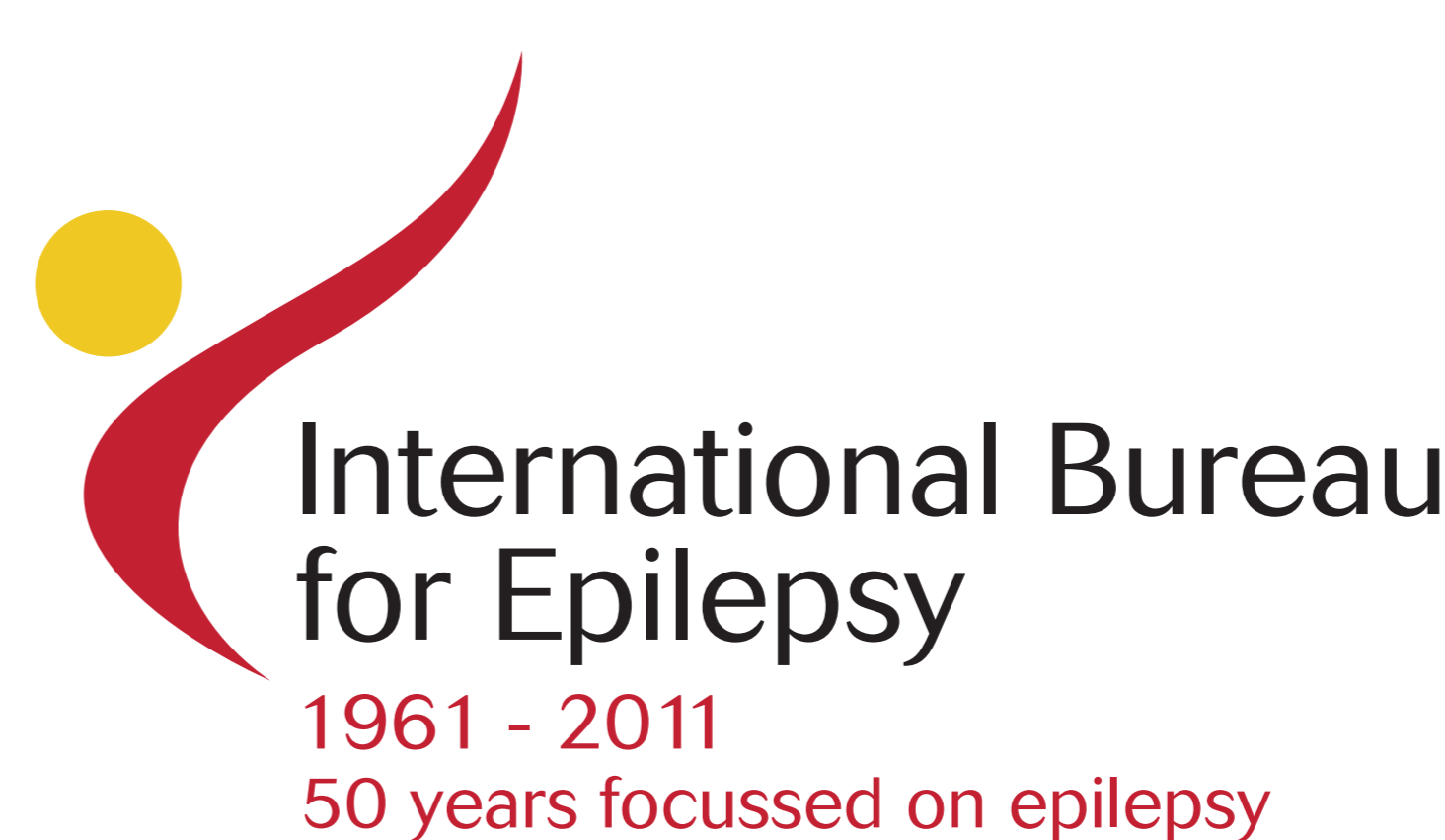
Included in the commemorations of the Portuguese Epilepsy's National Day, EPI and the Portuguese League Against Epilepsy, will assign the National Journalism Prize for Epilepsy: To form and inform... a new vision of Epilepsy.

The focus of this first edition is to promote an award for the journalistic work, in a civic and social line, that has best promoted a new vision of the disease. Work communications will be subject to assessment by an independent jury, consisting of medical professionals, health technicians and experts in the field of epilepsy.



CONTACT DETAILS

Epi Apfape (EPI),
Av da Boavista, 1015 Sala 601,
4100 128 Oporto, Portugal.
T/F: +351 22 605 49 59
epiporto@epilepsia.pt



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

EpiRomania



In the past year, with the support of IBE, through the Promising Strategies, our organization has addressed awareness and education issues in relation to epilepsy and the stigma around it.

THE MAIN OBJECTIVES WERE:

- to educate people with epilepsy and their families about epilepsy in order to ensure better management of the disorder
- to raise awareness and knowledge about epilepsy, by targeting a specific group of people. This group that can later on continue to raise awareness about epilepsy by targeting other groups

Although results are difficult to quantify, immediate feedback was positive and several members of our target group are already involved in activities that replicate the results of this project.

Starting this year the organization will take a major turn through its project called enklava. We have recognized that our efforts of raising awareness about epilepsy and our efforts to lobby with the authorities, although right and necessary, will be effective on the long term. However, people with epilepsy also need short term change. In this new light, enklava, as its name suggests, will try to offer people with epilepsy what they lack: sense of purpose and direction, social integration and employment ideas and opportunities.

Thus enklava is oriented on direct services to people with epilepsy and that shall be accomplished in two major ways:

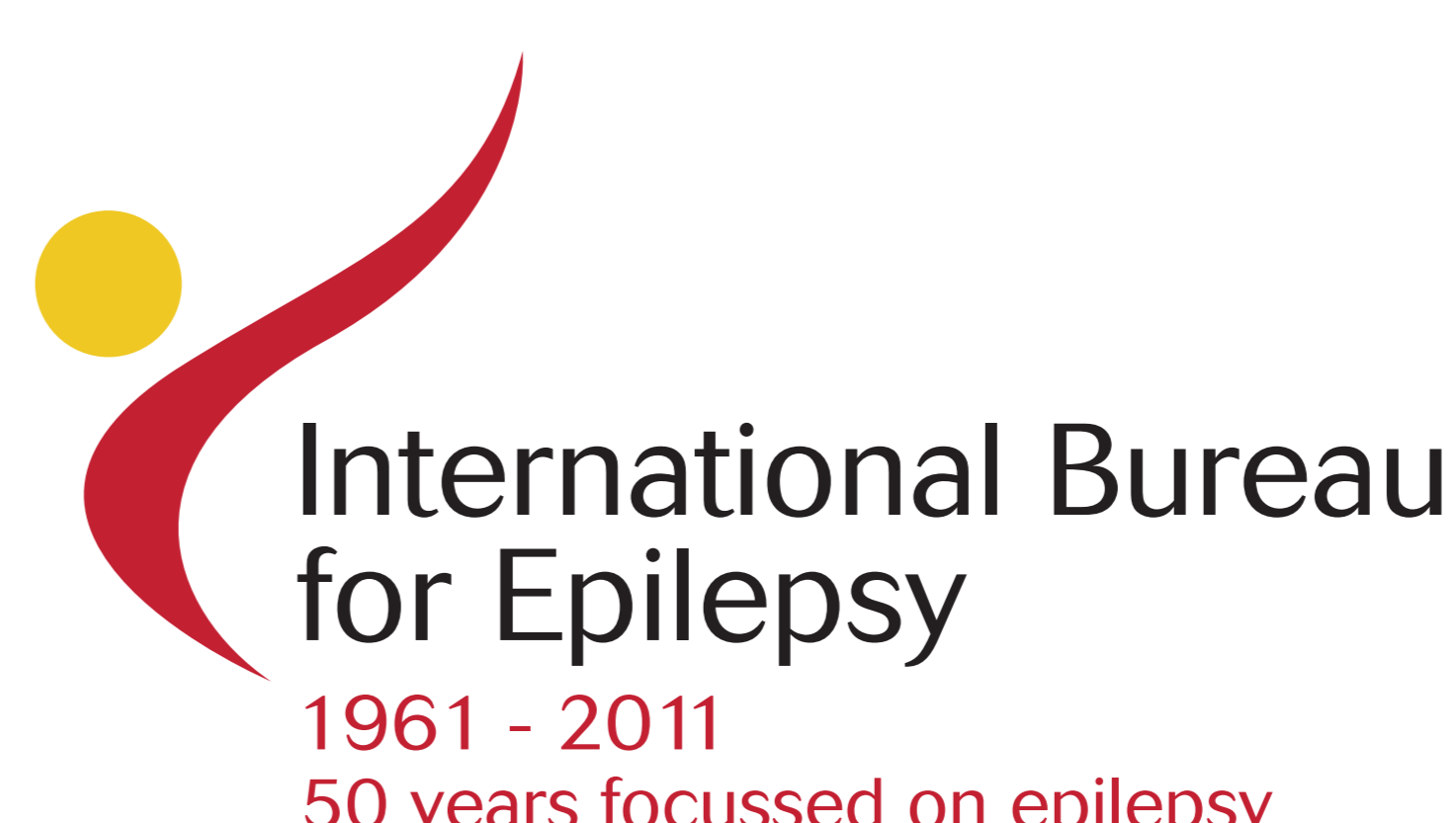
- Closed communities where people with epilepsy can find the much desired social integration without the fear of rejection; in these communities help, including financial aid, will be provided to people with epilepsy who are trying to create a job for themselves and possibly for others;
- Farms where people with epilepsy who cannot make their own living can live and work.

This project requires a tremendous amount of support in order to reach its maximum potential, but it can start small and build on itself in time, through itself and others.



CONTACT DETAILS

EpiRomania,
Str. Liviu Rebreanu nr 34, Cluj Napoca,
cod 400446, Romania.
T: +40 264 599 500
office@epilepsie.ro
Contact: Mr Gelu Stanculescu



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

THE SCOTTISH EPILEPSY CENTRE QUARRIERS



The Scottish Epilepsy Centre is a not for profit independent hospital, a national resource that provides epilepsy assessment to patients in partnership with the NHS.

Our patients are referred from NHS medical staff working in neurology, psychiatry and general medicine. All patient assessments are supported by local NHS boards who fund individual referrals.

We provide a flexible patient centred diagnostic, assessment and treatment service and support referrals for people with additional needs including complex social, psychological, physical and mental health issues, and patients with a learning disability.

The Scottish Epilepsy Centre is operated by Quarriers a leading national charity working to improve lives for people affected by epilepsy, providing clinical assessment and support, social care provisions, fieldwork services and campaigning services.

Quarriers work in partnership with other voluntary sector organisations and the NHS to develop and improve service provision for people with epilepsy and influence the policy agenda.

PATIENT REFERRALS

Referrals can be made for a number of reasons including:

- Diagnostic clarification
- Inpatient video telemetry, ambulatory EEG and routine EEG in a closely monitored environment for prolonged periods
- Review of treatment in a safe healthcare environment including rationalization of medication
- Ensuring patients with complex needs receive appropriate assessment
- Specific interventions including psychology, outpatient EEG services and specialist nursing outreach services
- Psychological evaluation and assessment
- Functional assessment to inform future care needs
- Continuing medical care for people with epilepsy

Our 10 bedded in-patient facility provides residential assessment for patients aged over 16, offering a multidisciplinary in depth assessment to people with the most complex diagnostic and treatment needs. Our service can accommodate over 100 in-patient assessments annually with the average length of assessment between 4-6 weeks.

EPILEPSY SPECIALIST:

- Neurologists
- Neurophysiologist
- Neuropsychologist
- Nursing

CONTACT DETAILS

Quarriers, Quarriers Village, Bridge of Weir, PA11 3SX, Scotland, UK
Tel: 01505 616000/616224 Fax: 01505 613906

ILLUSTRATIVE CASE STUDY

A 42-year-old woman with a mild learning disability had been given a diagnosis of epilepsy made at the age of 13 years. This patient had frequent admissions to hospital through the A&E department, including two admissions to intensive care for what was thought to be prolonged seizures. One recent hospital admission had lasted three months after the woman developed mobility problems.

Conventional hospital video-EEG monitoring had failed to capture events. Any attempt to reduce medication as an outpatient had resulted in further hospital admissions. The patient was admitted to the SEC for clarification of diagnosis and appropriate changes to treatment and management.

Clinical observation and monitoring demonstrated distinct epileptic and non-epileptic seizures. It was clear that frequent non-epileptic seizures (NES) had been responsible for all of her hospital admissions. During her assessment, phenytoin (500mg) and lamotrigine (400mg) were withdrawn. On discharge, she was taking 175mg of lamotrigine daily.

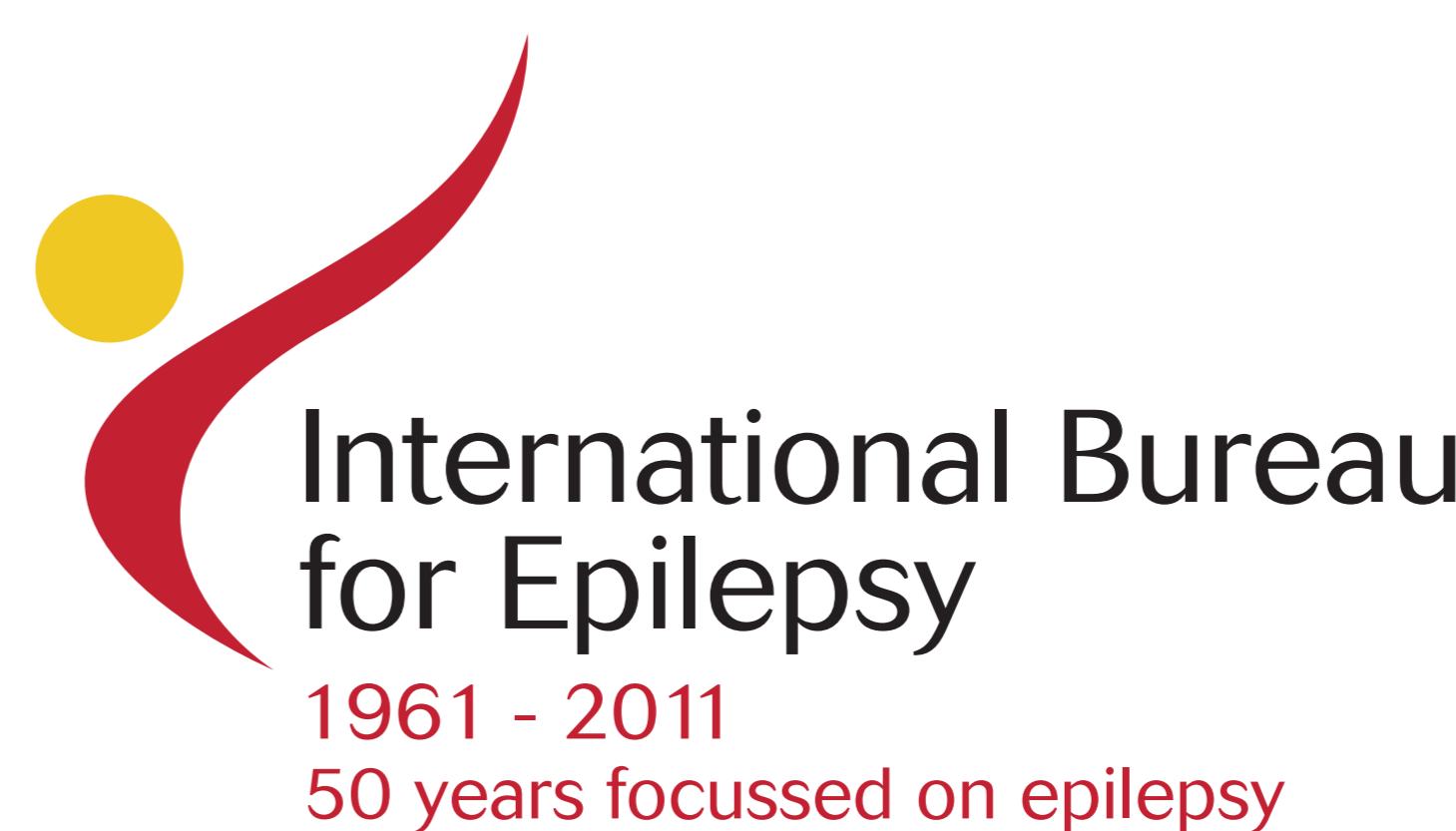
Both the patient and her carers were educated regarding her NES and alternative streams of management were put in place. Her epileptic seizures remained controlled. Her non-epileptic events occur occasionally, but are managed differently. The patient no longer makes repeated use of the local A&E department.

Gerard Gahagan
Service Co-ordinator
01505 616178
Gerard.gahagan@quarriers.org.uk

If you would like to receive our e-newsletter please email Gerard Gahagan to be added to the circulation list.

Quarrier was established in 1871, has been providing a medical epilepsy assessment service for over 40 years and is an Associate member of the IBE since 2005.

The Scottish Epilepsy Centre is part of Quarriers. Quarrier is a registered Scottish Charity No SC001960. Registered and Head Office:



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

SERBIAN SOCIETY FOR EPILEPSY



TYPE OF IBE MEMBER

Full member

Serbia is located in the central part of the Balkan Peninsula, in the south-eastern part of Europe and has a population of approximate 10 million. The majority of the population are Serbs (66 per cent), and numerous among 37 nationalities which also live in Serbia are Albanians (17 per cent), Hungarians (3.5 per cent), followed by Romanians, Croats, Bulgarians and others. All citizens have equal rights and responsibilities and enjoy full national equality.

LANGUAGE

The official language is Serbian and official alphabets are both Cyrillic and Latin.

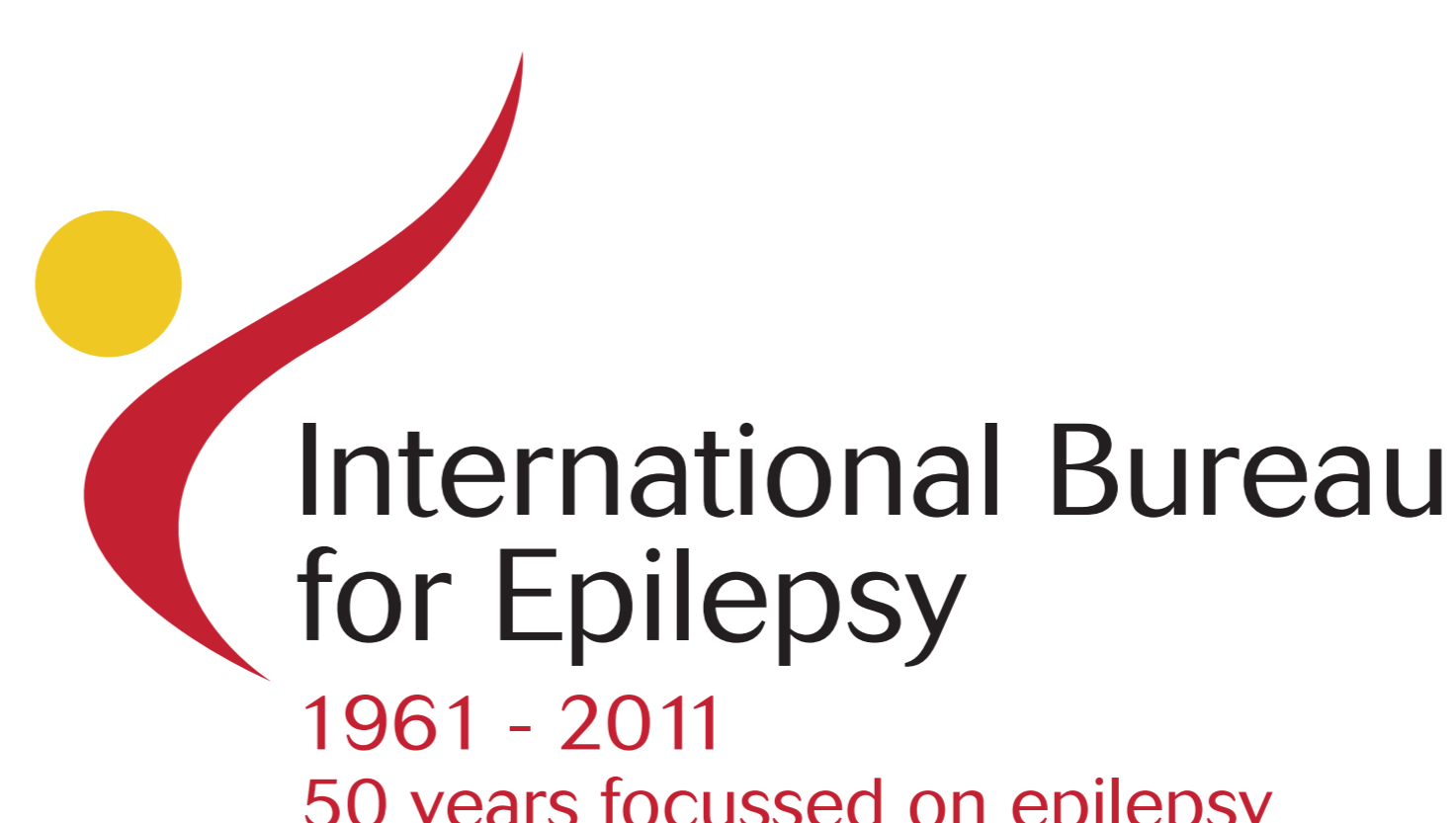
HEALTHCARE IN SERBIA

Serbian healthcare has been severely underfunded for many years and consequently, the standard of healthcare available is of poor quality. Medical staff are well trained; however equipment and facilities let the health system down considerably. Healthcare in Serbia is available to all citizens and registered long-term residents. Private healthcare is also available for those citizens who can afford it. The Health Insurance Fund (HIF) operates and oversees the health service in Serbia, the aim of the organisation is to make the health system equal for every citizen no matter what their status, but in practice this is often not the case.



CONTACT DETAILS

Serbian Society for Epilepsy
Dunavski kej 7/11, 11000
Beograd, Serbia.
T: +381 638 668 188
E: mpopovic@yubc.net
Contact: Dr Maria Popovic



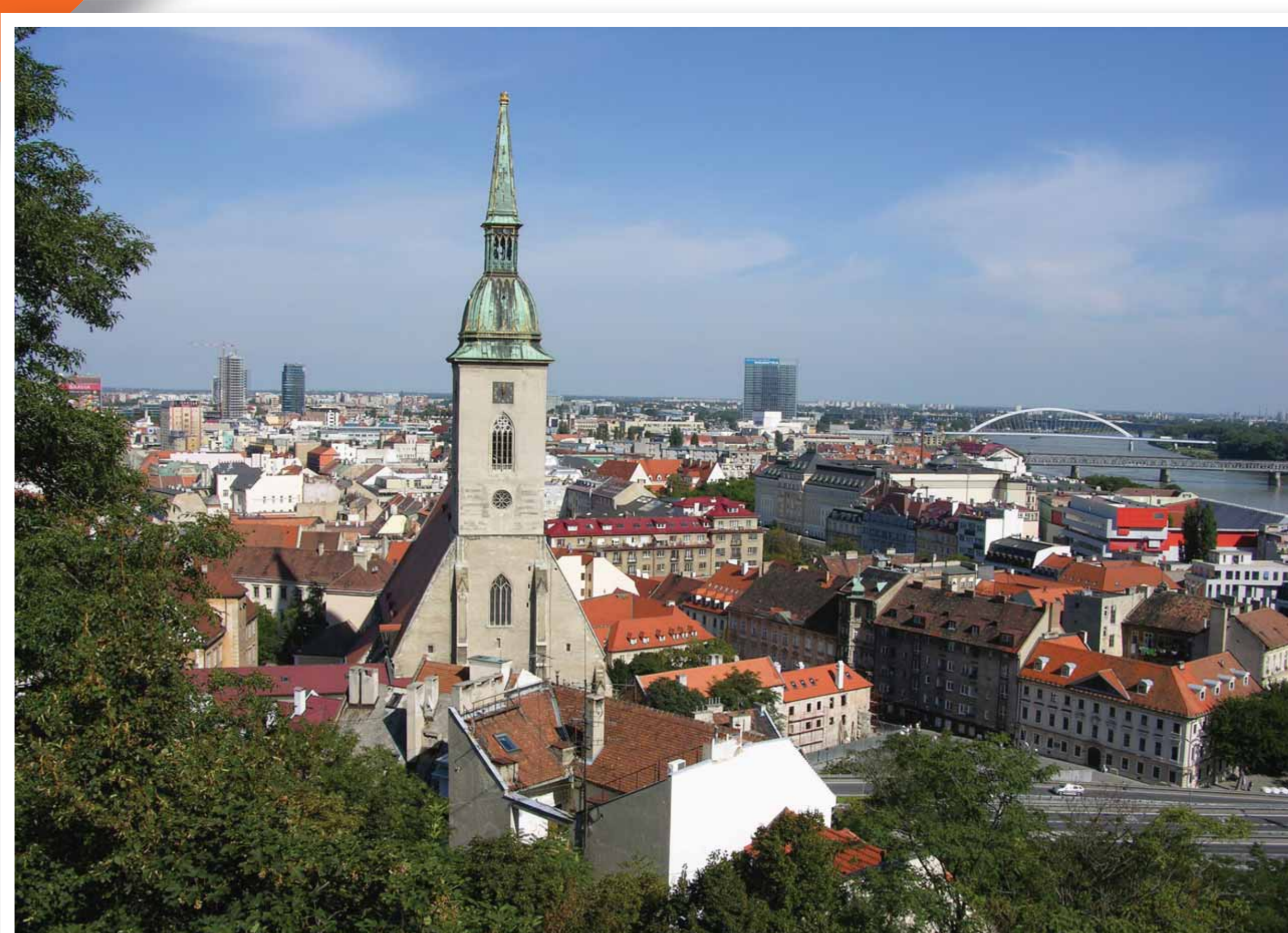
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ASSOCIATION OF SLOVAK CITIZENS WITH EPILEPSY AURA



FORMATION OF THE ASSOCIATION

The formation of the Association of Slovak Citizens with Epilepsy AURA required long time collaboration of specialists – Slovak neurologists and people with epilepsy. This non-governmental non-profit organization was established in Slovak Republic in December 1994 thanks to a group of people with epilepsy and the Slovak League of Doctors against Epilepsy.

The main goal of Association AURA is to support children and adults with epilepsy, their family members and volunteers, and to cooperate with specialists in the area of epilepsy treatments.

PREVIOUS AND PRESENT ACTIVITIES:

Since our establishment to the present day, the results of the work of AURA are mainly in care treatment for people with epilepsy and their social integration. We hold weekend health retreats, different congresses and communicate with similar domestic and foreign organizations.

We became a Full member of IBE in August 2005. This membership encourages us to develop relations with foreign countries and to collaborate on organizing collaboration with surrounding countries by holding joint events and exchanging mutual experiences in the area of epilepsy.

ACTIVITY OF OZ – AURA

There are circa 30 000 people with epilepsy in Slovakia (even though most of them disguise their condition). Our activities have successful and direct impact on families, work places, schools, the general public and the government of the Slovak Republic.

PROSPECTIVE OF OUR ACTIVITY

All these actions influence social and public life of people with epilepsy as well as the general public. Today, this activity is the crucial element for the development of fusions to interconnect the improvement of the quality of domestic and foreign activities.

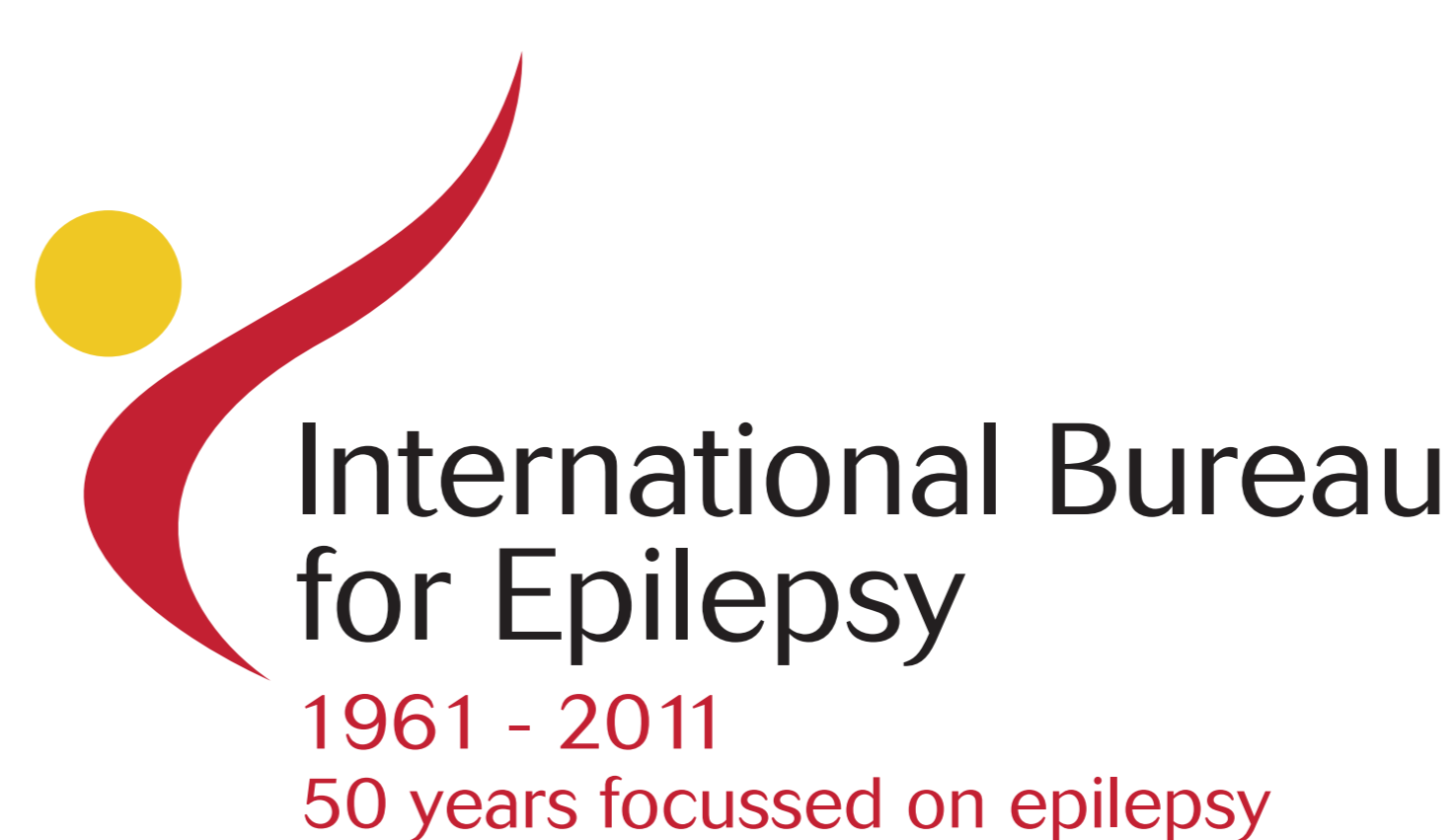
OUR ACTIVITIES INCLUDE:

- An annual three-day Congress – “My life with epilepsy”. It celebrates its 15th anniversary in 2011. Participants include epilepsy experts, epileptologists, members of the League Against Epilepsy (ILAE) Slovakia, people with a disability who have epilepsy, and volunteers – about 120 – 130 participants;
- Activities in regional clubs in all regions of Slovakia;
- Sport events;
- Publishing a Bi-monthly magazine – “Life with epilepsy” (also on the website www.epilepsiask.sk);
- Eva Ondrušová, author of the project “You can also save the life of a man with epilepsy” will receive the Slovak Donor of the Year Award. She is chairwoman of the regional club Žilina;
- Communication with the Government of the Slovak Republic and ministries;
- The organization of social activities to improve the quality of life of people with severe epilepsy.



CONTACT DETAILS

Zdruzenie obcanov Slovenska postihnutych epilepsiou AURA,
Po Box 116,
Dubravska cesta 1,
840 05 Bratislava 45,
Slovakia
zospe.aura@gmail.com
Contact: Dr Jozef. Vrátil
www.epilepsiask.sk
epilepsia@post.sk
zospe.aura@gmail.com
Call service: +421 907 531 908



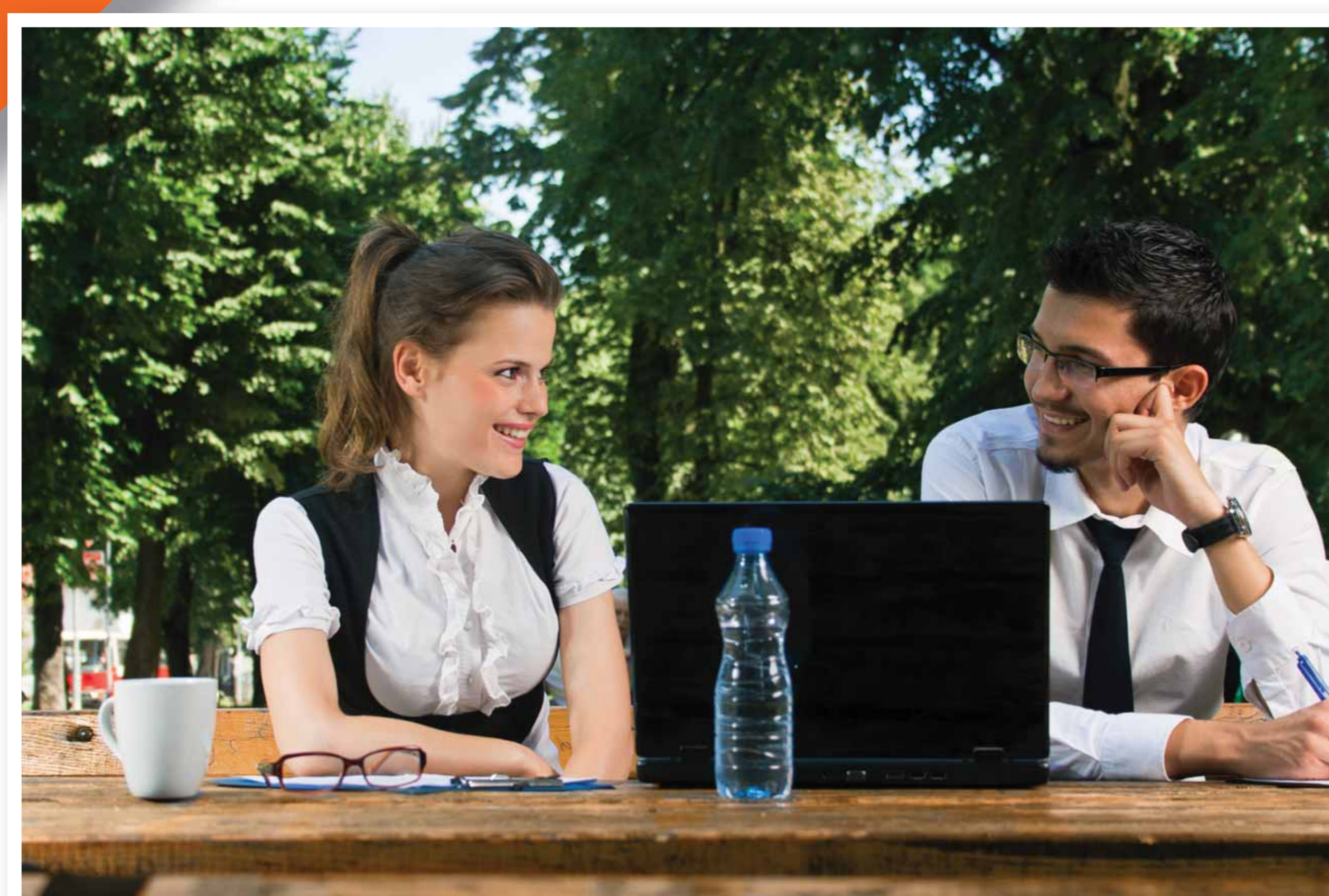
International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

ASOCIACIÓN ESPAÑOLA DE AYUDA A LA EPILEPSIA (AEAE), SPAIN



TYPE OF IBE MEMBER

Full member

POPULATION SIZE

44.7 million in 2006. Population density is less than in most other European countries. In recent years, following a longstanding pattern in the rest of Europe, rural populations are moving to cities. Urban areas are also experiencing a significant increase in immigrant populations, chiefly from North Africa, South America, and Eastern Europe.

Located at the crossroads of the Atlantic and the Mediterranean, Europe and Africa, Spain's history and culture are made up of a rich mix of diverse elements.

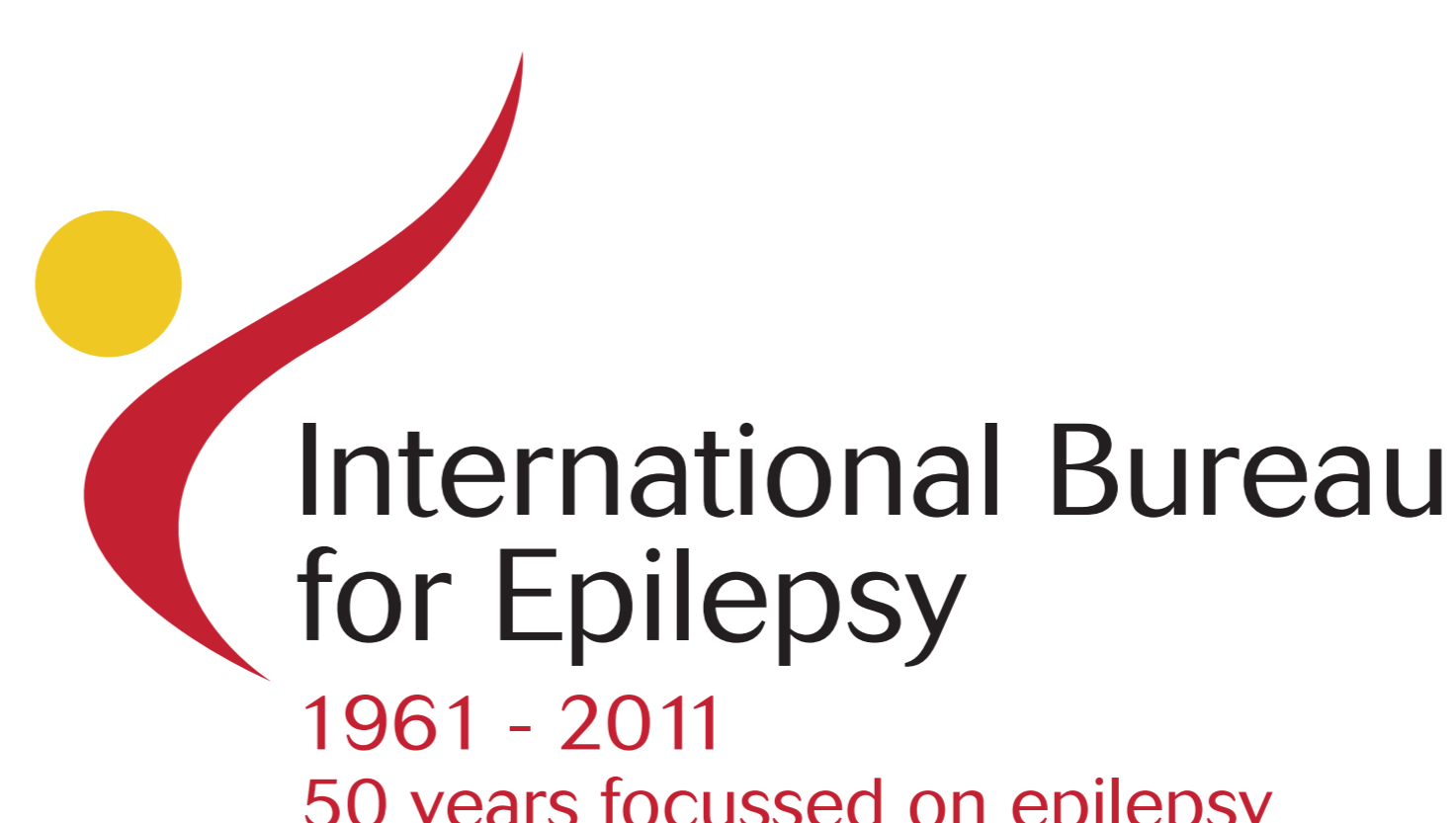
HEALTHCARE IN SPAIN

Spain is divided into 17 autonomous communities including the North African regions, the Canary Islands and the Balearics. The healthcare system was historically controlled by the central government, but today each region takes individual responsibility and the only jurisdiction the central government has is for the overall budget. The Spanish National Health System has an extensive network of health centres and hospitals throughout the country which offer primary health care services (family/GP services, paediatrics and nursing, with midwives, physiotherapists and social workers). The Spanish health system combines both public and private healthcare and within each separate state free or low cost health care is given to those who contribute to the Spanish Seguridad Social (social security).



CONTACT DETAILS

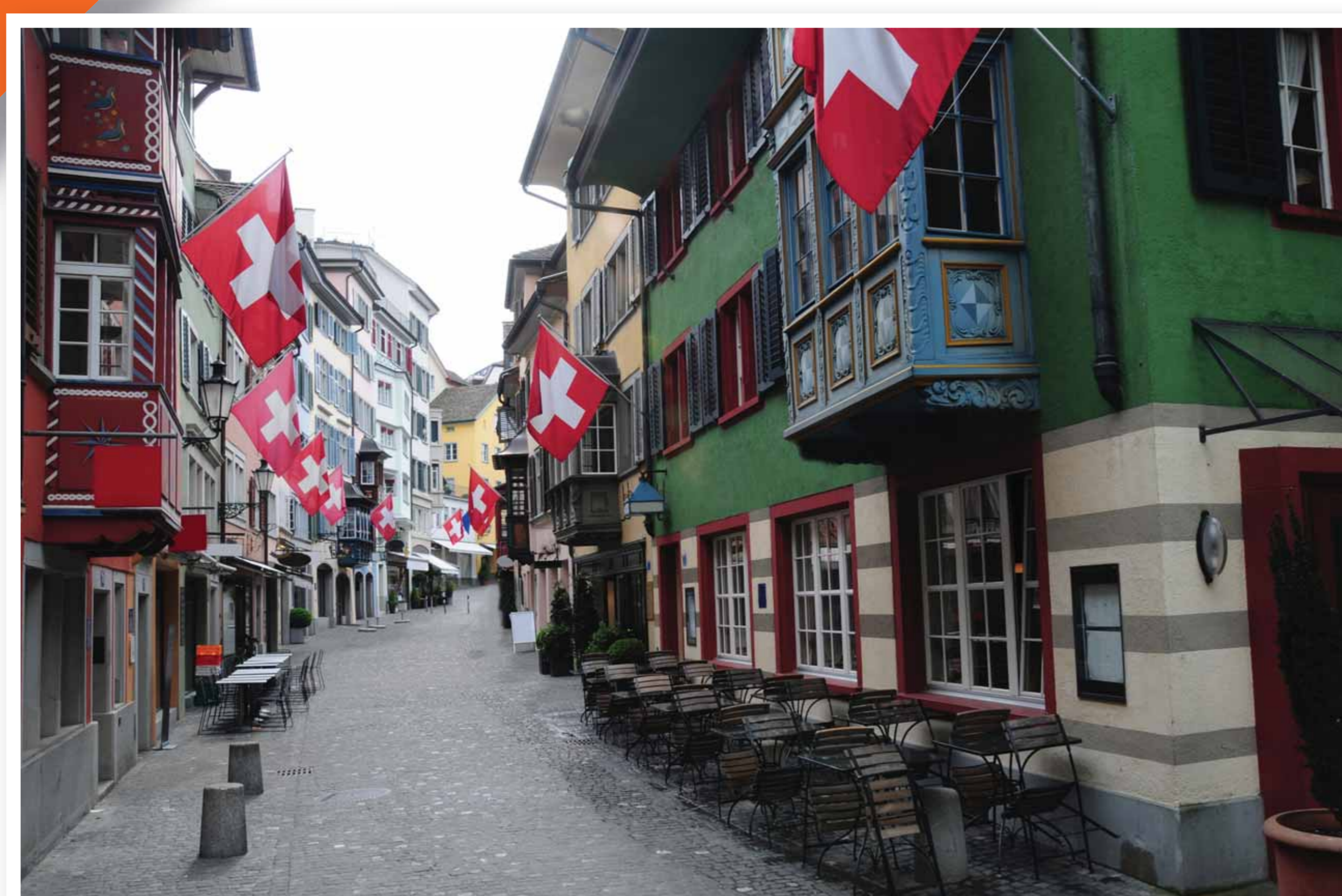
Asociación Española de Ayuda a la Epilepsia (AEAE),
c/Berlin 5, 4o Piso, 28028
Madrid, Spain.
T: +34 91726 2727
6764art@comb.es
Contact person: Antonio Russi



International Bureau for Epilepsy

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

EPI SWISS EPILEPSY CENTRE SWITZERLAND



Many people suffering from epilepsy are dependent on the services of specialised and competent clinical centres. For more than 100 years the Swiss Epilepsy Centre in Zürich has been dedicated to diagnosing, treating and caring for children, adolescents and adults suffering from all forms of epilepsy. Over the last decades the Swiss Epilepsy Clinic has developed into a modern interdisciplinary neurological centre.

ABOUT SWISS CENTRE FOR EPILEPSY

The Swiss Centre for Epilepsy was founded in the year 1886 by a Christian society. We still feel committed to the ideal of the founders, namely recognising the dignity of each individual. People with epilepsy in the EPI are treated not only competently but also with due respect. The focus of our task is the well-being of our patients.

The EPI is a private institution serving the public good and maintained by the Swiss Epilepsy Foundation. It is partly supported by public health care and receives subsidies from the Swiss Confederation and the Cantons.

MANDATE

The EPI, as it is warmly known, has become an institution of supra-regional importance treating patients from all over Switzerland as well as from abroad. Our main task consists of the diagnosis and treatment of people with epilepsy or other attack disorders.

We place emphasis on research into diagnostics and therapies, this in close cooperation with other organisations both in Switzerland and abroad. We cultivate close relationship with other neurological hospitals, neurologists, free practising doctors and other specialists in the field of epilepsy.

Another field of great importance is public education where with information material, symposiums, discussion groups and education programs we aim to improve knowledge about epilepsy this in turn leading to both increased understanding of

people with epilepsy and better integration into the community.

The EPI is an Epilepsy Centre. The term Centre means that the EPI offers the following facilities:

- out-patient diagnosis and treatment
- in-patient diagnosis and treatment in the hospital
- admission of children, adolescents and adults
- rehabilitation
- long-term residential care
- teaching and research

IMPORTANT FACTS AND FIGURES

In Switzerland approx. 70,000 people suffer from epilepsy.

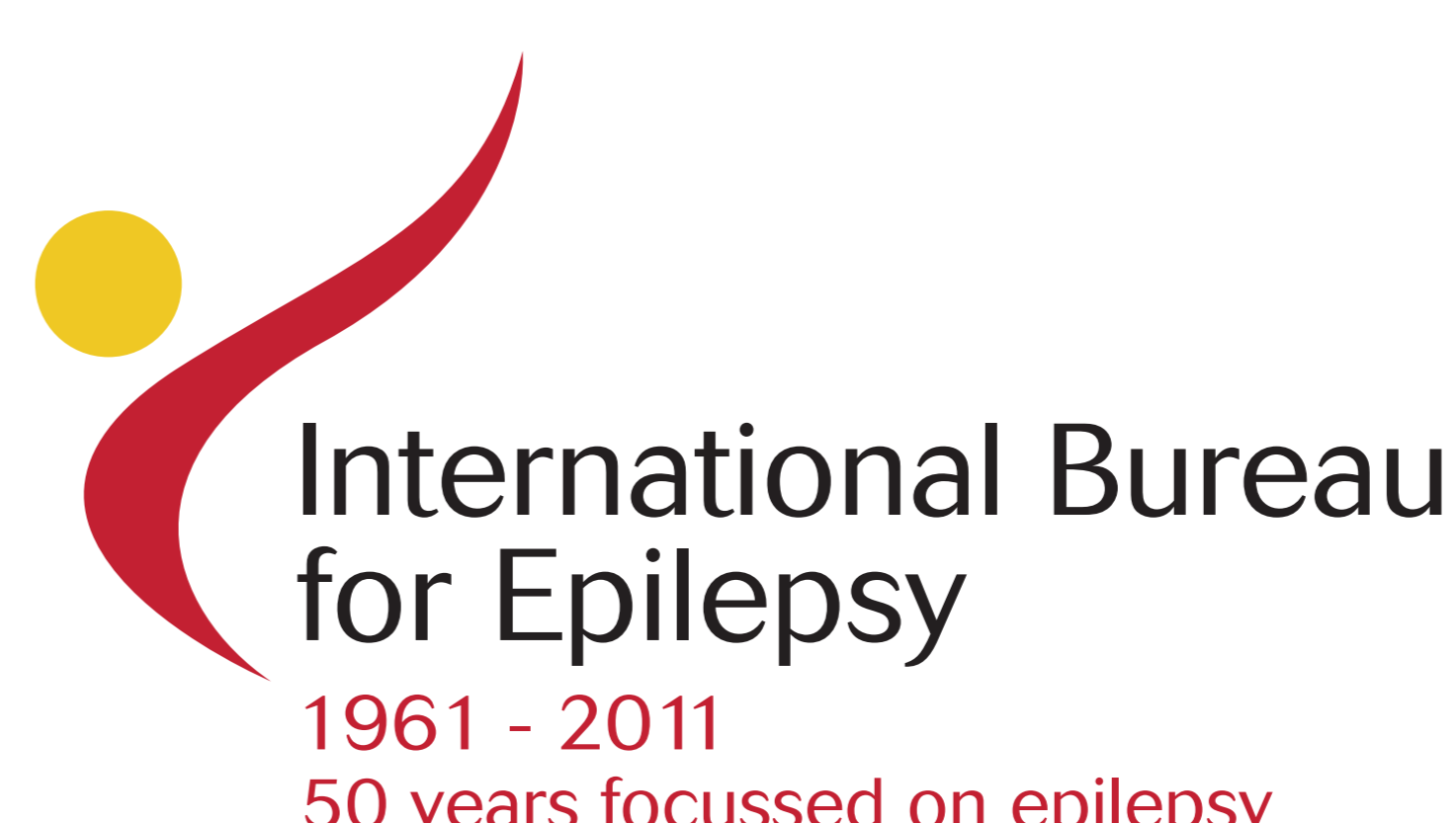
Thanks to diagnostic and therapeutic developments, the treatment of epilepsy has made great improvements and about 70% of all people with epilepsy will become free from attacks or have very few of them.

Most people with epilepsy are able to lead normal lives and work in various professions.

CONTACT DETAILS

EPI
Swiss Epilepsy Centre
Schweizerisches Epilepsie-Zentrum
Bleulerstrasse 60
CH-8008 Zürich

Tel. +41 44 387 61 11 (Reception)
Fax +41 44 387 62 49 (Office Managing Director)
Fax +41 44 387 63 96 (Office Medical Director)



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

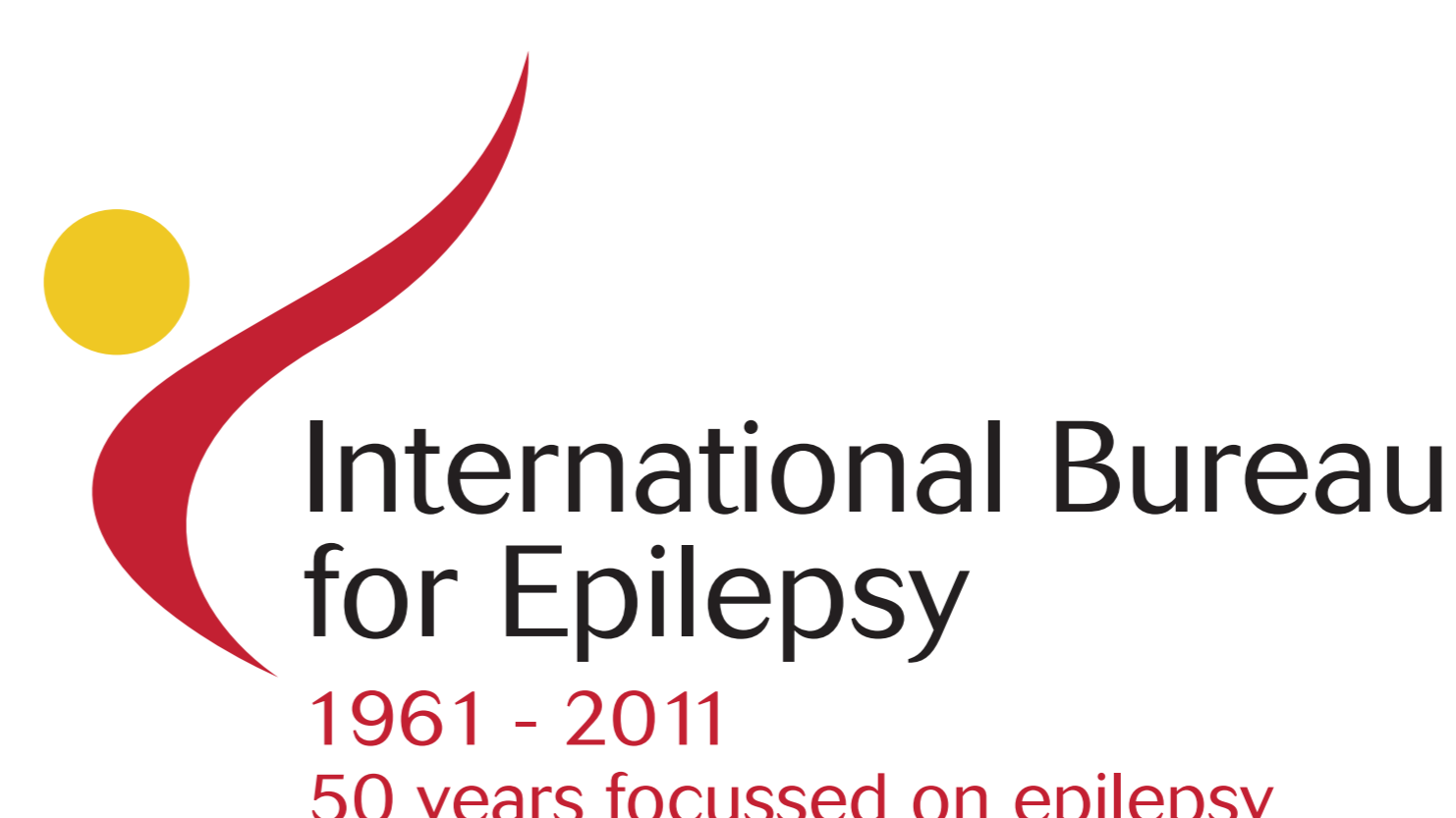
t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org

International Bureau for Epilepsy

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

MEMBERS IN THE EUROPEAN REGION

- AUSTRIA:** Epilepsie Dachverband
- BELGIUM:** Les Amis de la Ligue Nationale Belge contre l'Epilepsie/
Dr Vrienden van de Belgische Liga tegen Epilepsie
- BULGARIA:** Association for Assistance of Patients with Epilepsy
Associate Member: Association of Parents of Children with Epilepsy
- CROATIA:** Croatian Association for Epilepsy
- CYPRUS:** Cyprus Association of Support for People with Epilepsy
- CZECH REPUBLIC:** Spolecnost "E"
Associate Member: Epi Rodina
Associate Member: EpiStop
- DENMARK:** Danish Epilepsy Association
Associate Member: Danish Epilepsy Centre
- ESTONIA:** Estonian Epilepsy Association
- FINLAND:** Finnish Epilepsy Association
- FRANCE:** AISPACE
Associate Member: Epilepsie France
Associate Member: Epilepsie Euro Services
Associate Member: EOLE
- GEORGIA:** Epilepsy & Environment Association of Georgia
- GERMANY:** Deutsche Epilepsie Vereinigung
Associate Member: Interessenvereinigung fur Anfalls Kranke in Koln eV.
- GREECE:** Greek National Association against Epilepsy
- HUNGARY:** Association for Future of People with Epilepsy in Hungary
- ICELAND:** LAUF, The Icelandic Epilepsy Association
- IRELAND:** Brainwave The Irish Epilepsy Association
- ISRAEL:** Israel Epilepsy Association
- ITALY:** Associazione Italiana contro l'Epilessia (AICE)
- LITHUANIA:** Lithuanian Society of Patients with Epilepsy and their Sponsors
Associate Member: LESIA
- MALTA:** Caritas Malta Epilepsy Association
- MACEDONIA:** FYR: Epilepsija Aura
- NETHERLANDS:** EVN, Epilepsie Vereniging Nederland
Associate Member: National Epilepsie Fonds/
De Macht van het Kleine
Associate Member: SEIN
Associate Member: Stichting Kempenhaeghe
- NORWAY:** Norwegian Epilepsy Association
- POLAND:** Polish Association for People Suffering from Epilepsy
- PORTUGAL:** Epi Apfape (EPI)
- ROMANIA:** EpiRomania
- RUSSIAN FEDERATION:** All Russian Charity Foundation
- SCOTLAND:** Epilepsy Scotland
Associate Member: Epilepsy Connections
Associate Member: Quarriers
- SERBIA:** Serbian Society for Epilepsy
- SLOVAKIA:** AURA
- SLOVENIA:** Slovenian League against Epilepsy
- SPAIN:** Asociación Española de Ayuda a la Epilepsia (AEAE)
- SWEDEN:** Swedish Epilepsy Association
- SWITZERLAND:** Epi Suisse
Associate Member: Par Epi
Associate Member: Swiss Epilepsy Center
- UK:** Epilepsy Action
Associate Member: Gravesend Epilepsy Network
Associate Member: Epilepsy Society



International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.

t +353 1 210 8850 f +353 1 210 8450 e ibedublin@eircom.net www.ibe-epilepsy.org