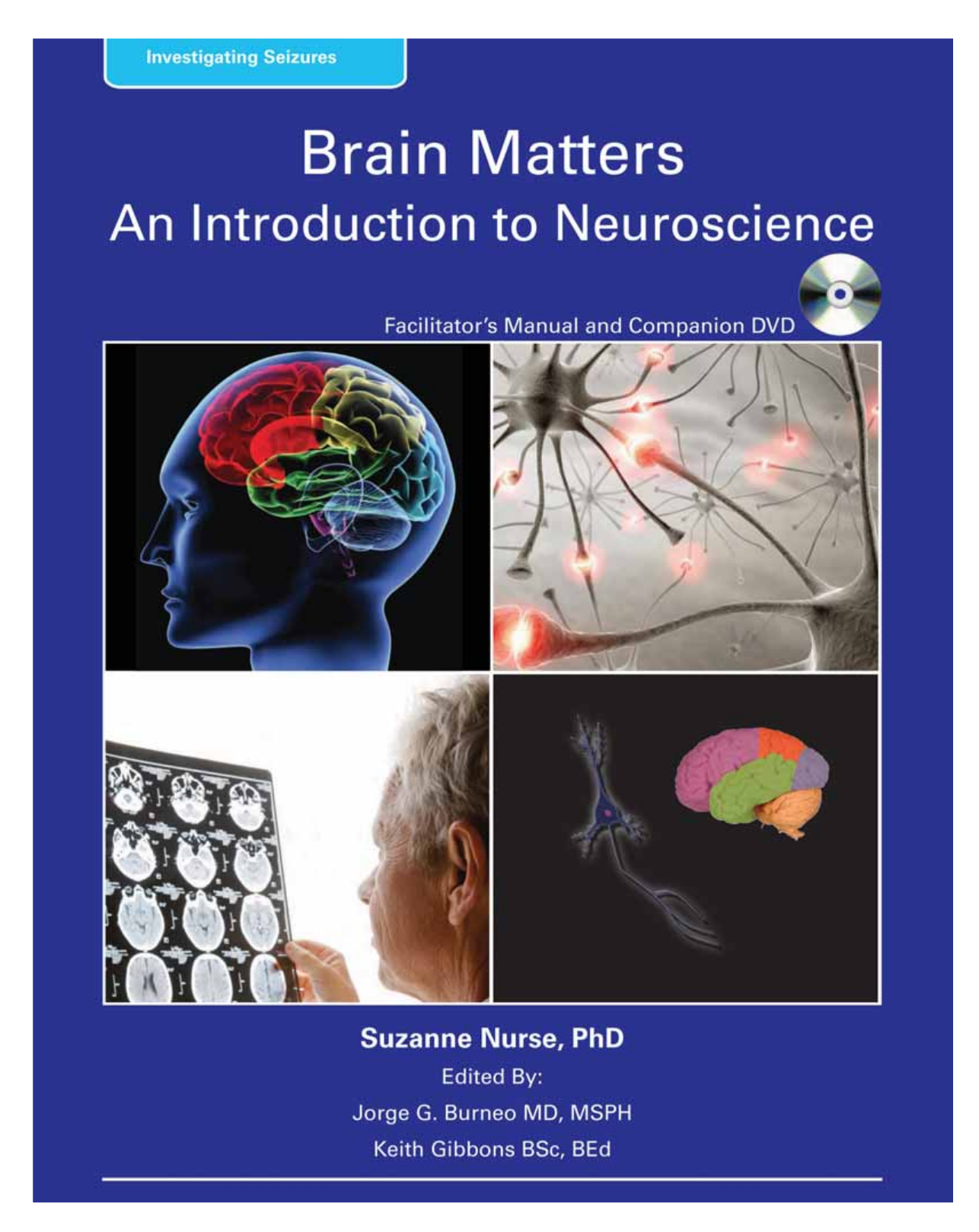
International Bureau for Epilepsy

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

CANADIAN EPILEPSY ALLIANCE/ ALLIANCE CANADIENNE DE L'EPILEPSIE


Investigating Seizures

Brain Matters

An Introduction to Neuroscience

Facilitator's Manual and Companion DVD

Suzanne Nurse, PhD

Edited By:

Jorge G. Burneo MD, MSPH

Keith Gibbons BSc, BEd

COUNTRY
Canada

TYPE OF IBE MEMBER
Full

DATE ORGANISATION CREATED
2000

DATE AFFILIATED WITH IBE
2008

TYPE OF ORGANISATION
Organisational Membership

RANGE OF OPERATION
National

GOAL OF THE ORGANISATION
The organisation is a collective of 24 independent epilepsy agencies. Together, these agencies are dedicated to the promotion of independence, quality of life, and full participation of Canadians with and affected by epilepsy. The organisation prioritises support services, advocacy, education and public awareness.

NUMBER OF CANADIANS AFFECTED
310,000

OVERVIEW OF THE SERVICES PROVIDED
- 1-866-EPILEPSY Toll Free Telephone Number
- French and English website: www.epilepsymatters.com
- 7 public service announcements in French and English
- National survey of attitudes and knowledge of 810 persons living with epilepsy
- Summer Camps
- Tutoring Programs
- Scholarship Programs
- Classroom programs for children in grades 5 and grades 12
- Series of 12 Educational booklets and 8 thematic newsletters
- Vocational training programs including a second hand clothing store
- Special events including Toronto's International Buskerfest
- Neurological Health Charities Canada


NHCC

Neurological Health Charities Canada

Working together to improve the lives of people living with chronic neurological diseases, disorders & injuries in Canada

Join the Canadian Brain Community Register Today to Stay Connected

Are you a: *

○ Person Living with a Neurological Condition

○ Caregiver or Family Member

Neurological Health Charities Canada (NHCC) is a collective of organisations that represent people with chronic, often progressive, neurological and/or neuromuscular diseases, disorders, conditions and injuries in Canada. The NHCC's role is to provide leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education and research projects, related to brain health.

The Canadian Epilepsy Alliance is an active member of the NHCC. Together we are working toward the development of a National Brain Strategy that would address the following priority areas: Research • Prevention • Integrated Care and Support • Caregiver Support • Income Security • Genetic Discrimination • Public Education and Awareness

In 2010, the National Population Health Study of Neurological Conditions (NPHSNC) was launched with $15 Million in funding from the Government of Canada. Epilepsy is one of the conditions that have been identified as a priority condition for the NPHSNC. As a result, several exciting initiatives and studies are now underway to increase our understanding of the burden of epilepsy in Canada (and internationally): (1) Studies on the epidemiology of epilepsy internationally using secondary data sources; (2) Studies on the epidemiology of epilepsy in Canada using population based data sources (national health survey and administrative data including validation studies of epilepsy coding from these data sources); (3) The addition of epilepsy to the Canadian Primary Care Sentinel Surveillance Network (CPCSSN); (4) The addition of epilepsy to the Canadian Longitudinal Study of Aging, and several other key studies on health services, risk factors, impact of epilepsy on patients, their families and caregivers, etc. The NPHSNC will also help us identify gaps where additional epilepsy research is needed in the near future.

BRAIN MATTERS: AN INTRODUCTION TO NEUROSCIENCE

Epilepsy has been a teacher to many neuroscientists and provides a unique way for students to learn about the brain. This unit is targeted to senior science biology students. These students are often naturally curious about the brain and how it functions. However, sometimes learning about synapses and neurons may seem very abstract and not very relevant to their life. The Brain Matters text and Companion DVD provides case studies of youth living with epilepsy that can act as a framework for students' inquiry into neuroscience. The teaching unit has a variety of components including classroom demonstrations, interviews of youth talking about their seizures, as well as interviews with various health care professionals and researchers. The components included in the unit provide a unique way to teach this material with a focus on developing scientific investigation skills and career exploration. There are currently 650 biology teachers in Canada using this unit to teach high school students about the brain through the study of epilepsy.

PURPLE DAY FOR EPILEPSY IS MARCH 26TH

On March 26 we celebrate Purple Day for Epilepsy. Founded in 2008 by a young girl named Cassidy Megan, Purple Day for Epilepsy increases awareness, reduces stigma and empowers individuals living with epilepsy.

The website: www.purpleday.org received 30,000 hits on March 26th alone!

Total 2011 media impressions were 4,705,831. This included articles in national newspapers, television, and radio and on the internet

CONTACT DETAILS
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Celebrating 50 years of IBE
29th International Epilepsy Congress
ROME 2011
28th August - 1st September

International Bureau for Epilepsy
1961 - 2011
50 years focussed on epilepsy

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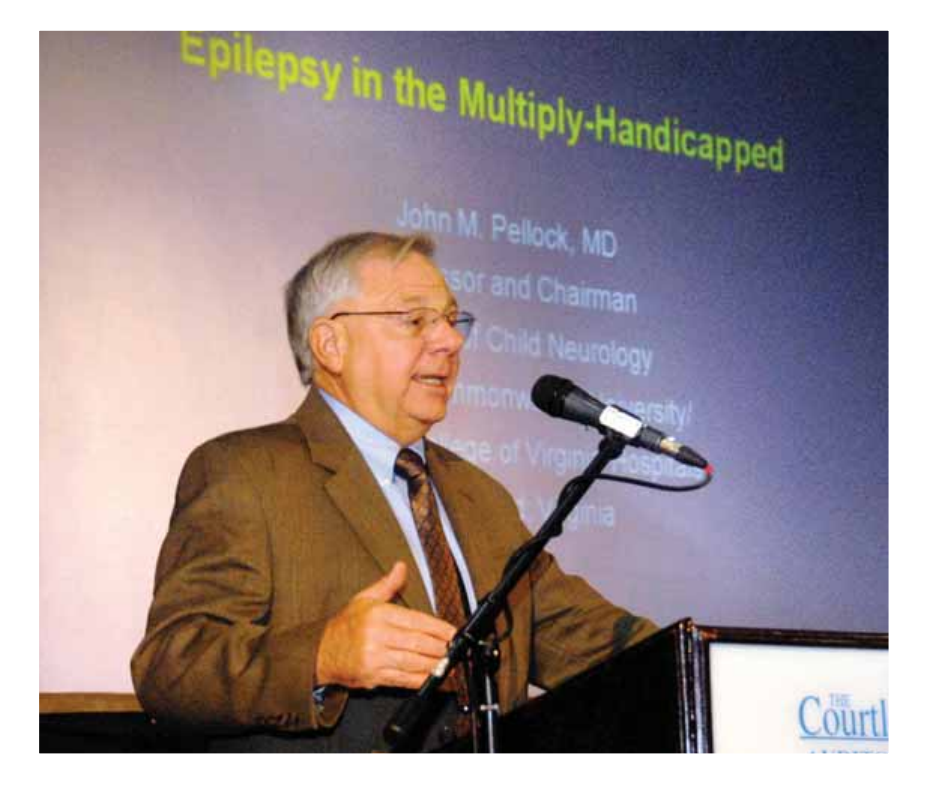
THE JAMAICAN EPILEPSY ASSOCIATION

The Jamaican Epilepsy Association



TYPE OF IBE MEMBER
Full Member

DATE ORGANISATION WAS CREATED
2002

DATE ORGANISATON FIRST AFILIATED TO IBE
2003

TYPE OF ORGANISATION
Individual Membership Organisation

RANGE OF OPERATION
We operate locally

GOAL OF THE ORGANISATION
- To improve the quality of life of persons with epilepsy in Jamaica.

OTHER INFORMATION
The JEA has approximately 70 members. All members either have epilepsy or have a family member with epilepsy. The JEA is administered by a board of Directors comprised of seven persons who offer their advice and services free of charge. The JEA administrative office is located at Andrews Memorial Hospital.

THE JEA OFFERS THE FOLLOWING SERVICES TO MEMBERS
1. Subsidised counselling with psychologists/psychiatrists.
2. Assistance with resume preparation and job placement in conjunction with a job placement company.
3. Financial aid for patients needing Video EEG monitoring.
4. Biannual newsletter which is circulated to all members.
5. Members' meeting with special guest speakers in an effort to educate members on epilepsy and other matters of interest.
6. Educational brochures, pamphlets, posters, medical alert cards and a children's book about a horse with epilepsy are given to all new members.

The JEA works very closely with the Jamaican League Against Epilepsy (JLAE) to advance clinical management through better diagnostic precision with the launch of the Video-EEG centre in 2004, a unique private-public effort with the Government of Jamaica. This Centre is administered by the JEA. Financial aid is offered to those unable to pay full fees.

Together with the JLAE the JEA has hosted many medical conferences to improve knowledge about epilepsy in the medical community. The most recent conference - The Second North American Regional Caribbean Congress on Epilepsy – was hosted by the North American Regional Commission of the ILAE on November 5-6 2010. The congress was attended by physician from North America and the Caribbean with many prestigious specialists speaking on epilepsy. Over 150 persons attended the conference.

Following the conference in November 2010, the JEA hosted a fund-raising walkathon at Emancipation Park for its members and the public in general.

The JEA continues to work towards improving the social aspects of persons with epilepsy in Jamaica as well as educating the general population about epilepsy.

EPILEPSY NEWS JAMAICA

THE JAMAICA EPILEPSY ASSOCIATION

Volume 6

April 2011

NEW YEAR MESSAGE

Dear members,
We take this opportunity to wish you all a prosperous and productive new year.

Despite the challenges of 2010 we at the JEA remain committed to serving you. With the global recession still affecting the world, we will have to expand our thinking and creative methods, so that we can keep the doors of the JEA open.

During the past year the JEA in its effort to be more effective to you the members, tried to implement several fund raising activities. However a walk-a-thon was what we eventually decided on. This took place in November of last year; it was a success despite the poor turn out of members. We are so encouraged by the support we got from the public that we have decided to make this an annual event.

Our vision for 2011 is to develop strategic plans so that the JEA can be more visible and the Jamaican public aware of the Association. This will only be possible through continued support from you, the members. To this end we are encouraging you all to make an effort to be more active in the association, only then can we really achieve.

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Walkathon 2010

Nora Perez President of the Jamaican Epilepsy Association and Dr. Amza Ali, Pose for the camera at the Emancipation Park after their fun walk at the Epilepsy Walkathon which was held on November 13, 2010.

A group of at the epile walkathon November 1

CONTACT DETAILS
The Jamaican Epilepsy Association (JEA)
c/o Andrews Memorial Hospital, 27 Hope Road, Kingston 10
Phone: (876) 968-8274 E-mail: jaepilepsy@cwjamaica.com

THE CONTACT PERSON TO INTERNATIONAL LIAISON
Mrs. Nora Perez - President
Mrs. Jennifer McCallum – Administrative Secretary

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EPILEPSY FOUNDATION OF AMERICA

The Epilepsy Foundation of America is the national voluntary agency dedicated solely to the welfare of the almost 3 million people with epilepsy in the U.S. and their families. The organisation works to ensure that people with seizures are able to participate in all life experiences; to improve how people with epilepsy are perceived, accepted and valued in society; and to promote research for a cure. In addition to programs conducted at the national level, epilepsy clients throughout the United States are served by more than 50 Epilepsy Foundation affiliates around the country.

Typical of the Foundation's national programs are its Jeanne A. Carpenter Epilepsy Legal Defense Fund, the H.O.P.E. (Helping Other People with Epilepsy) Mentoring Program, a Public Policy Institute, Seniors' and Women's Health Initiatives, the Kids Speak Up! advocacy program, a school personnel training program, outreach to youth and to the Hispanic community, employment programs and a research grants program. Services commonly provided in local communities are information and referral, counseling, patient and family advocacy, school and community education, support groups and camps for children. Its Web site,www.epilepsyfoundation.org, offers the most comprehensive, medically approved consumer information about epilepsy and seizures on the Internet and is the trusted source for millions of people who seek reliable information about epilepsy.

The Epilepsy Foundation was established in 1967 as the Epilepsy Foundation of America, merging two largely regional epilepsy organisations. It began operating as the Epilepsy Foundation on January 1, 1998, formalising the name most often used by the public in referring to the organisation. It is a 501(c)(3) tax-exempt charitable organisation existing under the laws of the State of Delaware, with a national office in metropolitan Washington, D.C.

The Foundation is governed by a Board of Directors comprising business leaders, health care professionals and client representatives, with the advice and counsel of a 50 member Professional Advisory Board made up of the country's leading epilepsy physicians and health experts. National staff of the Foundation is overseen by Richard P. Denness, President and CEO. The national board of directors is chaired by Joyce Bender, CEO of Bender Consulting Services in Pittsburgh, Pa. The Foundation's professional advisory board is chaired by Page B. Pennell, MD, Director of Research for the Epilepsy Division of the Department of Neurology at Brigham and Women's Hospital, a Harvard Medical School teaching affiliate in Boston, Mass.

The Epilepsy Foundation is funded primarily through individual donations from the general public and receives restricted grant support from the federal government, foundations and private industry. The organisation is a participant in the Combined Federal Campaign and a member of the National Health Council and of the International Bureau for Epilepsy.

CONTACT DETAILS

Epilepsy Foundation,
8301 Professional Place,
Landover, MD 20785 2238,
USA. T: +1 301 459 3700
info@efa.org

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EPILEPSY FOUNDATION OF NEW JERSEY

The Epilepsy Foundation of New Jersey, an affiliate of the National Epilepsy Foundation, is a state-wide, non-profit charitable agency dedicated to helping to improve the quality of life for people affected by epilepsy and their loved ones.

The Epilepsy Foundation of New Jersey, will ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through services, education, advocacy and research.

We provide comprehensive support, personalised services and advocacy for individuals and their families in order to maximise their participation in society.

THE FOLLOWING PRINCIPLES GOVERN ALL PROGRAM ACTIVITIES OF THE FOUNDATION

- The person shall participate to the fullest extent possible in their own care. The family and community are vital resources for the individual.
- Volunteer leadership and participation of affected people is essential to the success of the organisation.
- Duplication of effort shall be avoided as resources and services are developed for the persons we serve.
- Services and activities shall address the full spectrum of our clients special needs.
- Program activities shall meet defined program standards set by the National Epilepsy Foundation and others relevant accrediting bodies.

CONTACT DETAILS

Epilepsy Foundation of New Jersey
429 River View Plaza, Trenton, New Jersey 08611, USA
T: +1 609 392 4900

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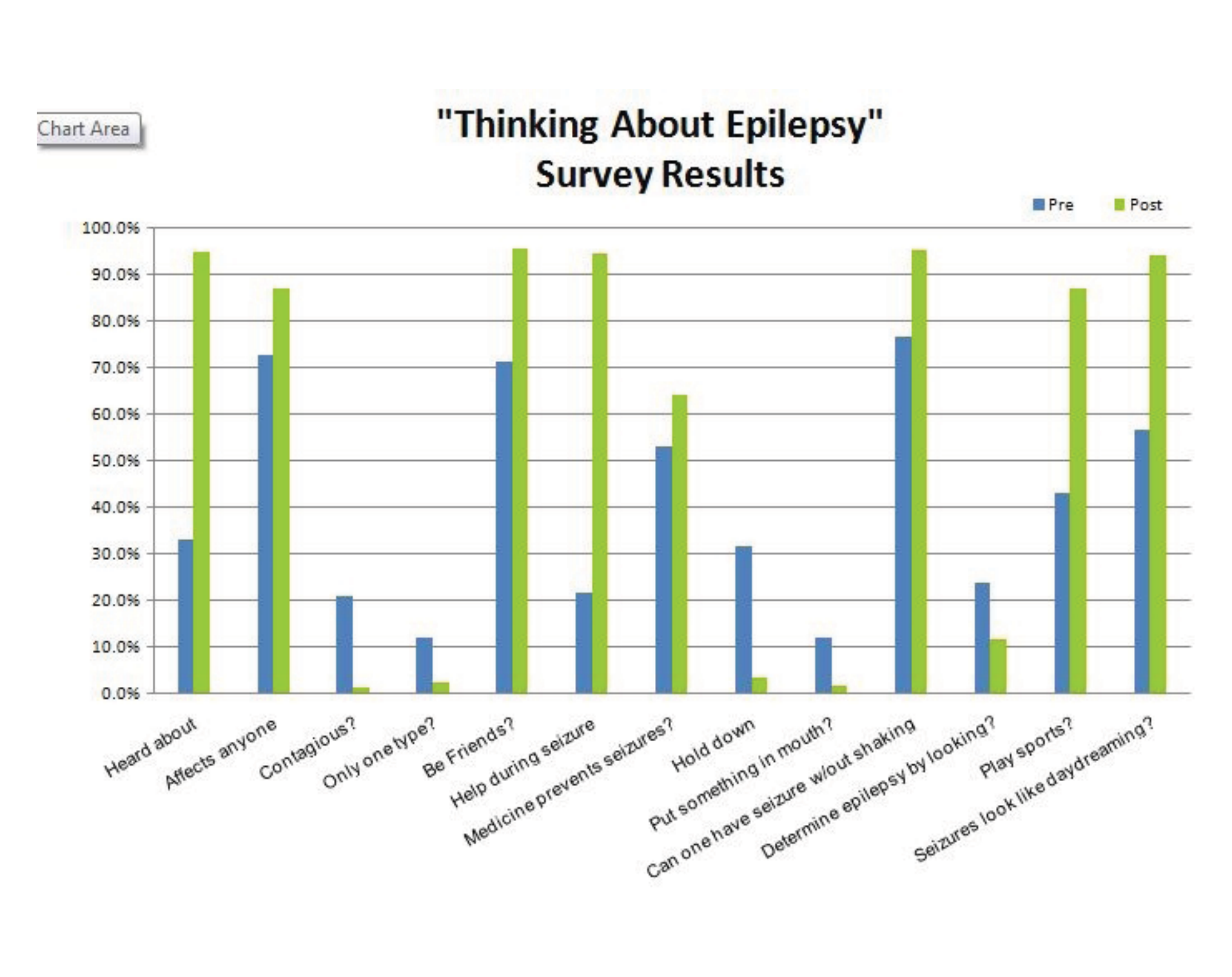
THE ANITA KAUFMANN FOUNDATION (AKF)



NAME
The Anita Kaufmann Foundation (AKF)

COUNTRY
United States of America

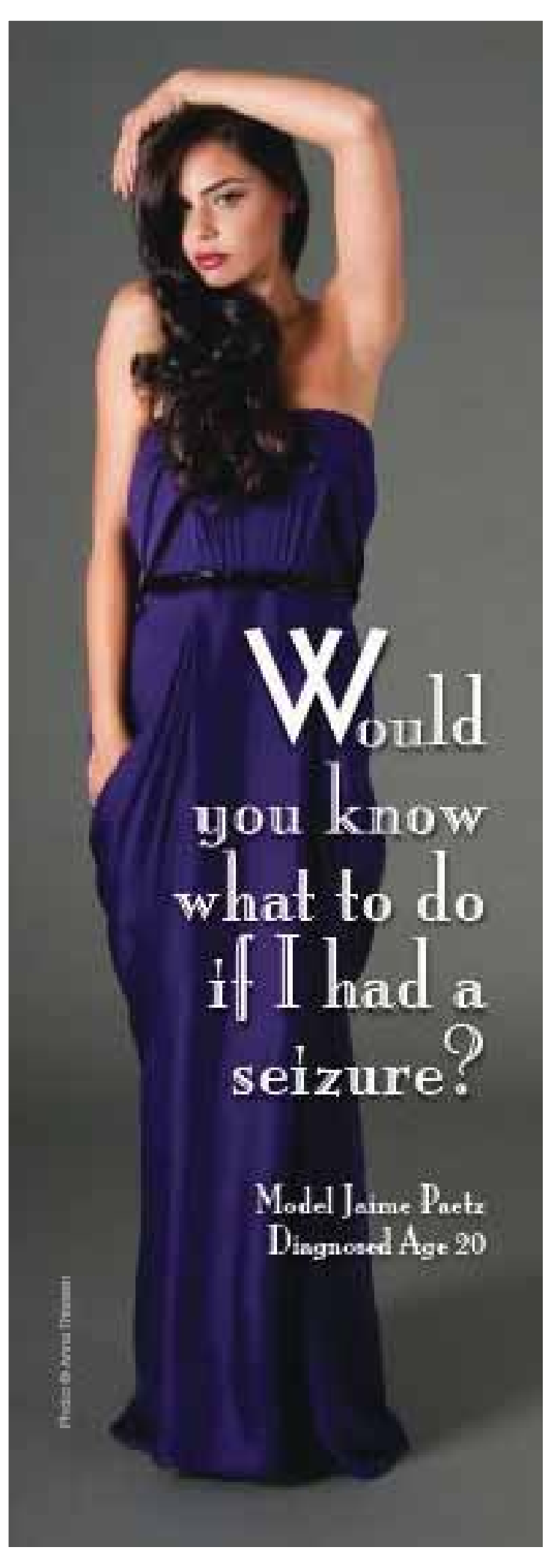
STATUS
Associate Member

DATE OF CREATION
December 29, 2003

DATE OF IBE AFFILIATION
September 3, 2008

TYPE OF ORGANISATION
Public Charity Created by Bequest

RANGE OF OPERATION
Range of Operation:



Seizure First Aid

Be calm
Remove dangerous objects
Always time the seizure
If person has fallen, turn on side & put something soft under head
Never put anything in mouth and never hold the person down

Call 911 if:

- Seizure lasts longer than 5 minutes or repeats
- Person is injured or the seizure occurred in water
- Person does not resume breathing after the seizure
- Person has no ID stating they have epilepsy

The Anita Kaufmann Foundation
Educating the public not to fear epilepsy and seizures
201-655-0420
Visit www.akfus.org
Global Sponsor of Purple Day
www.purpleday.org

GOAL
To educate the public not to fear epilepsy and to eliminate stigma.

HISTORY
AKF was created by a bequest from Anita Kaufmann's will. Anita Kaufmann was an attorney and business person who had epilepsy and felt that the discrimination and stigma were worse than the condition itself. She was a kind and giving person whose goal was to better the world and make it a better place for persons affected by epilepsy and seizures.

ACTIVITIES
AKF, in furtherance of its mission offers the following initiatives:

FIFTH GRADE EDUCATION PROGRAM – The fifth grade Thinking About Epilepsy program is offered free of charge to elementary schools across the US and consists of a 45-minute presentation that builds on the elementary science curriculum. The program provides information on how the brain works, the causes of epilepsy, how to detect epilepsy and seizures, how to provide seizure first aid and the importance of empathy and understanding. Students are required to complete a pre and post presentation questionnaire. The changes in knowledge and attitudes have been enormous. For example, the pre presentation questionnaire shows that only 20% of students know what to do in the event of witnessing a seizure; the post presentation questionnaire shows that 90%now know what to do in the event of witnessing a seizure.

PUBLIC EDUCATION PROGRAM – Free outreach programs that provide seizure first aid training to businesses and organisations. For instance, AKF arranged for all 50,000 employees of the New York Metropolitan Transit Authority to receive seizure first aid bookmarks with their paystubs.

PURPLE DAY FOR EPILEPSY AWARENESS – Global Sponsor of Purple Day. Assists in sponsoring awareness events across the US and internationally. Over 1 million participants worldwide. Various governmental offices have issued Purple Day Proclamations, including US Senators, US Governors, US mayors and more.

EDUCATIONAL MATERIALS – AKF designs and publishes attention getting materials including posters, bookmarks and purple scroll pens. Materials are in English and Spanish.

STATE OF ILLINOIS
EXECUTIVE DEPARTMENT

Proclamation

WHEREAS, epilepsy is one of the most common neurological conditions, estimated to affect over 3 million people in the United States, and more than 50 million worldwide; and,

WHEREAS, epilepsy is a group of disorders of the central nervous system, specifically the brain, characterized by recurrent unprovoked seizures; and,

WHEREAS, a seizure occurs when the normal electrical balance in the brain is lost, causing the brain's nerve cells to misfire, either firing when they shouldn't or not firing when they should. Seizures are the physical effects of these sudden, brief, uncontrolled bursts of abnormal electrical activity; and,

WHEREAS, the type of seizure depends on how many cells fire and which area of the brain is involved. A person that has a seizure may experience an alteration in behavior, consciousness, movement, perception and/or sensation; and,

WHEREAS, one in ten persons will have at least one seizure during his or her lifetime; and,

WHEREAS, the public is often unable to recognize common seizure types, or how to respond with appropriate first aid; and,

WHEREAS, Purple Day is a global effort initiated in 2008 dedicated to promoting epilepsy awareness in countries around the world; and,

WHEREAS, Purple Day is celebrated on March 26 annually to increase understanding, reduce stigma and improve the quality of life for people with epilepsy;

THEREFORE, I, Pat Quinn, Governor of the State of Illinois, do hereby proclaim March 26, 2011 as PURPLE DAY in Illinois, in support of this important effort to raise awareness of epilepsy.

In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of Illinois to be affixed.

Done at the Capitol, in the City of Springfield, this FOURTH day of MARCH, in the Year of Our Lord two thousand and ELEVEN, and of the State of Illinois the one hundred and NINETY-THIRD

Jesse White
SECRETARY OF STATE

Pat Quinn
GOVERNOR

CONTACT DETAILS
Debra Josephs,
Executive Director;
debra@akfus.org;
T: 201 655-0420
Website: www.akfus.org; www.purpleday.org

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MEMBERS IN THE NORTH AMERICA REGION

CANADA	Canadian Epilepsy Alliance/Alliance Canadienne de l'Epilepsie
JAMAICA	Jamaican Epilepsy Association
USA	Epilepsy Foundation of America
	Epilepsy Foundation of New Jersey (Associate Member)
	Anita Kaufmann Foundation (Associate Member)

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