

PHILIPPINE LEAGUE AGAINST EPILEPSY
ANNUAL REPORT FOR 2001

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Health Care Delivery

National Epilepsy Registry

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JOURNAL :

None

INFORMATION MATERIALS : Printed September 2001 :

"What you Need to Know about Epilepsy"
"Mga Kaalaman Tungkol sa Epilepsy "(Filipino)

SCIENTIFIC OR EDUCATIONAL MEETINGS

A. First National Epilepsy Congress

The First National Epilepsy Congress of the Philippine League Against Epilepsy was held at the Westin Philippine Plaza last September 7-8, 2001. (See souvenir program enclosed) World famous epileptologists, Dr. Martha Morrell from the Columbia-Presbyterian University in New York and Dr. Antonio Delgado-Escueta from the University of California delivered several important plenary lectures. Dr. Cabral-Lim, President of the organization gave a plenary lecture on the "State of Epilepsy in the Philippines". The Congress was preceded by a pre-convention dinner lecture by Dr. Morrell on "Setting up of Epilepsy Centers/ Programs"; this was attended by a small group consisting of PLAE officers, training officers/representatives of the different Neurology Residency Training Programs and neurologists from the different regions of the country. In spite of the times, there was a good turn-out of participants which included neurologists, pediatricians and family/general physicians. All the sessions were well attended and appreciated. The Lay Symposium scheduled on the afternoon of the 2nd day, which was patterned after the "Living with Epilepsy" Sessions of the ILAE was attended by about 400 people, most of them non-doctors. The scientific sessions were described by the participants as being rewarding and well-rounded, addressing the interests of various groups.

B. Teaching Modules in partnership with the Philippine Neurological Association

The teaching module entitled "Epilepsy-an interactive teaching module designed for non-neurologists" a project of the Continuing Medical Education Committee of the PLAE has been adopted by the Philippine Neurological Association as its teaching module for Epilepsy in its regular out-of-town lectures for the benefit of general practitioners and non-neurologists in the provinces.

ACTIVITIES RELATED TO THE GLOBAL CAMPAIGN AGAINST EPILEPSY

LAUNCHING OF THE "Epilepsy: Out of the Shadows" PHILIPPINES

Finally, after about a year of preparation, the Philippine League against Epilepsy formally launched its National Campaign against Epilepsy entitled after the Global Campaign slogan: "Epilepsy : Out of the Shadows" PHILIPPINES The Launch was held during the closing dinner of the PLAE's first National Epilepsy Congress at the Westin Philippine Plaza in the city of Manila last September 8, 2001.

The launch was attended by PLAE members, congress delegates, media volunteers and representatives from various pharmaceutical companies and the media. During the launch, Dr. Josephine Casanova-Gutierrez one of the campaign directors, presented the Project Rationale and Project Description. The President of the PLAE and co-campaign director, Dr. Leonor Cabral-Lim further elaborated on the directions towards improving epilepsy care delivery in the country. The PLAE also took the opportunity for the group to preview the six television and four radio advertisements that were produced within the year. These advertisements were produced from donations from various sponsors and through the help of advertising and media volunteers who offered their services pro bono in support of the mission of the PLAE. These media/creative volunteers were also recognized during the night and were given plaques of appreciation and congratulated by the PLAE President, Dr. Lim, for the well crafted and impressive advertisements.

During that night, ten PLAE members who volunteered to conduct epilepsy seminars in their provinces or regions were presented. These volunteers, designated as "Epilepsy Awareness Volunteers", were given information module/kits which contained a 16-minute teaching video entitled, "Journey into the Mind" produced by the Lay Education Committee through an educational grant from Pfizer last February 2001, as well as a slide module entitled " What You Should Know About Epilepsy" . The kit also contained print materials ready for dissemination in local newspapers

and the core messages of the campaign. Copies of the TV and radio advertisements and the newly produced brochure, "What You Should Know About Epilepsy" in English and Tagalog (local dialect) will be made available to the Epilepsy Awareness Coordinators upon request. These volunteers were tasked to hold at least two Epilepsy Seminars/year among caregivers, patients and school teachers in their respective provinces or regions and shall report their accomplishments to the Lay Education Committee after a year.

The PLAE Website was viewed and the Epilepsy Hotline number (632) 8674765 featured in the advertisements was announced to be open beginning that day during the dinner. The night was a truly rewarding culmination of months of hard work and preparations.

A press conference was also held the day before the launch of the campaign. The officers of the organization also granted tv interviews about epilepsy and the campaign. Newspaper articles and press releases related to epilepsy and the campaign also came out a few days before the launch and in the succeeding weeks after that.

The TV ads started airing right after the launching of the campaign and were aired until December 2001 in a major TV Channel (Channel 2-ABS-CBN). These ads, had generated an average of 5-11 calls/day to the Epilepsy Hotline. The organization is working on having the radio ads aired in 2002.

A booth for the campaign was also put up during the Philippine Neurological Association 23rd Annual Convention held in Iloilo City, Panay Island from Nov.28-Dec.1, 2001 to disseminate the campaign in the Visayas. (one of the three major islands of the country)

ACCOMPLISHED ACTIVITIES RELATED TO THE GLOBAL CAMPAIGN AGAINST EPILEPSY

I. Local Data Gathering

- A. Gathered available statistics and researches on K.A. P. 's on Epilepsy
- B. Collected hospital data on epilepsy among the different Neurology Training Institutions.
- C. Collected data on available epilepsy care services (professional care, epilepsy clinics, facilities)
- D. Developed Research Protocols and Conducted Researches
 - 1. **" Public Knowledge , Attitudes and Perceptions about Epilepsy"**
(telephone survey, status : finished)
 - 2. **"Quality of Life among Persons with Epilepsy"** (data gathering phase)
 - 3. **"Knowledge, attitudes and Perceptions among persons with Epilepsy thru Focused Group Discussions"** (collation of data and writing phase)

II. Production of Multimedia Educational Materials

- A. Video : **"Journey into the Mind"** , produced February 2001
(*This is a sixteen minute teaching video in English featuring Filipino neurologists discussing the etiologies,, clinical manifestations, treatment, and social consequences of epilepsy. This can be used for the educated lay person or a non-neurologist.*)
- B. Teaching Slide Modules for use in Lay Seminars
 - 1. **" What You Should Know About Epilepsy "**
(*basic epilepsy information*)
 - 2. **"Practical Daily Living Guidelines"**
(*safety tips for persons with epilepsy*)
 - 3. **" Epilepsy : What we can do about it"**
(*proactive approach to epilepsy, patient responsibility, the value of support groups*)
 - 4. **" Cognitive and Behavioral Issues in Epilepsy"**
(*common school and behavioral problems among children with epilepsy: causes and approach to management*)
- B. Brochures on Epilepsy
 - " What You Should Know About Epilepsy"**
 - " Ang Katotohanan tungkol sa Epilepsy "** (*in Filipino*)
 - " Epilepsy 101 "** (*quiz on epilepsy knowledge and practices with answer key*)

- D. Television Advertisements (in Tagalog, the most commonly used local dialect)
1. **"Kim"** – 15 second and 30 second versions of the Tagalog ad featuring Kim, a young boy with epilepsy in real life, set in an old Manila house, playing alone and expressing his dream to become a famous baseball player someday. The ad ends with the words, "Nagagamot ang Epilepsy" or "Epilepsy can be treated" and gives the number of the Epilepsy hotline.
 2. **"Tsismis" (Gossip)** - a 30 second Tagalog ad featuring close ups of mouths talking in series as they sit in a local public jeepney, gossiping about a neighbor who was just diagnosed to have epilepsy. It highlights various misconceptions of different people about the causes and prognosis of persons with epilepsy. It ends with the announcement of the Epilepsy Hotline.
 3. **"Orasan" (Clocks)** – two different ads featuring an alarm clock ringing violently amidst a host of clocks. It highlights the unpredictability and self-limiting nature of an epileptic attack. It also ends with an invitation to call up the Epilepsy Hotline for more information.
 4. **"Epilepsy "** – a 15 second ad showing the word Epilepsy shaking and trembling as in a video that is not working right. It suddenly stops when someone tries to fix the screen. It compares the condition to epilepsy being a disorder which can be fixed or treated.
- E. Radio Advertisements (in Tagalog also)
1. **"Kisay" (Derogatory Nickname for a Seizing/ Shaking Girl)**- features a young girl being ridiculed by playmates because of her epilepsy, then being refused in school because of school teachers fears about managing the seizures It ends with the Epilepsy Hotline number.
 2. **"Inday"** (Visayan nickname for a young provincial lass, most often a domestic helper) – features a young provincial lass singing out of tune for all the neighbors to hear. She is scolded by a neighbor to stop. After a few days of practicing, she learns to sing well and is praised for her singing. It highlights the correctability of epilepsy as a condition. It gives the Epilepsy hotline number.
 3. **"Romy"** – features a man with epilepsy in the workplace that co-employees are talking about. It showcases common public misconceptions about the disease. It gives the Epilepsy hotline number at the end.
- F. Construction of **PLAE Website** : www.plae.home-page.org

III. Media Campaign

- A. Newspaper articles/Press releases
1. "Epileptics can still lead productive lives"
Philippine Star, April 2, 2001
 2. " NGO seeks law to protect epileptics"
Manila Standard, April 3, 2001
 3. "Mental Health Disorder, tampok sa World Health Day"
Kabayan, April 7, 2001.
 4. "World Health Day 2001 focuses on Mental Health"
Department of Health Press Release, April 4, 2001
 5. "Bringing Epilepsy Out of the Shadows"
Prevention magazine 1st Anniversary Issue July 2001
 6. " Living with Epilepsy"
Philippine Daily Inquirer, September 1, 2001
 7. "Discrimination starts at home, says study"
Philippine Daily Inquirer, September 1, 2001
 8. "Should we allow persons with epilepsy to drive?"
Philippine Daily Inquirer, September 12, 2001

9. "Understanding Epilepsy"
Manila Standard, September 28, 2001
 10. "Epilepsy in the Philippines"
Manila Standard, September 28, 2001
 11. "Epilepsy and Driving "
Manila Standard, October 2001
 12. " Epilepsy "
Manila Bulletin, October 2001
- B. Radio- Interviews in relation to World Health Day Celebration
- with PLAE Officers, April 2001
- C. Television
1. Health segment features on Epilepsy, "**Alas Singko y Media**"
Channel 2-ABS-CBN, September 2001
 2. TV Health Program Interview : "**Kapwa Ko Mahal Ko** "
Channel 7 -GMA, September 2001
 3. TV Advertisements -"**Kim**" and "**Tsismis**" aired daily at Channel 2 daily during morning , noon and late night time slots
Channel 2-ABS-CBN, September up to December 2001.
- D. Art Exhibit- featuring award winning art works of persons with epilepsy of the "**Color My World**" art contest project of the Philippine Neurological Association and Novartis Health Care Philippines held April 3-8. 2001; Museo Pambata, Manila, Philippines as part of the World Health Day Celebration
- E. "**Epilepsy: Out of Shadows** " **PHILIPPINES** booth .The campaign booth was open for three days (November 30-December 1, 2001 during the 23rd Annual Philippine Neurological Association Convention in Iloilo . It was an opportunity to inform the neurological association members and guests of the ongoing campaign. New members were recruited.

II. **PLAE Organized Lay Forum / Epilepsy Seminars in Metro Manila and selected provinces :**

A. Lay Forum/Epilepsy Seminars:

March 29, and August 2001: Philippine General Hospital, Manila
Two sessions of "Focused Group Discussions Among Persons with Epilepsy"

March 31, 2001 :
Makati Medical Center, Manila
"Understanding Epilepsy"

August 2001 : Lucena, Quezon
"Mga Kaalaman Tungkol sa Epilepsy (Some Information About Epilepsy)"

September 8, 2001: National Epilepsy Congress afternoon session
Devoted to "*Living with Epilepsy*" Symposium with about 400 professionals, patients, families and caregivers, and non-governmental organizations.

September 26, 2001-Neuroscience Week Celebration at the Philippine General Hospital, Manila, "*Epilepsy Lay Forum*"

October 16, 18 and November 5, 2001 : Nueva Vizcaya, Luzon
Three Epilepsy Seminars for Private School Teachers, Public School Teachers and Caregivers and Patients

- B. Appointment of Ten Provincial Awareness Volunteers for Epilepsy (P.A.V.E.) who will conduct at least two seminars for lay people in their respective provinces/regions in one year: one for schoolteachers and one for patients and care-givers. Each volunteer was provided with campaign kits complete with brochures, slide modules, films, radio advertisements and other materials.

IV. **Epilepsy Hotline-** operational since September 8, 2001; Tel. No. (632) 8674765 During first two months of operation calls ranged from 5-11 calls per day.

VI. Continuing Medical Education Programs for Neurologists and Non-Neurologists

- A. Produced Teaching Module on basic clinical epilepsy entitled, "**Epilepsy: an Interactive teaching Module Designed for Non-neurologist**", intended for primary care physicians and used by the PLAE for small group / round table discussions and by the Philippine Neurological Association for its regular Outreach Programs in the provinces.
- B. "**National Epilepsy Congress**" – the first congress solely devoted to epilepsy in the Philippines. Held September 7-8, 2001 at the Westin Philippine Plaza.

VI. Collaborative Meetings with Concerned Organizations

- A. Participation in the Department of Health-WHO World Health Day Celebration (April 2001). The National Mental Health Policy which includes epilepsy as one of the priority brain disorders was issued by the Department of Health as Administrative Order No. 8s.2001, on April 5, 2001.
- B. Participation in the WHO Regional (Western Pacific) Consultation on Epilepsy Meeting, November 14-15, 2001, Manila Philippines
- C. Collaboration with existing Support Groups : Philippine Foundation for Epilepsy and Epilepsy Support Group of Cebu

VII. Advocacy

- A. Adoption of the "*National Declaration Against Epilepsy*", September 8, 2001
- B. Formal launch- "*Epilepsy: Out of the Shadows*" PHILIPPINES, September 8, 2001

OTHER ACTIVITIES :

Year End Evaluation and Strategic Planning Meeting . Held at the Richmond Hotel at Ortigas, Pasig City last November 17, 2001 attended by outgoing and incoming officers of the PLAE and committee members. The initial part of the meeting was spent reviewing the organization's objectives and accomplishments. The group spent the rest of the meeting formulating strategies and coming out with projected outcome measures to achieve priorities set for the incoming term 2002-2003.

SUMMARY STATEMENT

From being an obscure organization, the Philippine League Against Epilepsy is now recognized as an active and dynamic professional group working for the welfare of persons with epilepsy. People in the medical and paramedical professions, in the pharmaceutical industry, patients, teachers, media, government agencies and the general public in the Philippines are now aware that the PLAE exists and is consistently and energetically accomplishing its objectives one at a time. The successful first National Epilepsy Congress was a landmark accomplishment. It affirmed the confidence, strength, efficiency and resourcefulness of the Executive Committee. The Philippine Epilepsy Campaign is ongoing and tapping every possible opportunity for information dissemination and education. This is facilitated by the availability of locally produced educational materials in different media and the willingness of the members to volunteer to improve epilepsy education in their respective regions. The League holds regular scientific activities for its members and also conducts continuing medical education programs to promote the education and training of primary care physicians in the country. Recently, the organization has been working hand in hand with the Philippine Neurological Association in educating and updating general practitioners in the provinces about epilepsy care through regular out of town lectures.

The organization has also researched on and collected data on Epilepsy statistics and the availability of epilepsy care services in the country. This data will be useful not only in identifying needs, but also in working out solutions on how to respond to these needs.

The PLAE is now more financially viable and independent. There are now 103 members. The strength of the organization lies in the active participation of the members and support of the leadership towards the achievement of the mission/vision of the organization. The organization has also established a good and regular working relationship with the active and existing patient support group.

Links have been made with the Department of Health by participating in the World Health Day Celebration and the World Health Organization Western Pacific Region by participating in the recent Western Pacific Consultative Meeting on Epilepsy.

Communications with the DOH (Department of Health) has also been started towards working out a collaboration on how to improve the quality and delivery of epilepsy care in the country.