

1ST NATIONAL EPILEPSY CONGRESS: A BIG SUCCESS

November 2001

Amidst threats of coups, Abu Sayyaf kidnappings and global economic depression, the PLAE valiantly marched on to its 1st National Epilepsy Congress last September 7-8, 2001 at the Westin Philippine Plaza. World famous epileptologists, Dr. Martha Morrell from the Columbia-Presbyterian University in New York and Dr. Antonio Delgado-Escueta from University of California delivered several important plenary lectures. The Congress was preceded by a small dinner among the PLAE officers and training officers of Neurologic institutions in Manila with Dr. Morrell giving a short talk on her work with the Epilepsy Foundation of America. 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 we patterned after the "Living with Epilepsy" Sessions of the ILAE was also attended by about 400 people, most of them non-doctors. The scientific sessions were described by participants as being rewarding and well-rounded, addressing the interests of various groups. No way we were to know that 3 days after the congress, the World Trade Center will be attacked by terrorists and trigger more severe travel restrictions and global recession and a possible world war ! We just finished in the nick of time!

How can you help?

TREAT...

Be a Epilepsy Manager or an Epilepsy referral physician in an underprivileged area where there are no specialists.

TEACH...

Help your patients and families to understand epilepsy. Educate your community.

TRAIN...

Teach students, technicians, residents, local doctors about better epilepsy management.

TRUST....

Encourage persons with epilepsy to live a fuller life.
Give them guided opportunities for education, employment, gainful occupation and a normal social life.

PLAE ELECTS NEW SET OF OFFICERS FOR THE TERM 2002-2003

The General Elections and Annual General Assembly and Business Meeting was held on the first day of the National Epilepsy Congress. The COMELEC, headed by Dr. Ces Alincastre with members, Dr. Philip Oliva and Dr. Chinky Rivera, announced the new set of officers and members of the Board of Trustees for the term 2002-2003:

Executive Committee:

Dr. Leonor Cabral-Lim
Dr. Elma Maranon
Dr. Johnny Lokin

Dr. Conrad Nievera
Dr. Martha Lu-Bolanos
Dr. Martesio Perez
Dr. Imelda David
Dr. Cora Danguilan
Dr. Lourdes Ledesma
Dr. Josephine Gutierrez

New Committees, New Members

As of September 19, 2001, the PLAE has a total of 109 members. PLAE's Reelected President, Dr. Leonor Cabral-Lim recently called for an Evaluation Meeting of the organization's past targets and a Strategic Planning Meeting to set the direction of the PLAE in the next two years. The whole day meeting was held at Richmond Hotel in Ortigas, Pasig last November 17, 2001 and facilitated by the very effective Mrs. Cecille Batalla, Human Resources Manager from Mercke-Sharp and Dowe. It was attended by eighteen members, some of who were former committee members, but there were also a lot of young members who volunteered to help out in the programs of the PLAE this coming year. The new committee formed this year is the Advocacy Committee, which will be chaired by Dr. Martesio Perez. This committee will work on facilitating legislation regarding issues that concern persons with epilepsy like the National Mental Health Program, rules on driving and education and employment rights. Dr. Lim announced that for the coming term, her priority projects will be the National Campaign Against Epilepsy, the Primary Care Physicians Training Program and the Advocacy program. Those of you who are interested to work for any of the committees are most welcome. Please get in touch with the concerned committee chair.

LAY EDUCATION COMMITTEE

Chair : Josephine Gutierrez

Members : Glicerio Alincastré
Julette Batara
Lourdes Ledesma
Elma Maranon
Nellie Severo
Benilda Sanchez

Provincial Volunteers : Butch Liban
Ray Espinosa
Philip Oliva
Cora Danguilan
Hazel Paragua
Vicky Bael
Lourdes Canto/ Michelli Yusay
Evelyn Madriaga
Art Surdilla

CONTINUING MEDICAL EDUCATION COMMITTEE

Chair : Leonor Cabral Lim

Members : Hazel Paragua
Darwin Dasig

ADVOCACY COMMITTEE

Chair : Martesio Perez

Members : Malen Ortiz
Cora Danguilan
Leonor Cabral-Lim

CABRAL-LIM REPRESENTS R.P. IN W.H.O. WESTERN PACIFIC REGIONAL CONSULTATION ON EPILEPSY

Report from the PLAE President

Last Nov. 14-15, I was invited by the WHO Western Pacific Region to participate in a Consultative Meeting on Epilepsy. As participants, we were tasked with the ff. objectives:

1. Review the draft Regional Report on the present state of epilepsy in the region.
2. Review the implementation of the WHO/ILAE/IBE Global Campaign Against Epilepsy in the countries of the Western Pacific region.
3. Develop a framework for action for countries in the region.

Prior to the meeting, country representatives were requested to submit a paper on the "State of Epilepsy" in their respective countries. The meeting was attended by 12 representatives from member countries in the Western Pacific which included Australia, Cambodia, China, Fiji, Japan, Republic of Korea, Laos, Malaysia, Papua New Guinea, Philippines, Singapore and Vietnam as well as Mrs. Hanneke de Boer, Chairperson of the Global Campaign Against Epilepsy; Dr. Leonid Prilipko, Programme Leader, Neurological Diseases and Neuroscience, WHO and Dr. Helen Herrman, Acting Regional Adviser in Mental Health, WHO. Other attendees include Dr. Schichuo Li, WHO Representative and Dr. Jianzhong Wu from the Beijing Neurological Institute.

Mrs. Hanneke de Boer and Dr. Wang Wenzhi gave plenary lectures on the Global Campaign and the Demonstration Projects in China respectively. The afternoon and the rest of the day was devoted to plenary presentations on the present state of epilepsy among the countries represented and group discussions on the activities of the Global Campaign in the countries and the framework of action in the different countries. There was also a panel discussion on the role of government and non-government organizations in public awareness and service provision for epilepsy and the Western Pacific Regional Report on Epilepsy.

At the end of the day, the group agreed that although there are basic differences among the different countries not only in terms of economies, cultural factors and available resources, common problems exist although at different degrees and level. The following common needs and priorities were identified: accessibility of treatment, availability of drugs, increasing public education/awareness, improving training at the primary care level, lack of legislation, lack of diagnostic/treatment facilities, lack of community/government support, lack of epidemiological data/research, employment/vocational programs/social rehabilitation and setting up of NGO's.

The role of the WHO in the implementation of the Global Campaign in the countries of the Western Pacific Region was also discussed. It was quite clear that the initiative for asking support from the WHO should come from the Department of Health from each country and the WHO will give the necessary support if funding is available or help obtain support from funding from other agencies. It was also emphasized that this is the best time for the different Departments of Health to seek WHO support while epilepsy is a priority.

The Consultative Meeting although quite hectic and taxing was truly very rewarding in terms of achieving the objectives set. At the end of the meeting, despite diversities within the Western Pacific Region, I realized the "oneness" and the common direction to which we were all going, that is improving the quality of life of persons with epilepsy not only in our own countries, not only in the Western Pacific Region but also globally.

We have to give recognition to Mrs. Hanneke de Boer for chairing the Meeting, Dr. Helen Herrman and Dr. Leonid Prilipko not only as moderators for the panel discussions but also as the responsible officer for the meeting and Programme Leader respectively, officers and staff of the WHO Western Pacific who made the meeting possible, Drs. Li Shichuo, Wu Jianzhong, Michael Salzberg for preparing the draft report and all the country representatives for their very active participation.

Let us all continue to work together and enjoin others to support the Global Campaign Against Epilepsy to truly bring "Epilepsy: Out of the Shadows".

LETTER FROM DR. MORRELL

New York, September 14, 2001

Dear Dr. Cabral-Lim:

Thank you so much for your message of concern. I and my family are entirely safe but no one remains untouched by this terrible act. This is truly an encounter with evil and there will be horrid loss with which we will all have to deal. New York still feels like a war zone - road blocks and inspections of bridges coming in. Nevertheless, this City is reacting in an extraordinary manner and we have also seen many heroes amongst us.

Before all this happened, I was preparing to write a thank you note for the gracious hospitality shown to me by you, your colleagues and by the Pfizer representatives. Although I was only there a short time, I felt as if I had been there much longer because I was able to experience so much of your city. More importantly, I had the opportunity to meet a group of supremely dedicated people. You all deserve the highest congratulations for organizing such a successful Congress and for including Scientific as well as lay oriented events. I can only imagine the work you put into developing what I know will be a very successful chapter of ILAE.

I admire you all for your dedication to persons with epilepsy. Given what you must deal with, in terms of social and medical challenges in your country, this requires more effort and commitment from each of you personally than we need to make in the United States. I was also impressed by the sophistication of the neurologists in the area of epilepsy. Your patients are fortunate to have access to all your experience, knowledge and wisdom. I will always remember my visit there and feel as if I came away with many new friends. I look forward to seeing you all as our paths cross. I must thank the Chapter for the supremely generous gift.

Please let me extend my invitation to any of the chapter members to visit the Columbia University if you ever plan to come to New York. I would be thrilled to have you share your experiences with our faculty, fellows and residents.

Sincerely,
Martha Morrell

LAUNCH OF THE CAMPAIGN AGAINST EPILEPSY: "EPILEPSY : OUT OF THE SHADOWS - PHILIPPINES"

Finally, after a year's work, the Philippine League against Epilepsy formally launched its National Campaign against Epilepsy titled after the Global Campaign title: "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, the director for the information campaign, Dr. Josephine Gutierrez, spoke on the Project Rationale and Project Description. The President of the PLAE and co-campaign director in charge of Health Care Delivery, Dr. Leonor Cabral-Lim further elaborated on the directions in improving epilepsy care delivery.

The PLAE also took the opportunity for the group to preview the six televisions and four radio advertisements that were produced by the Lay Education Committee 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. Incidentally, one of these TV Advertisements earned a bronze medal as finalist in the Best Public Service TV Ad in the recently concluded National Ad Congress in Lahug, Cebu.

The media/creative volunteers were also recognized during the night of the Launch and were given plaques of appreciation and were 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 newly opened PLAE Website was presented and the Epilepsy Hotline number 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.

Prior to the launching of the campaign, a press conference was also held the day before. The officers of the organization were featured in news briefs and in certain TV programs with health segments. 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 will be airing until December in a major TV Channel, Channel 2-ABS-CBN. These ads had generated a range of 5-11 calls/day to the Epilepsy Hotline. The radio ads are scheduled to be aired starting January 2002.

Information about the campaign will be disseminated in the Visayas (one of the three major islands in the country) through the Philippine Neurological Association whose officers have agreed to provide the free use of a booth for the campaign during their 23rd Annual Convention, which will be held in Iloilo City from Nov.28-Dec. 1,2001.