

1st EPILEPSY AWARENESS WEEK

June 2002

As part of the "EPILEPSY :Out of the Shadows" PHILIPPINES campaign, the Philippine League Against Epilepsy (PLAE) is going to observe the first week of September this year as "Epilepsy Awareness Week". PLAE president, Dr. Leonor Cabral-Lim has appointed the dynamic Dr. Josephine "Jojo" Casanova-Gutierrez, as the over-all chair for this event.

During this week, Epilepsy Seminars will be held for non-medical audiences in several areas/regions of the country. These epilepsy seminars will be coordinated by the PAVEs (Provincial Awareness Volunteers for Epilepsy) in the 15 provinces around the country. Seminars will also be held in some medical schools, and Neurology training institutions coordinated by our VPs Drs. Elma Marañon and Johnny Lokin respectively.

The CME Committee will also hold Round table discussions for primary care physicians in several areas of the country during this week coordinated by Dr. Darwin Dasig.

This weeklong celebration will be capped by a Walkathon called "Walking Out of the Shadows of Epilepsy" on September 8, 2002 at 6:30 AM starting at the Quezon Memorial Circle. All PLAE members are invited to participate in this event. Patients, caregivers, medical students, and friends from the pharmaceutical industry are also invited. Breakfast will be served and free t-shirts will be given to the 1st 500 registered participants. Dr. Marañon will also hold a simultaneous walkathon in Iloilo City. Let us all join forces and help bring Epilepsy Out of the Shadows for persons with epilepsy in our country, majority of whom can lead normal lives and contribute to a better Philippines for all.

EPILEPSY MANAGER PROGRAM TO BE PILOTED IN 4 PAMPANGA TOWNS

The "epilepsy manager" program is the major project of the CME committee for the next two years. The program is a 10 month "hands-on/tutorial and consultation" training program preceded by a 1½ day Epilepsy review course with the objective of training an "epilepsy manager" who is a doctor competent in managing persons with epilepsy at the primary care level.

The program will be piloted in 4 towns in Pampanga selected from a group of primary care physicians who had volunteered to commit their participation in the program. Participants in the program are Drs. Cabugawan, Eulogio Tayag Jr., Arnel Syquia and Ma. Isabel Lagman-Calilung from the towns of Apalit, Arayat, Macabebe and Guagua respectively.

The outcome of the program will be evaluated ff. completion, and if successful will be presented to the Department of Health, the different local government units and other concerned agencies for possible wider implementation.

The committee is looking forward that the wider implementation of the program will pave the way towards achieving the vision "to make available to the Filipino people within a radius of one hour bus ride or less from their homes a doctor competent in managing persons with epilepsy at the primary care level-an epilepsy manager".

WHAT'S UP WITH THE COMMITTEES?

Lay Education Committee

The committee led by chair Dr. Josephine "Jojo" Gutierrez has been conducting lay forums in different parts of the country through the PAVE group (Provincial Awareness Volunteers in Epilepsy).

The lay forum in Lucena was held on May 14, 2002, with Drs. Conrad Nievera, Lourdes Ledesma and Gutierrez as speakers. We heard the best part was the hospitality of the host Dr. Ces Alincastre, who also pampered the group with all the delicacies in the region.

The UP-PGH Department of Neurosciences lay forum was held on May 27, 2002 at the UP College of Medicine with Drs. Fe Bacsal, Gutierrez and Ledesma as speakers. Dr. Ging Orteza and her group of psychologists facilitated the "focused group discussions".

Last June 21, an epilepsy seminar for school teachers was held in Morong, Rizal, organized by Dr. Julette Batarra, who together with Dr. Gutierrez also conducted the seminar. The seminar was attended by close to a hundred participants.

The Lay Education Committee also created an Organizing Cluster, headed by Dr. Lourdes Ledesma to develop the organization of a lay support group which will be called "Friends of PLAE".

Come July, Dr. Fe de los Reyes will also hold an Epilepsy Camp in Naga city, Bicol on the 17th. Speakers will be Drs. Leonor Cabral-Lim, Aida Salonga and Lourdes Ledesma. An epilepsy seminar for school teachers will also be conducted this month at the De la Salle Medical Center, in Dasmariñas, Cavite; organizers are Dr. Gutierrez and Dr. Madeleine Sosa. Drs. Evelyn Madriaga and Vicky Bael will hold epilepsy seminars in Tacloban, Leyte and in Cebu city respectively.

From August 15 to September 15, Dr. Gutierrez is preparing for a Multimedia Blitz. This is in connection with the Epilepsy Awareness Week celebration of which she is the overall chair. A full report of the activities lined up for the Epilepsy Awareness Week is featured in the front page.

Continuing Medical Education Committee

Steering the CME committee in full gear is Dr. Ma. Felicidad "Mic-mic" Soto. The committee also has liaisons for the specific projects.

CME liaison for members, Dr. Myrna Fojas is in charge of the joint PLAE-PNA Epilepsy Council satellite dinner symposium on "Clinical Dilemmas in Epilepsy Management" which will be held during the PNA Annual Convention in La Union on November 20, 2002. The symposium is limited to the 1st 150 registered participants, so all members are enjoined to register early for the symposium.

Dr. Darwin Dasig is liaison for the round table discussions for primary care physicians and the tie-up with the PNA outreach programs.

Dr. Conrad Nievera, CME liaison for the different medical societies has arranged for PLAE participation during the last PMA Convention, in which we conducted a session on Epilepsy Management and the "EPILEPSY: Out of the Shadows" PHILIPPINES campaign last May 23.

The major project of the CME Committee for the next two years is the "epilepsy manager" program.

Health Care Delivery Committee

In order to bring epilepsy care to the grassroots, the committee has embarked on developing a network-referral system wherein problematic cases among epilepsy patients seen by general practitioners and rural health physicians (primary care) in different areas of the country can have access to neurologists (secondary care) and experts in the field of epilepsy (tertiary care).

The core of the network-referral system is a group of volunteer neurologists (Epilepsy Referral Consultant Group) who will evaluate charity patient referrals from primary care physicians within their area of practice.

An organizational meeting of the Committee with the volunteers in March led to a successful whole day Consultative Meeting Workshop on Epilepsy Health Care Delivery last June 7. During the workshop, volunteers grouped into regions reviewed the status of epilepsy health care delivery and presented their strategies on how to provide secondary level epilepsy care for charity patients in their particular region. There was also a presentation and discussion on establishing links with tertiary epilepsy specialty clinics as part of the workshop.

At the end of the day, the group achieved the workshop objective of formulating a practical network-referral system that aims to provide access to epilepsy care from the grassroots to the

experts in epilepsy in the different regions represented. To cap it all, after a productive and inspiring meeting an acronym BRIDGES (Bridging Referrals to Improve Delivery of Grassroots Epilepsy Services) for the project.

National Epilepsy Registry and Research Committee

Dr. Madeleine Sosa, committee chair presented a 5-year plan to the PLAE officers last June 8, with the following goals:

1. To organize the research committee composed of PLAE members
2. To conduct researches regarding the epidemiology of epilepsy in the country
3. To develop a database of epilepsy
4. To evaluate the efficacy of the advocacy projects of the society
5. To conduct workshops in research, EBM, practice guideline development, quality of care and other related topics
6. To present results of the different studies in local and international forums.

Fund Raising Committee

The committee is chaired by our VP's Drs. Elma Marañon and Dr. Johnny Lokin. It was agreed during the 1st Executive Committee meeting last January that the 1st fund raising activity of the Committee will be for the "EPILEPSY: Out of the Shadows" PHILIPPINES campaign.

Advocacy Committee

This committee was created during the last strategic planning in Nov. 2001 and is headed by no less than Drs. Martesio "Mart" Perez and Ma. Corazon "Cora" Dañguilan. The committee's task is to promote the protection of the rights of persons with epilepsy related to employment, schooling and driving. Each member will be in charge of addressing a particular issue; Dr. C. Dañguilan for Employment, Dr. M. Ortiz for Schooling, and Dr. J. Lokin for Driving.

BIRTH OF THE "FRIENDS OF PLAE"

Discussing epilepsy with medical colleagues is an entirely different experience compared with meeting the patients themselves. One not only gets engrossed listening to what they go through during their "attacks" and ways of "controlling" them, but also feels the reality of the impact of epilepsy to their quality of life.

The initial meeting of the "Friends of PLAE" group was held on April 11, 2002 at the Novartis office in Makati City, through the efforts of the Organizing Cluster Group headed by Dr. Lourdes "Wally" Ledesma. This meeting was mainly a "getting to know" everybody affair, the group consisting of parents without their child with epilepsy, patients, and some patients with their parents and the rest of the organizing cluster group consisting of Drs. Myrna Fojas, "Jojo" Gutierrez, Glicerio "Ces" Alincastre and Martha Bolaños. Ces got the directory and started an egroup right away. The group agreed to hold monthly meetings thereafter, with Novartis agreeing to host the meetings.

During the second meeting, the number of attendance doubled, with the patient/parent group deciding on organizing a mini-seminar on Epilepsy June 19. Dr. Conrad Nievera was invited as speaker. Atty. Miguel Nepumuceno was unanimously chosen as the "volunteer" head of the group.

A successful mini-seminar was held last June 19. Mark Fernandez started the activity with the opening prayer. Carmela Pajarillo gave a short introduction and welcome address. Dr. Conrad Nievera gave a lecture aptly entitled "Primer on Epilepsy". Dr. Cabral-Lim, PLAE president who was invited to grace the occasion, gave a brief talk about the PLAE and its "Epilepsy: Out of the Shadows" PHILIPPINES campaign.

She also mentioned supporting the organization of lay self-help groups not only as part of the campaign but as one of the ways of achieving the mission of the organization. The rest of the evening was spent in an informal sharing/discussion moderated by Margie Colayco, and everybody had their own share of experiences and inputs. Atty. Miguel Nepomuceno had to put an halt to the never-ending discussion, as most of them were parents who needed to be with their children with

epilepsy, or they are patients who cannot sleep late. The group gave a small token to Dr. Nievera to show their appreciation.

2ND NATIONAL EPILEPSY CONGRESS

The 2nd National Epilepsy Congress will be held on Sept.5-6, 2003 in Manila. Dr. Ma. Felicidad Soto has been appointed as Over-all Chair of the Organizing Committee.

NIEVERA RECEIVES FELLOWSHIP GRANT EPILEPSY SCHOLARSHIP

Dr. Conrad Nievera has been granted a fellowship to participate in the "Advanced International Course-Bridging basic with clinical epileptology" which will be held at the Venice International University in San Servolo, Venice, Italy from July 21-August 4, 2002. This Residential Course is sponsored by the ILAE (International League Against Epilepsy), ISNV (International School of Neurological Sciences), and the NATO Science Programme. The course aims to encourage interactions between basic scientists and neurologists to promote an integrate view of epileptogenesis/epilepsy. 30 scientists and clinicians from different countries will be participating in the course. The course will be handled by a faculty consisting of a group of internationally renown epileptologists.. Course directors are Drs. Giuliano Avanzini from Italy and Amel Mrabet from Tunisia.

PLAE IN PPS

PLAE put up an "EPILEPSY: Out of the Shadows" PHILIPPINES campaign booth during the Philippine Pediatric Society Convention last April 8-10, 2002 held at the Philippine International Convention Center. Abbott Laboratories was kind enough to give us a space for the booth in their hospitality suite. Leaflets about the campaign and epilepsy information materials were given out in the booth.

The booth was manned by volunteer members: Drs. Cabral-Lim, Bolaños, Alincastre, Gutierrez, Nievera, Jeannie Ahorro, Bitty Palines, Beny Sanchez, Bernie Terencio, Joan Viado and many others. Thanks to all who have made this activity possible.

DATES TO REMEMBER June 2002

September 2-8	Epilepsy Awareness Week
September 8	6: 30 AM Walkathon Quezon Memorial Circle, Q.C.
September 11-14	Epilepsy Awareness Week 4th Asian and Oceanian Epilepsy Congress (AOEC) 2002 Nagano, Japan
October 6- 10	5th European Epilepsy Congress 2002 Madrid Spain
November 20	6-7: 30pm PLAE Annual Business Meeting Oasis Hotel, San Fernando, La Union 7: 30pm PLAE-PNA Epilepsy Council Satellite Dinner Symposium "Clinical Dilemmas In Epilepsy Management" Oasis Hotel, San Fernando La Union

