



INTERNATIONAL BUREAU FOR EPILEPSY

11 Priory Hall, Stillorgan, Dublin 18, Ireland

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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

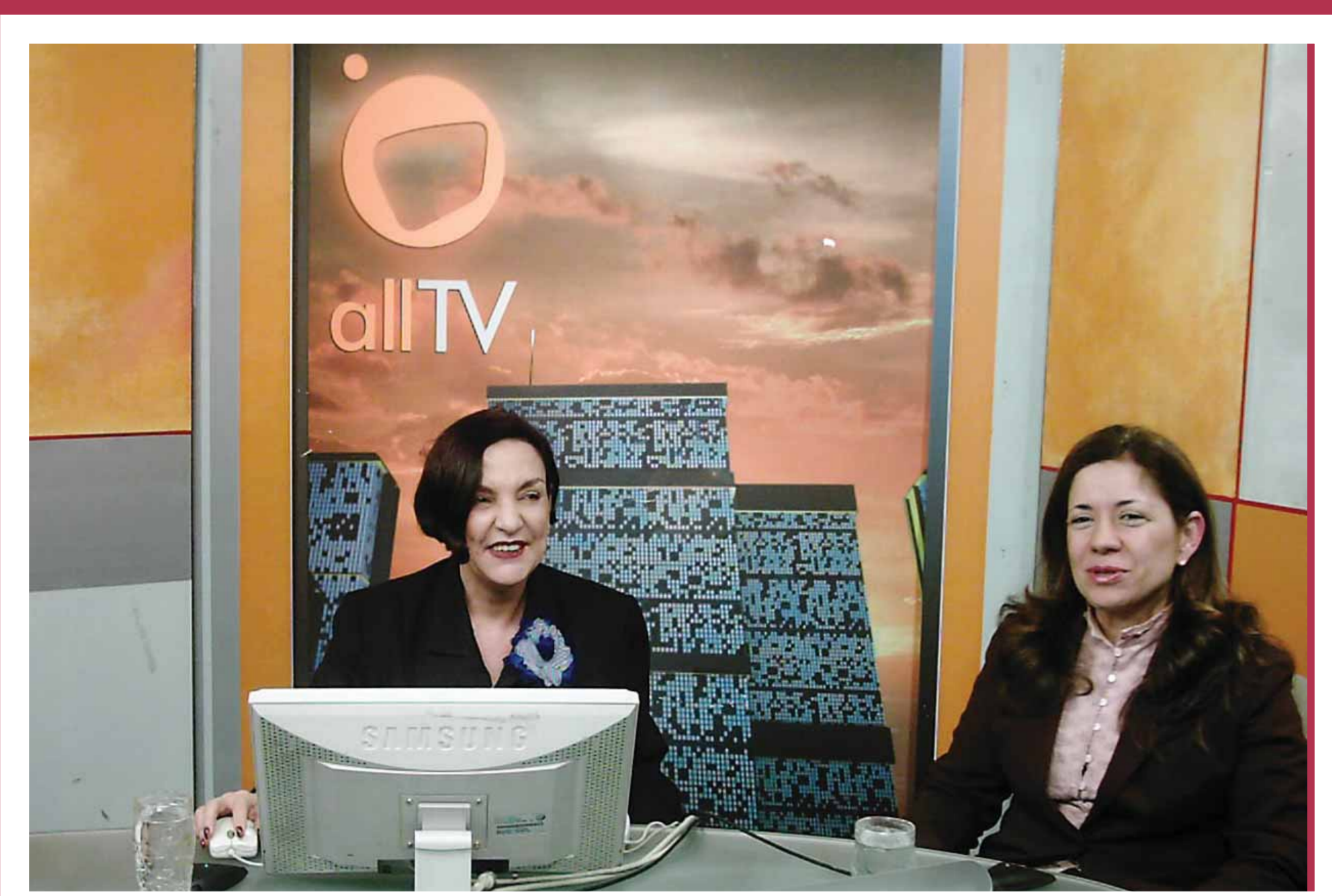
National with regional branches

- | São Paulo, SP (Southeast)
- | Ribeirão Preto, SP (Southeast)
- | Rio de Janeiro, RJ (Southeast)
- | Porto Alegre, RS (South)
- | Teresina, PI (North)
- | 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 and public hospitals



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 Brazil) 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
- ▷ **DELEGATES RECRUITMENT**
- ▷ **PSYCHOLOGY/QUALITY OF LIFE:** Validation of Inventories (ESI-55, QOLIE-31, QOLIE-89, SSS)



CONTACT DETAILS

BRAZILIAN ASSOCIATION OF EPILEPSY

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website www.epilepsiabrasil.org.br

THE CONTACT PERSON TO INTERNATIONAL LIAISON

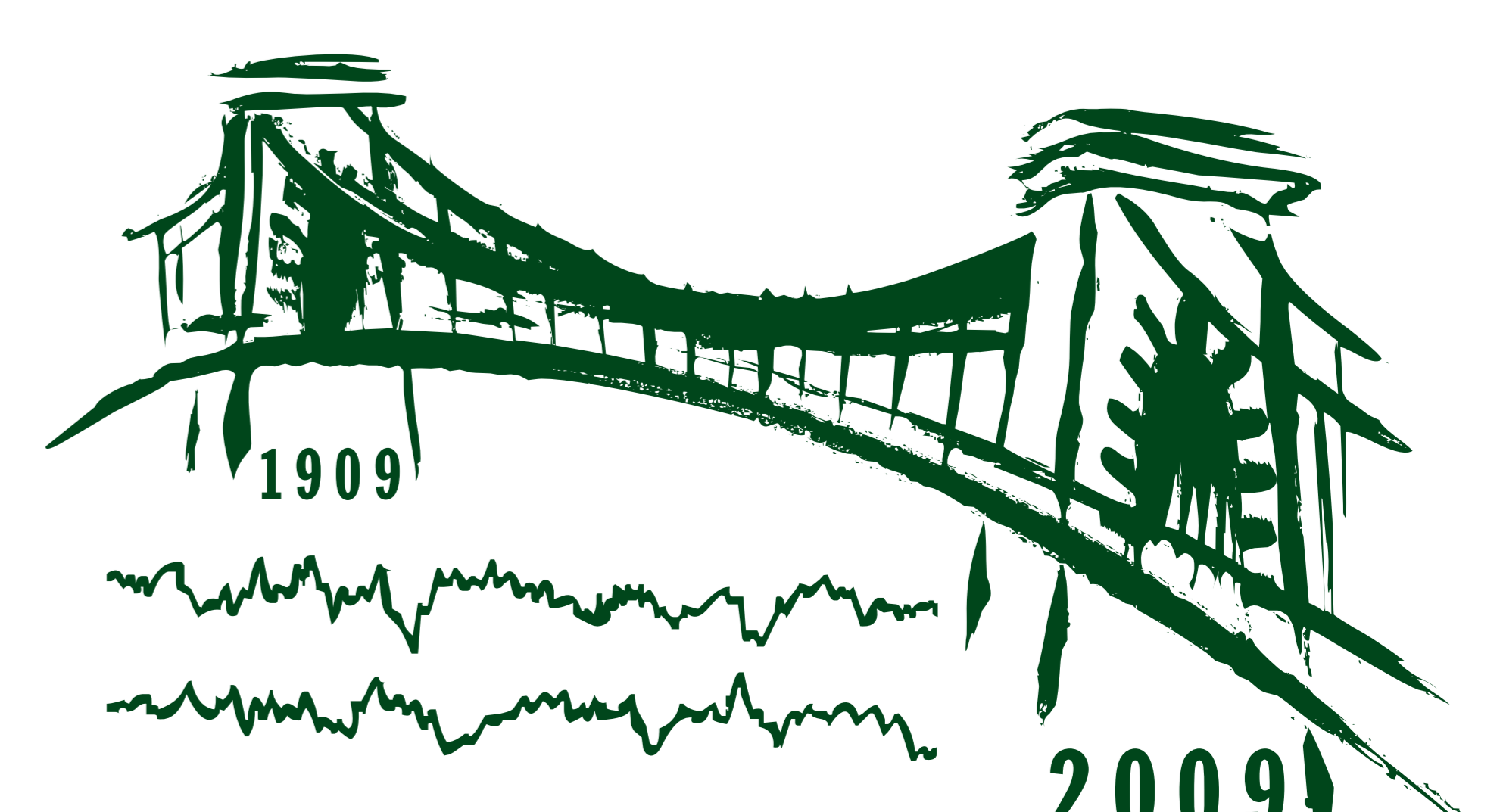
Laura Guilhoto, MD, PhD, President



B U D A P E S T

28th INTERNATIONAL EPILEPSY CONGRESS

 Eisai Supported by an educational grant from Eisai Co. Ltd





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CANADIAN EPILEPSY ALLIANCE/ ALLIANCE CANADIENNE DE L'ÉPILEPSIE

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

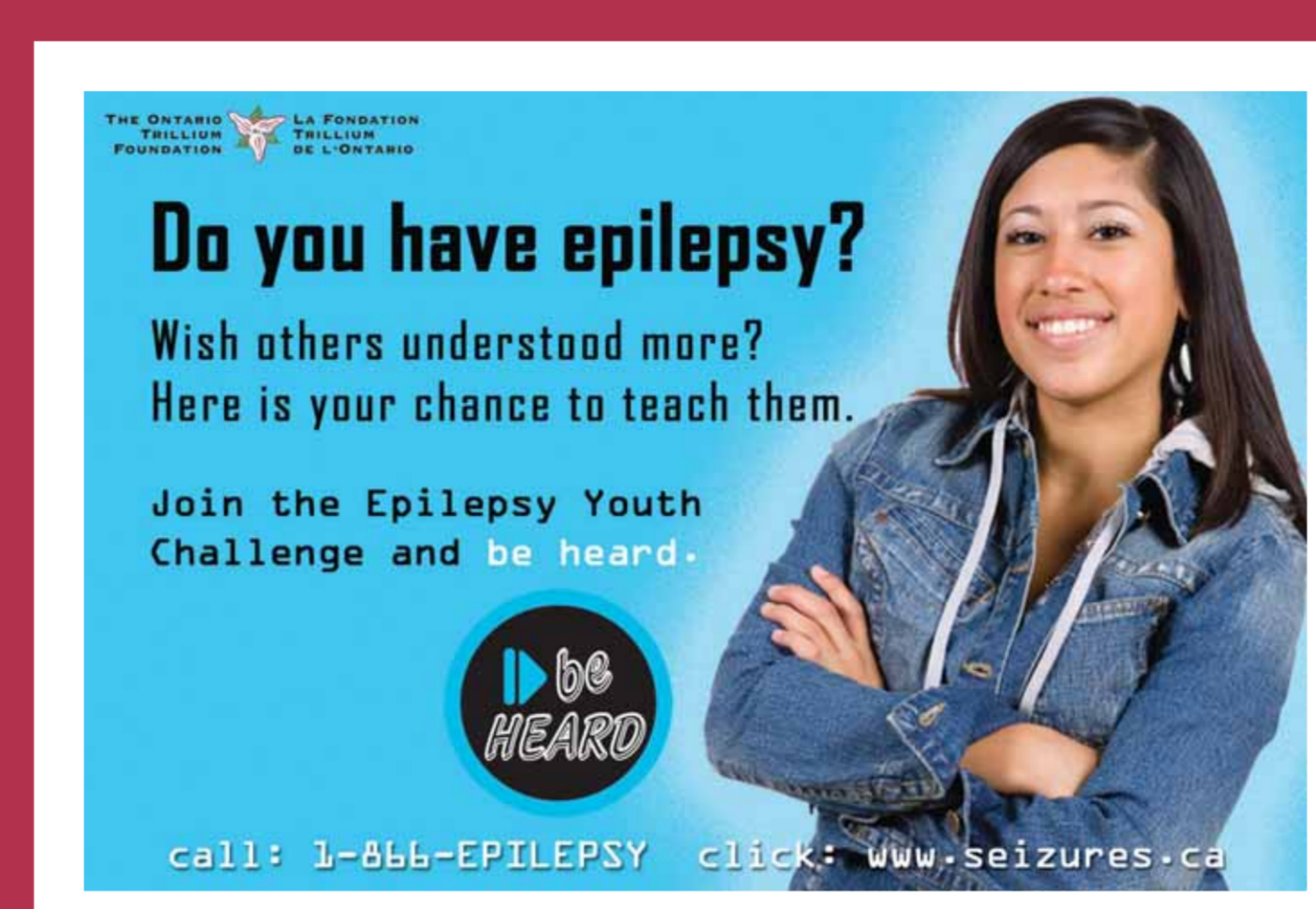
- I We value people's rights to live with dignity as full participants in their community.
- I We believe it is a person's right to be informed and to participate meaningfully in their own health management.
- I We believe that health encompasses social and emotional well-being.
- I We believe society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

AN OVERVIEW OF SOME OF OUR INITIATIVES

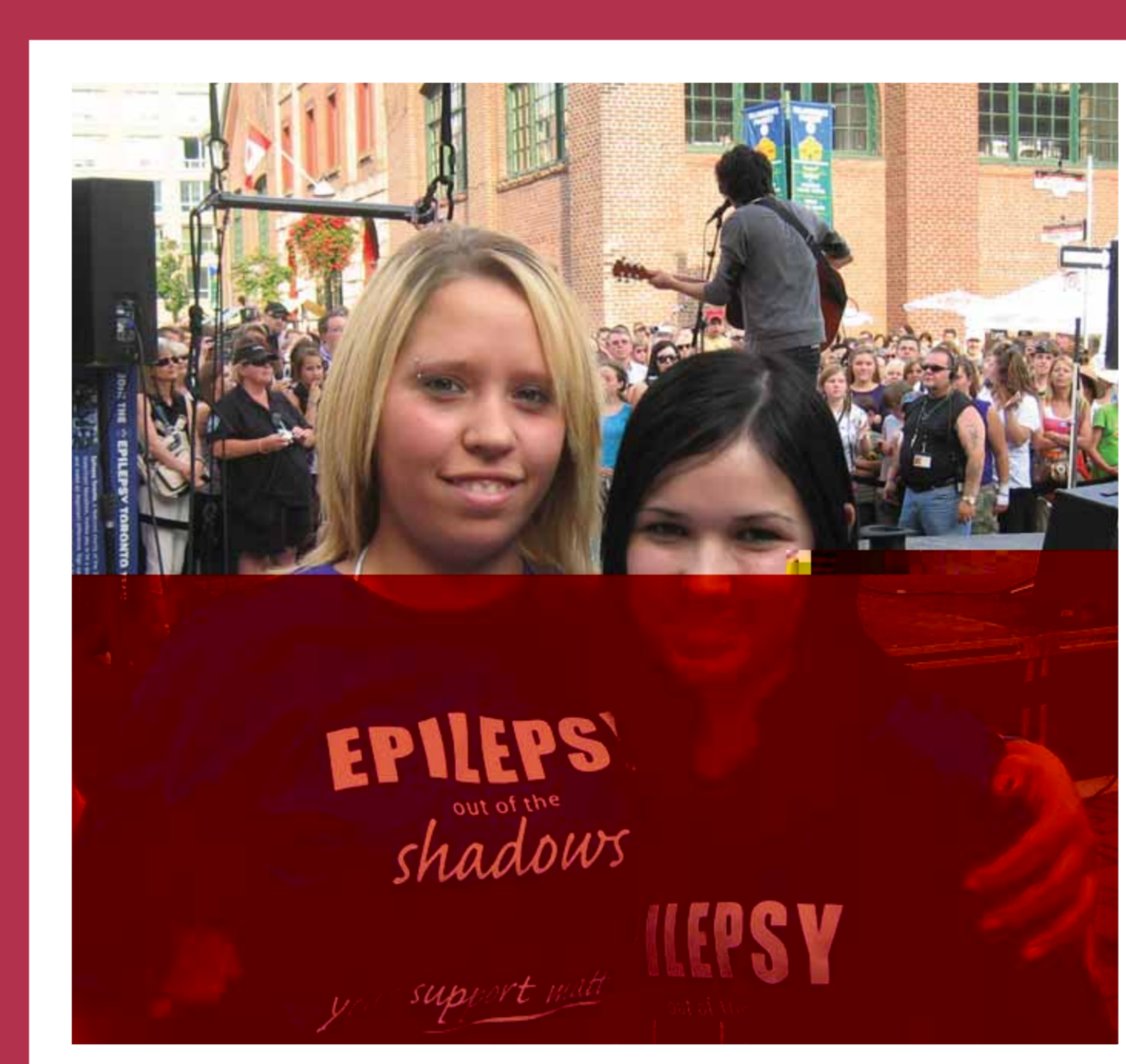
- I 1-866-EPILEPSY Toll Free Access from anywhere in Canada
- I French and English website: www.epilepsymatters.com
- I 7 public service announcements ranging from 30-60 seconds that identify seizure types and challenge discrimination.
- I National survey of attitudes and knowledge of 810 stakeholders.
- I Summer Camps, Tutoring and Scholarship Programs
- I Series of 12 Educational booklets and 8 thematic newsletters
- I Vocational training programs including a second hand clothing store that employs 26 individuals
- I Special events including Toronto's International BuskerFest that attracts an audience of over 1 million people.



BE HEARD YOUTH CAMPAIGN

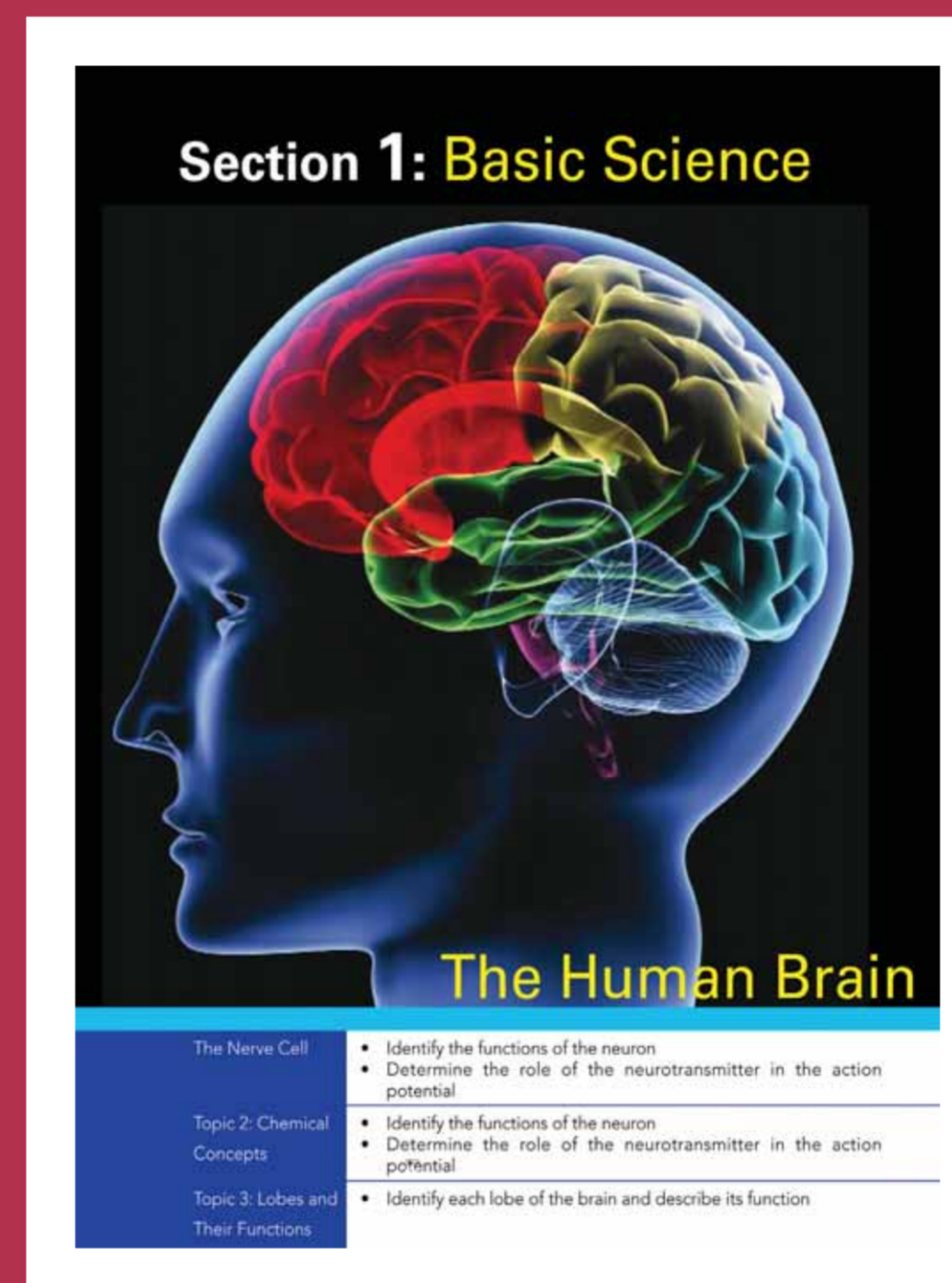


Twenty-four youth with epilepsy gathered in Toronto for a first-of-its-kind youth conference for a very important reason—to be heard. During this four day conference, these young individuals told their personal stories of how epilepsy impacted their lives. They gave particular attention to the stigma of epilepsy and the misconceptions that cause the most negative impact. They were asked the very important question, "If you could 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 putting limitations on their abilities or 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 explain 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 founded 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:

- I 28 provincial and federal proclamations for epilepsy awareness in the legislatures with Members of Parliament wearing purple ribbons, purple ties and purple clothing
- I 219 schools participated by wearing purple to school, hosting purple classroom parties and holding epilepsy information assemblies
- I 9200 members joined the purple day Face Book site
- I www.purpleday.org website was created with 100,000 visitors in March 2009
- I Purple day media exposure in 44 newspapers, on 54 television stations and 27 radio stations across Canada
- I 12 illumination projects including the CN Tower and Niagara Falls.



CONTACT DETAILS

CANADIAN EPILEPSY ALLIANCE
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website www.epilepsymatters.com

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

 **Eisai** Supported by an educational grant from Eisai Co. Ltd

