ASSOCIAÇÃO BRASILEIRA DE EPILEPSIA (ABE)

COUNTRY OF OPERATION
Brazil

TYPE OF MEMBER
Full Member

DATE ORGANISATION WAS CREATED
1987

DATE ORGANISATION WAS FIRST AFFILIATED TO IBE
2001

TYPE OF ORGANISATION
Individual Membership and Organisational Membership

RANGE OF OPERATION
National with regional branches
- São Paulo, SP (Southeast)
- Ribeirão Preto, SP (Southeast)
- Rio de Janeiro, RJ (Southeast)
- Porto Alegre, RS (South)
- Salvador, BA (Northeast)
- Maceió, AL (Northeast)

GOAL OF THE ORGANISATION
- To promote the understanding about epilepsy in Brazil
- To disseminate knowledge in order to improve medical and social understanding about epilepsy
- To divulge information to public with the aim to reduce stigma and prejudice about epilepsy
- To form support groups and to permit professional inclusion of people with epilepsy
- To fight for the regular supply of antiepileptic medication in primary care settings

In Brazil approximately 3 millions people have epilepsy. ABE has 1,000 members, which include people with epilepsy and their families, as well as medical professionals. Supporters of ABE activities are: Federal University of São Paulo, regional small private companies and Pharmaceutical Industries (Abbott Brazil, Jansen-Cilag Brazil, Novartis Brazil, Medley, Torrent Brasil) and others (Companhia de Seguros Aliança do Brasil). ABE has made great effort to increase the number of associates and to have regional representations in other cities.

ABE has a full time social worker and the Association works with the following departments:

- ART AND CULTURE: painting classes for delegates, poetry lab, handicraft office. ABE promotes regular Vernissages with the material made by the volunteers
- SCIENTIFIC: papers published in Brazilian journal of Epilepsy and Neurophysiology (quarterly journal); ABE has recently performed a survey among people with epilepsy about their knowledge and experience with different formulations of antiepileptic drugs
- DIVULGATION: classes in Health sectors, Schools, Television, Newspapers, Monthly reunions for delegates since its founding in 1987. There are periodically group reunions in the Assembly Hall of São Paulo State, the richest of the nation
- SOCIAL: Children’s and Christmas’ parties for delegates
- PSYCHOLOGY/QUALITY OF LIFE: Validation of Inventories (SIS55, QOLIE-31, QOLIE-89, SSS)

CONTACT DETAILS
BRAZILIAN ASSOCIATION OF EPILEPSY
Rua Botucatu, 740 CEP 04023-900 São Paulo – SP, BRAZIL
phone +55 11 5549 3819 e-mail abe@epilepsiabrasil.org.br
website www.epilepsiabrasil.org.br

THE CONTACT PERSON TO INTERNATIONAL LIASON
Laura Guilhoto, MD, PhD, President
Canadian Epilepsy Alliance/Alliance Canadienne de l'Epilepsie
A Cure May Be Found Tomorrow, But Someone Needs Your Help Today

Country of Operation
Canada

Type of Member
Full Member

Date Organisation Was Created
2000

Date Organisation Was First Affiliated to Ibe
2008

Type of Organisation
Organisational Membership

Range of Operations
National

Goal of the Organisation
The organization is currently a partnership between 22 Canadian grassroots epilepsy organizations. We are dedicated to the promotion of independence, quality of life, and full community participation of persons with and affected by epilepsy. We will achieve our goal through innovative support services, advocacy, education and public awareness.

Number of Canadians with Epilepsy
300,000

Our Values
1. We value people's rights to live with dignity as full participants in their community.
2. We believe it is a person's right to be informed and to participate meaningfully in their own health management.
3. We believe that health encompasses social and emotional wellbeing.
4. We believe society has an obligation to be accessible to all its members and opposing of all discrimination.
5. We respect confidentiality, self-determination and choice.
6. We believe that strength is found in the ties that bind.

An Overview of Some of Our Initiatives
1. 1-866-EPILEPSY Toll Free Access from anywhere in Canada
2. French and English website: www.epilepsymatters.com
3. 7 public service announcements ranging from 30-48 seconds that identify seizure types and challenge discrimination.
4. National survey of attitudes and knowledge of 810 stakeholders.
5. Summer Camps, Tutoring and Scholarship Programs
6. Series of 12 Educational booklets and 8 thematic illumination projects including
7. Vocational training programs including a second hand clothing store that employs 26 individuals
8. Special events including Toronto's International BuskerFest that attracts an audience of over 1 million people.

Be Heard Youth Campaign
Twenty-four youth with epilepsy gathered in Toronto for a first-ever kind youth conference for a very important reason—to be heard. During this four day conference, these young individuals told their personal stories of how epilepsy impacted their lives. They gave particular attention to the stigma of epilepsy and the misconceptions that cause the most negative impact. They were asked the very important question, “If you were to send out a message to thousands of your peers about epilepsy, what would you say?”

The youth expressed frustration of being “put in a box” or “labeled” because they had epilepsy. The biggest challenge was often caused by others placing limitations on their abilities in assuming they weren’t fully independent because they had seizures. The Canadian Epilepsy Alliance will use their feedback to create an effective educational campaign, youth website and documentary.

Publication of a Neuroscience Unit
We have published a curriculum unit for senior science biology students. The unit includes an 80 page teacher’s manual, first aid DVD, seizure footage, case studies, labs and a careers section. The program introduces students to key concepts in neuroscience and uses epilepsy as a way to explore and illustrate neurons, the parts and functions of the brain, action potentials and drug interactions.

The goals of the unit are to dispel stigma, teach seizure first aid and to introduce epilepsy as a career choice to future health scientists.

Purple Day for Epilepsy
Purple Day was launched in March 2008 by nine-year-old Cassidy Megan of Nova Scotia, Canada. Cassidy’s dream is to inform people from around the world about epilepsy. In her words: “I want people to know that if you have epilepsy you are not alone.”

On March 26, 2009 PURPLE DAY was launched by the Canadian Epilepsy Alliance. We are proud of the education and exposure that this initiative has created.

1. 28 provincial and federal proclamations for epilepsy awareness in the legislatures with Members of Parliament wearing purple ribbons, purple ties and purple clothing
2. 215 schools participating by wearing purple to school, hosting purple classroom parties and holding epilepsy information assemblies
3. 920 members joined the purple day Face Book site www.purpleday.org
4. We have created: Purple Day media exposure in 44 newspapers, on 54 television stations and 27 radio stations across Canada and the world
5. 28 provincial and federal proclamations for epilepsy awareness in the legislatures with Members of Parliament
6. 219 schools participating by wearing purple to school, hosting purple classroom parties and holding epilepsy information assemblies
7. 920 members joined the purple day Face Book site www.purpleday.org
8. We have created: Purple Day media exposure in 44 newspapers, on 54 television stations and 27 radio stations across Canada and the world
9. 28 provincial and federal proclamations for epilepsy awareness in the legislatures with Members of Parliament
10. 219 schools participating by wearing purple to school, hosting purple classroom parties and holding epilepsy information assemblies