

Name of Chapter: Philippine League Against Epilepsy, Inc.
Publications: PLAE Newsletter-September 2004, September 2005
Meeting: 3rd National Epilepsy Congress- 11th PNA Midyear Convention
Legend Hotel, Puerto Princesa, Palawan, May 5-8, 2005
Officer Election Date: September 5, 2003, for the term January 1, 2004 to
December 31, 2005
Report by: Leonor I. Cabral-Lim, M.D.

Summary of Activities in 2004 and 2005

Advocacy and Awareness

2004

- * Addressed issue of availability of AEDs particularly Phenobarbital
 - Communication with DOH
 - Communication with Mercury Drug
 - Meeting with PDEA and Pharmacists Group
 - Meeting with Dangerous Drugs Board
- * Addressed issue of affordability of AEDs
 - Tapped BRIDGES volunteers
 - Explored the possibility of putting up a Drug Bank (cooperative)
- * Rights of Persons with Epilepsy
 - Rights of Persons with Epilepsy Symposium
UP-PGH Medical Center, Sept. 6, 2004
 - Living with Epilepsy Forum
Health Forum, Annabel's Restaurant, Sept. 7, 2004
 - Rights of Persons with Epilepsy Lecture
Asia-Pacific Congress of Legal and Forensic Medicine
Manila Hotel, Sept. 21, 2004
- * Epilepsy Exemplar Awards
 - Awarding Ceremonies
Network Hotel, Manila, Sept. 6, 2004
- * Outstanding PWE in Asia-Oceania
Bangkok, Thailand, August 28, 2004
- * Establishment and development of support groups
 - Strategic Planning Workshop, Epilepsy Support Group
March 2004
 - Affiliation of EAAI (Friends of PLAE) as a provisional chapter of the
International Bureau of Epilepsy, August 2004
- * Continuation and Expansion of PAVEs project
 - Tapped support groups to participate in the awareness campaign
 - Expanded scope of awareness campaign and target groups
 - Improvement of educational materials
- * 3rd National Epilepsy Awareness Week (Sept 6-12)
"Seize the Day"
- * Multi-media Programs

- Radio and TV interviews
- Newspaper / magazine articles and press releases

2005

- * Addressed issue of availability and affordability of AEDs
 - AED's available at a cheaper price at selected BRIDGES clinics
 - AED's available at Epilepsy Manager clinics
 - Allocation of funds for Drug Bank Project
- * Rights of Persons with Epilepsy
 - Epilepsy in the Workplace Symposium
Makati Medical Center, Sept. 10, 2005
- * 2nd Epilepsy Exemplar Awards
Launching,
Philippine Columbian, Plaza Dilao, Paco, Manila, Sept 12, 2005
- * Establishment and development of support groups
 - Strategic Planning Meeting and Elections, Epilepsy Awareness Advocacy, Inc.,
Orchid Garden Hotel, Vito Cruz, Manila
 - Affiliation of EAAI (Friends of PLAE) as a national chapter of the International Bureau of Epilepsy, August 2005
- * Continuation and Expansion of PAVEs project
- * 4th National Epilepsy Awareness Week (Sept 5-11)
"Building Lives, Building Ties"
- * 3rd National Lay Symposium "Marriage and Family Issues"
- * Multi-media Programs
 - Radio and TV interviews
 - Newspaper / magazine articles and press releases

Health Care Delivery

2004

- * Two BRIDGES meetings for 2004
- * Formal launching of BRIDGES Project, Sept. 8 and 9, 2004
- * Increase in the number of volunteers and clinics
 - 40 Epilepsy Referral Consultants (as of Nov 2004)
 - 25 BRIDGES clinics
- * Expansion of the Project to PLAE Registry

2005

PAVE-BRIDGES-REGISTRY Meeting May 2005
Data Collection in BRIDGES Clinics

Fund Raising

2004

Walkathon – Sept. 12, 2004

2005

Bingo Socials, September 12, 2005

For further information on PLAE ongoing projects, log on to www.plae.org.ph

Summary Statement

Over the last two years the organization has

1) continued to improve

a) the quality and delivery of epilepsy care to the grassroots through the i) ongoing CME for primary care physicians ii) wider implementation of the BRIDGES Project iii) expansion of the Epilepsy Manager Program

b) the professional growth of the members through the National Epilepsy Congress, Clinical Dilemmas Series and participation in Regional and International Epilepsy Meetings/Workshops and Courses.

c) the promotion of epilepsy awareness nationwide through the PAVE's, National Lay Symposium, National Epilepsy Awareness Week Celebration, tri-media information campaign and web page.

2) advocate for PWE through a) Organization of the "Epilepsy Awareness Advocacy Inc.", the umbrella organization for all the epilepsy lay support groups in the country and its official affiliation with the IBE. b) Launching of the Epilepsy Exemplar Awards c) addressing patient concerns-availability and affordability of AED's, availability and access to epilepsy care services and rights of persons with epilepsy

3) embarked on the Epilepsy Registry Project.

4) Encourage further training in Epileptology.

Summary of Activities in Relation to Global Campaign in 2004 and 2005

The PLAE, Inc. formally launched the "Epilepsy: Out of the Shadows" PHILIPPINES, a national campaign against epilepsy last September 8, 2001 and this has been an ongoing active campaign. The national epilepsy campaign is an initiative of the PLAE and is continuously being developed within the already existing national health care system in collaboration with the Department of Health, with the public and private sectors, relevant non-governmental organizations, patients, families and their caregivers as partners.

The "Epilepsy: Out of the Shadows" PHILIPPINES has been pursued along the same strategy of the Global Campaign. This strategy includes two parallel and simultaneous tracks

I to raise general awareness and understanding of epilepsy

II to support the Department of Health in identifying the needs and promoting education, training, treatment, services, research and prevention nationally.

I A Information Campaign

Campaign Targets

a. public-(multimedia campaign) newspaper articles, press releases, press

conferences, radio and TV appearances, radio ads, epilepsy brochures, webpage www.plae.org.ph , epilepsy information booth

b. patients, families and caregivers

b1. local epilepsy lay seminars-implemented by the PAVE's Provincial Awareness Volunteers in Epilepsy in their respective provinces(covering several provinces in the country.).For the year 2004 and 2005 about 50 lay forums were held each year in selected hospitals in Metro Manila and in the different regions nationwide (majority during Epilepsy Week) The epilepsy lay seminars are ongoing for the year 2006 with each PAVE volunteer committed to at least 2 seminars/year (one for patient's, families and caregivers, and one for school teachers and or employers)

b2. National Lay Symposium

3rd National Lay Symposium, "Epilepsy Marriage and Family"

September 11, 2005, Philippine Columbian Plaza Dilao, Paco, Manila

b3. support organization of self-help groups

* Establishment and development of support groups

-Strategic Planning Workshop, Epilepsy Support Group

-Orchid Garden Suites, Manila, March 27,2004

-Strategic Planning Meeting and Elections,Epilepsy Awareness Advocacy,Inc.,

Orchid Garden Hotel,Vito Cruz, Manila, Sept. 10,2005

-Affiliation of EAAI (Friends of PLAE) as a national chapter of the International Bureau of Epilepsy, August 2005

IB Epilepsy Awareness Week Celebration

* 3rd National Epilepsy Awareness Week (Sept 6-12)

"Seize the Day"

* 4th National Epilepsy Awareness Week (Sept 5-11)

"Building Lives, Building Ties"

IC Advocacy

1C a. protection of rights of persons with epilepsy.

Symposium on "**Rights of Persons with Epilepsy**"

2004

- Rights of Persons with Epilepsy Symposium

UP-PGH Medical Center, Sept. 6, 2004

- Living with Epilepsy Forum

Health Forum, Annabel's Restaurant, Sept. 7, 2004

- Rights of Persons with Epilepsy Lecture

Asia-Pacific Congress of Legal and Forensic Medicine

Manila Hotel, Sept. 21, 2004

2005

-Epilepsy in the Workplace Symposium
Makati Medical Center, Sept. 10, 2005

IC b. Epilepsy Exemplar Awards

2004

- Epilepsy Exemplar Awards
Awarding Ceremonies
Networld Hotel, Manila, Sept. 6, 2004

2005

- 2nd Epilepsy Exemplar Awards
Launching,
Philippine Columbian, Plaza Dilao, Paco, Manila, Sept 12, 2005

II Collaboration with the Department of Health

IIA Needs Assessment

a. availability of health professionals, programs/services that provide care for persons with epilepsy in the different regions of the country. Data on epilepsy care services in the country gathered by the Health Care Delivery Committee. Information on the list of epilepsy clinics and epilepsy services in the country made available to patients.

b. Availability and affordability of antiepileptic drugs.

2004

* Addressed issue of availability of AEDs particularly Phenobarbital

- Communication with DOH
- Communication with Mercury Drug
- Meeting with PDEA and Pharmacists Group
- Meeting with Dangerous Drugs Board

* Addressed issue of affordability of AEDs

- Tapped BRIDGES volunteers
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2005

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c. Lack of local statistics in epilepsy-Data gathered on available local statistics.

IIB Promoting education, training, treatment

Education and training of health workers in the diagnosis and management of epilepsy (see CME, Summary of Activities)

IIC Improvement of Health Care Delivery

(See BRIDGES Project, Summary of Activities)

Educational Activities

CME

2004

- * For Primary Care Physicians
- Industry assisted lecture on "Epilepsy : Primary Care"
- * For PLAE Members
- Clinical Dilemmas in Epilepsy Management Series
Cebu City, Sept. 9, 2004
- First PLAE Regional Meeting
Cebu City, Sept 9, 2004

2005

- * For Primary Care Physicians
- Industry assisted lecture on "Epilepsy in the Movies"
Modules on Diagnosis and Treatment, Quality of Life (nationwide)
EURAP Orientation
Epilepsy Manager Program 2005-2006
Area-Iloilo
- * For PLAE Members
- 3rd National Epilepsy Congress-11th PNA Midyear Convention
"Raising the Bar in Epilepsy Diagnosis", May 5-8, Legend Hotel,
Puerto Princesa, Palawan
- Lecture Series on Status Epilepticus in cooperation with the Philippine
Neurological Association Epilepsy Council (nationwide), September-December
2005.
- Epilepsy and Pregnancy/EURAP Orientation Lectures-Regional,
September-December 2005

Activities in conjunction with local IBE Affiliate

2004

Mar. 27 - **Strategic Planning Workshop, Epilepsy Support Group**
Orchid Garden Suites, Manila

Sept. 6 - **Rights of Persons With Epilepsy Symposium**
UP-PGH Medical Center
- **Epilepsy Exemplar Awards, Awarding Ceremonies**
Network Hotel, Manila

Sept. 6-12 - **3rd National Epilepsy Awareness Week (Nationwide "Seize the Day")**

2005

Sept. 5-11 - **4th National Epilepsy Awareness Week**
“Building Ties, Building Lives”
Nationwide

Sept. 10 - **Strategic Planning Meeting and Elections**
Epilepsy Awareness Advocacy, Inc.,
Orchid Garden Hotel, Vito Cruz, Manila
- **Epilepsy in the Workplace Symposium**
Makati Medical Center

Sept. 11 - **Bingo Socials for the Benefit of PLAE Drug Bank Project**
Launching, 2nd Epilepsy Exemplar Awards
Philippine Columbian, Plaza Dilao, Paco, Manila
- **3rd National Lay Symposium, “Epilepsy Marriage and Family”**
Philippine Columbian
Plaza Dilao, Paco, Manila

Future Plans

- * Outcome Measures for Ongoing Projects
- * Establishment of Drug Bank
- * Regional Development
- * 2nd phase launch National Epilepsy Campaign.
with EAAI and DOH
Work closely with EAAI in the Awareness and Advocacy Activities
- * Epilepsy Registry Project.
Advancement of Epilepsy Education and Training