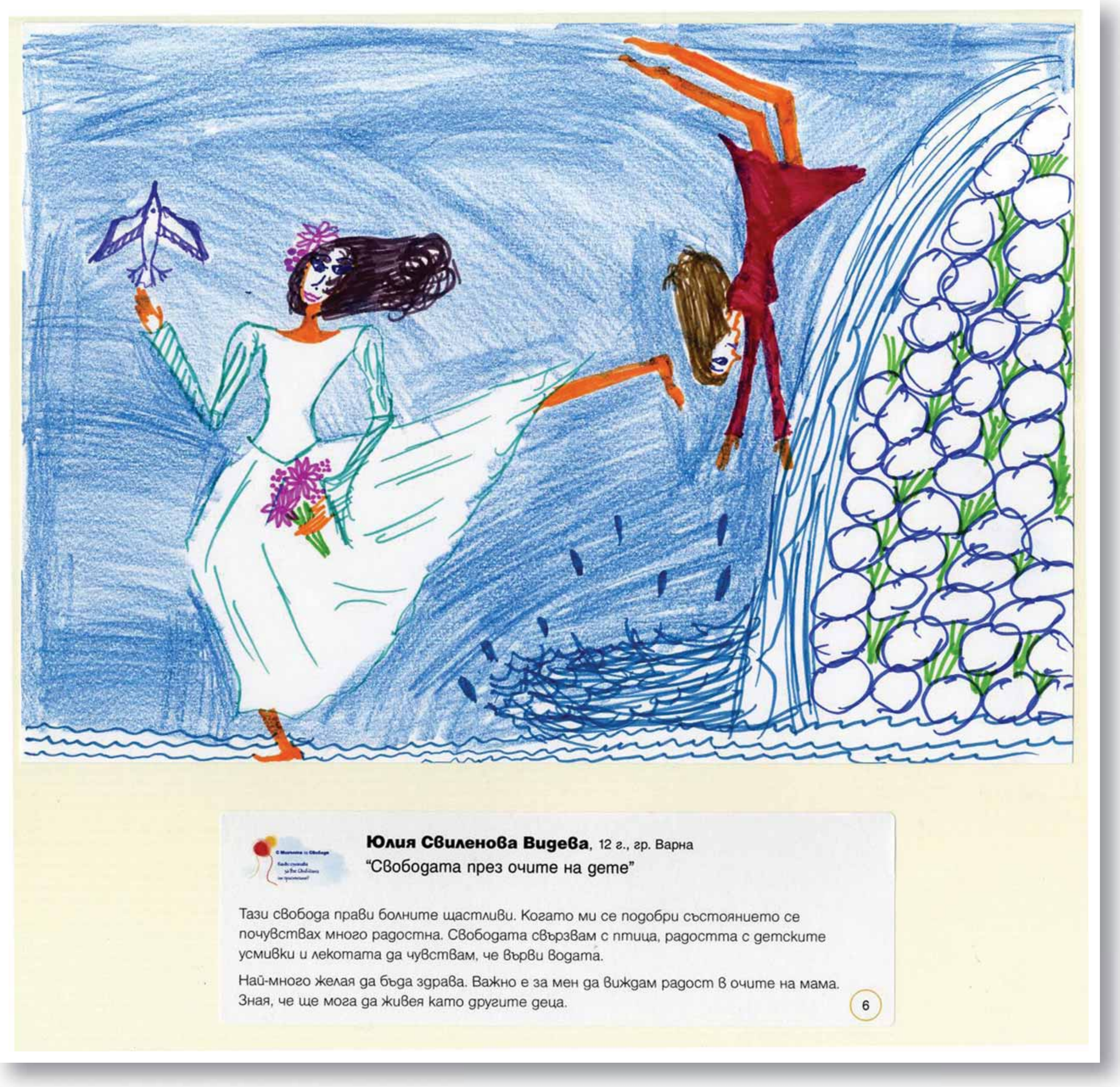
International Bureau for Epilepsy

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.



Юлия Свиленова Видева, 12 г., гр. Варна
"Свободата през очите на дете"

Тази свобода прави болните щастливи. Когато ми се подобри състоянието се почувствах много радостна. Свободата свързвам с птица, радостта с детските усмивки и лекотата да чувствам, че върви водата.

Най-много желая да бъда здрава. Важно е за мен да виждам радост в очите на мама. Зная, че ще мога да живея като другите деца.

6

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

25th-27th August 2010
PORTO
12th European Conference on Epilepsy & Society

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 (part of civic association "EPI-RODINA")

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, theirs families, friends and other concerned.

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
- Special activities during 2008 - 2010
- 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: Sobeslavska 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/

25th-27th August 2010
IBE PORTO
12th European Conference on Epilepsy & Society

International Bureau for Epilepsy

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

The "EpiStop" Association

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

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 (e.g. organizational and medial support of related concerts)

SPECIAL ACTIVITIES DURING 2009
- 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

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

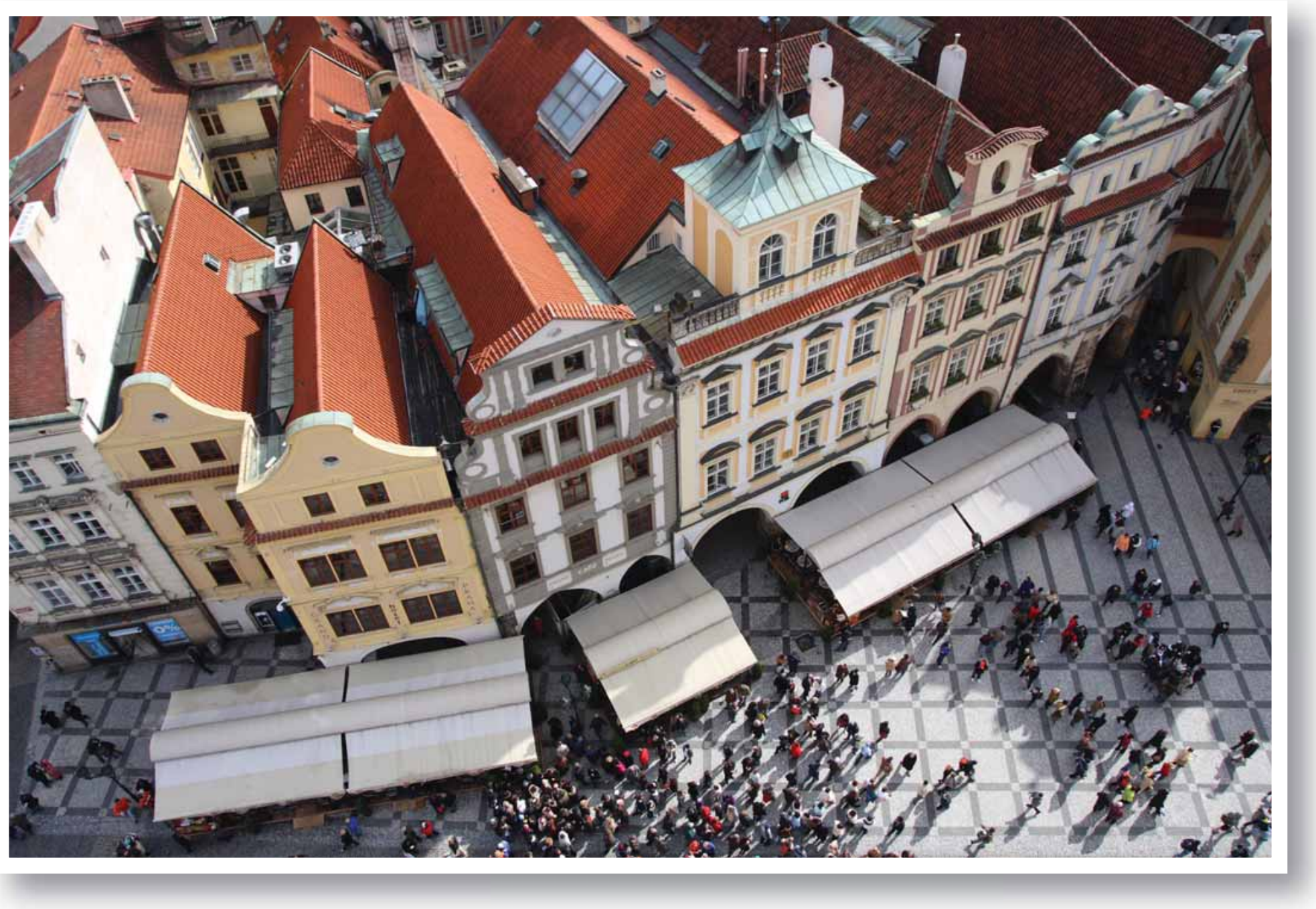
CONTACT DETAILS
The „EpiStop" Association
Address: Thomayer University Hospital with Polyclinic, Videnska 800, 140 59 Prague 4, Czech Republic
Contact Person: Jana Zarubova, M.D.
Website: http://www.epistop.cz/

25th-27th August 2010
PORTO
12th European Conference on Epilepsy & Society

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.



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

Spolecnosti „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

Spolecnost "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.

SPOLEČNOST „E"
Czech Epilepsy Association, o. s.

CONTACT PERSON:

Alena Cervenková, Chairwoman
Spolecnost „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.spolecnost-e.cz

25th-27th August 2010
IBE **PORTO**
12th European Conference on Epilepsy & Society

International Bureau for Epilepsy

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

Danish Epilepsy Association

Dansk Epilepsiforening

COUNTRY OF OPERATION
Denmark

TYPE OF IBE MEMBER
Individual member

FOUNDING DATE
September 27, 1962

INITIAL AFFILIATION TO IBE
Full IBE member since 1967

TYPE OF ORGANISATION
Individual membership

RANGE OF OPERATION
National

MISSION

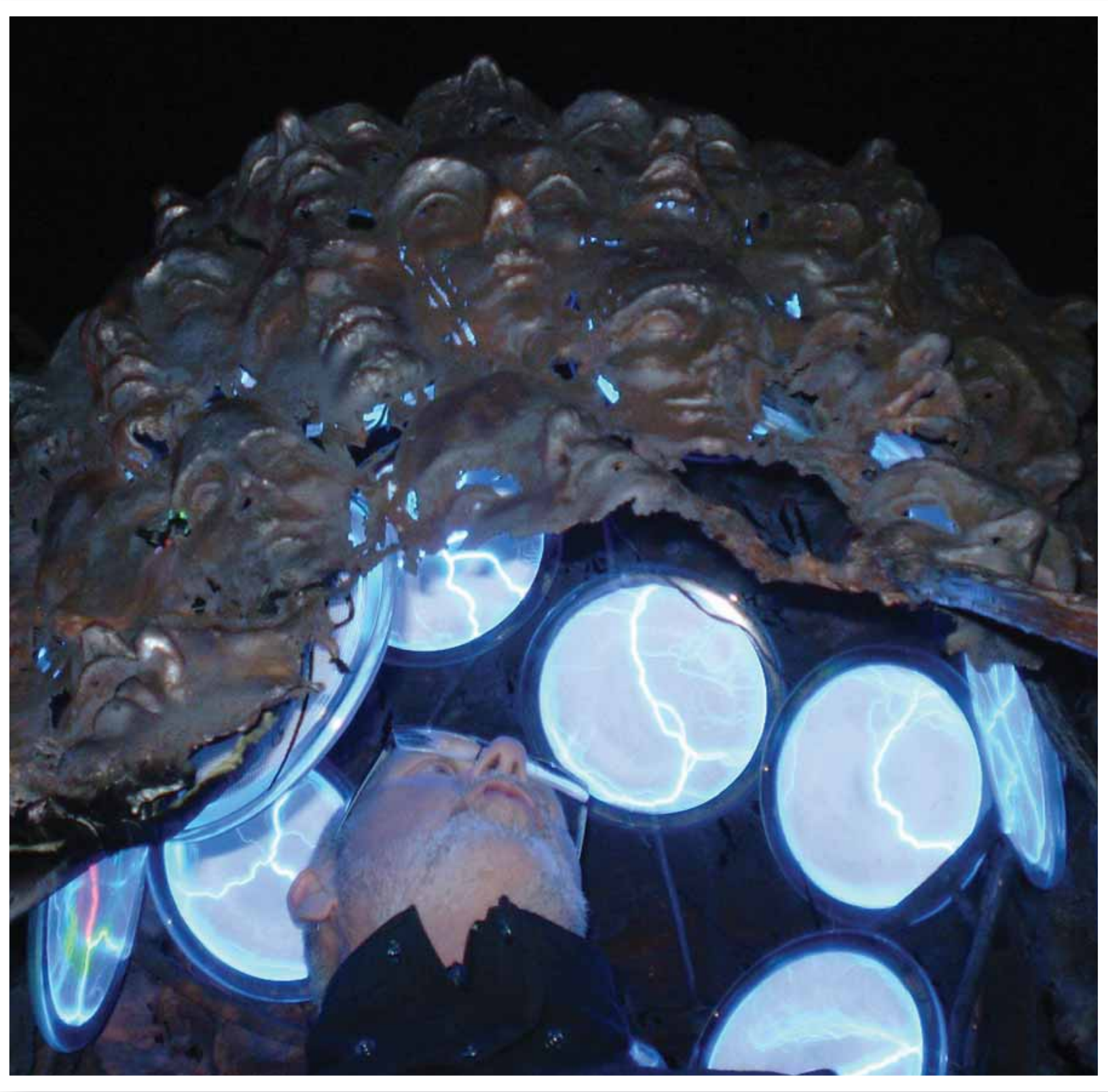
We would like to provide people with epilepsy with the best possible treatment and our aim is to make sure that they are not limited in their everyday life.

FIGURES

DEA has approximately 5,500 members. 55,000 Danes suffer from epilepsy.

RECURRENT ANNUAL ACTIVITIES

Information (courses, gatherings, the DEA quarterly magazine, information pamphlets and films)
Local and national network activities
Professional counseling by phone and on the website
Social activities (summer camp, youth- and teenage camp)
Aid program in Uganda supporting The Epilepsy Support Association of Uganda (abbr. ESAU)
Support for research
Information corps which make presentations to schools and institutions when invited



The sculpture "Brainstorm"

A scene from the play "Fit for Fight"

SPECIAL ACTIVITIES IN 2009-2010

- Touring with "Fit for Fight" a play about living with epilepsy during which the audience may join in and suggest how the conflicts of the play might be solved.
- Touring with the interactive sculpture "Brainstorm". Spectators may step inside the sculpture, which is made up of hundreds of faces, with sound effects which make numerous plasma plates light up thus artificially imitating what happens in the brain during a seizure.
- Exhibit of photographs from Uganda entitled "The country you support".
- Participation in the biggest running event in Denmark – the "Eventyrløbet" (The Adventure Race)

CONTACT

René Bøgh-Larsen
Dansk Epilepsiforening
Kongensgade 68, 2.
5000 Odense C
Denmark
rene@epilepsiforeningen.dk
Website: www.epilepsiforeningen.dk

25th-27th August 2010
IBE PORTO
12th European Conference on Epilepsy & Society

IBE

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**