

## November 2002

### • GMA DECLARES NATIONAL EPILEPSY AWARENESS WEEK

On August 12, 2002, Philippine President Gloria Macapagal-Arroyo signed Proclamation No. 230, declaring the first week of September of every year as "National Epilepsy Awareness Week" under the auspices of the Philippine League Against Epilepsy, Inc.

The whole week of September 2-8 was full of activities with members of the PLAE shuttling from one lecture to another. Over-all Chair of the Epilepsy Awareness Week was Dr. Josephine (Jojo) C. Gutierrez. PLAE President Leonor Cabral-Lim kicked off the celebrations starting earlier on August 31, with a very well attended lay symposium on "Epilepsy and Psychosocial Issues" at the Chinese General Hospital. This was followed in the afternoon by a lecture on "Basic Clinical Epilepsy" (BCE) by Dr. Fe Bacsal for the CGH doctors. UP-PGH had their own lay symposium entitled "Magagamot pa ba ang epilepsy ko?" on September 2. The following day, the UST Hospital doctors treated their patients in Jollibee Dapitan not only with their favorite meal, but also with a lecture on "Usapang Epilepsy sa UST". JRMHMC had a lay symposium aptly titled, "Usapang Epilepsy" on September 5. The Philippine Children's Medical Center had a mini-Epilepsy Camp, "Pag-unawa sa Epilepsy", for the children and their parents on September 6. PCMC actually holds their own annual Epilepsy Camp every December.

The Friends of PLAE organized a well-researched lecture on "Rights of Persons with Epilepsy" held at the Makati Medical Center on September 7. Actual cases of discrimination were narrated by PLAE members, Carmela Pajarillo for employment; Rose Marie Cruz, a mother of a PWE, regarding her experience with her son's school (excerpts published in page 4) and Maribeth Santos, on why she was denied insurance for her son with epilepsy. Resource persons were lawyers and "Friends" members Mon and Ianne Guerrero who talked on existing laws and how it applies to people with epilepsy; Adrian Gutierrez, position and job details for Human Resources; Maruxa Pita, former Directress of Poveda Learning Center, on education; and Tina Latoja, position and job details on Insurance. On the same day, but on another time slot, St. Luke's Medical Center had their own lay symposium on "Mga Haka-haka at Kuru-kuro Tungkol sa Epilepsy". The Metropolitan Hospital also had a session on BCE during their house staff conference on September 6, with Drs. Herminigildo Gan and Martha Lu-Bolaños giving the lectures. Topics were different at each institution for the whole week, not only to give the attendees a choice but also the opportunity to attend several forums as well.

The regional members were also busy coordinating their respective symposia. Cebu city led by Dr. Victoria Bael had their own week-long celebration starting on September 1 with an afternoon Sunday mass, followed by parlor games, drawing contest for the children, and a lecture on "What is Epilepsy" for adults and caregivers. The next day, they had a follow-up talk on "Myths and Fallacies on Epilepsy". Then on September 6, they had another lay symposium in the Health Center of Barangay Guadalupe. They also had interactive sessions using the BCE for doctors in the towns of Mandaue, Danao, Compostela and Consolacion. This was capped by a TV appearance on September 7 to stress the definition of epilepsy and removing its stigma in the community. Kudos to Dr. Bael!

Other provincial PLAE members who worked hard during this week are Drs. Nellie Severo and Fe de los Reyes who had a lay symposium as well as a lecture on Basic Epilepsy at the Bicol Medical Center in Naga city. Dr. Jorge Padilla organized a lay symposium at the Dr. P. Ocampo Hospital in Cotabato city, and a lecture on BCE at the Cotabato Regional and Medical Center. There was also a lecture on BCE followed by a lay symposium as far as Zamboanga Medical Center led by Dr. Lucille Barrera. In Ozamis City, Dr. Jona Handumon gave lectures in the lay symposium as well as BCE lecture at the MHARS-RTTH after a motorcade and an Epilepsy clinic. Dr. Brenda Diputado held a lecture on BCE for doctors in Dumaguete City. Dr. Art Surdilla gave a lecture in BCE in Cagayan de Oro city. He also sponsored an Epilepsy Information booth for the whole week, aside from having an Epilepsy Clinic.

Drs. Ging Madrid and Bitty Palines also lined up a lot of activities for their patients in Batangas extending until October. During the first week of September, Drs. Madeleine Sosa and Dr. Palines gave a lecture for the PPS-STC group, then, in Batangas city, Dr. Palines was joined by Dr. Ging Madrid for an interactive session. After two weeks, they gave the same lecture to the Lipa Medical Society, and on October 22, with the Tanuan Medical Society. After which, this was followed two days later by an epilepsy lay forum for parents, nurses and midwives from the district hospitals. There were also doctors who attended this session. Dr. Madrid gave a lecture on basic knowledge about epilepsy and its classification, followed by a simpler lecture on "Ano ang epilepsy sa bata" by Dr. Palines. They were joined by developmental pediatrician, Dr. Joel Lazaro for "Developmental Problems seen in Epilepsy, and Dr. Agnes Manalang, on "Rehabilitation in Epilepsy". Film clips on epilepsy were also shown.

In Laguna, Dr. Rommel Montes conducted a round table discussion in Sta. Cruz, Laguna on September 6, held at the Columbia Garden Restaurant. It was attended by 23 MHOs of Laguna headed by their president, Dr. Guia Abad (also president of the Association of Municipal Health Officers of the Philippines).

Another RTD was held at the Department of Medicine, Laguna Provincial Hospital this November.

In the north, Dr. Robert Luzod gave a BCE lecture in Ilocos Norte, at the Don Mariano Marcos Hospital. Dr. Philip Oliva had their lay symposium and a lecture on BCE in Dagupan city. Dr. Gener Maylem handled the BCE lecture at the Ilagan Provincial Hospital Conference Hall, Isabela. In Pampanga alone, there were 5 lay symposiums. The towns reached were Guagua, Apalit, Arayat, and Macabebe. A lay forum was also held at the Angeles University Foundation in Angeles city organized by Drs. Romy Enriquez, Jovy Mamangun Johnny Lokin

Dr. Ana Javelosa represented the PLAE and gave a lecture at the PAFP midyear convention in Bacolod city, Sept. 7.

Dr. Lim was also able to invite the press in some of our activities. A press conference was held during the "Health Forum" session September 3 at Annabel's Restaurant, attended by Drs. Cabral Lim and Gutierrez and Dr. Ivan Escartin from the DOH. Announcement regarding the Walkathon was also made (a report follows). The weeklong celebrations were also published in the Philippine Daily Inquirer and Manila Bulletin (Sept. 4, 2002.) Please see webpage for the original articles.) The forum at the Makati Medical Center organized by the MMC Department of Neurosciences and the Friends of PLAE was covered by GMA-7.

UERMMMC held their lay symposium a week later, on September 14, entitled "Wag Matakot sa Epilepsy". DZRH also called us up for an interview and Dr. Bolaños represented the PLAE answering basic questions on epilepsy and answering phone-in questions. She was later joined by Mr. Miguel Nepumuceno, Ms. Margie Colayco and mother (Friends of PLAE) for another hour who talked on the patients' point of view and concerns. With all these activities, I won't be surprised if we have to celebrate Epilepsy Awareness Month next year!

**(Contributors: Dr. Bitty Palines, Dr. Rommel Montes. Compiled by: Dr. Martha Bolanos)**

#### **'Walking Out of the Shadows' WALKATHON**

The Epilepsy Awareness Week was culminated with a Walkathon on September 8, 2002, held at the Quezon City Memorial Circle Golden Bell Peace Park. As early as six in the morning, participants were starting to pour in from different hospitals and sectors of the society. Novartis took care of registration, giving out free T-shirts with the "Epilepsy, Out of the Shadows" campaign logo, and individual numbers for the walkathon.

The program started with Dr. Cabral-Lim, PLAE President giving the welcome remarks, followed by Dr. Jojo Gutierrez, "Epilepsy Awareness Week" Over-all Chair, giving the mechanics and the rules for the contest. Everybody was raring to go with each group identified with their hats, their own T-shirts, and arm bands. We thought it was just a short walk, but for many who hasn't found time to exercise lately, it was quite tiring too, especially with the heat of the rising sun. But Dr. Johnny Lokin was on close watch with his ambulance team cruising at the end of the line. So far, there were no morbidities. Thanks to the Quezon city police for providing 20 traffic aides to ensure smooth traffic flow as we walk along the inner circle. We got the motorists' attention with our logos and colorful banners carrying our theme "Nagagamot ang Epilepsy." Thanks to Janssen who acted as marshalls and helped Peace and Order Committee Chair Dr. Ces Alincastre.

After the walk, everybody reached for a cold drink and breakfast provided by UCB. Other pharmaceutical companies provided food too. The program and awarding ceremonies started with Dr. Wally Ledesma minus her partner, who I heard had a 'hangover'. The 1st place went undisputedly to one of the regular joggers of the Quezon city Circle members. Second place was Charlie Laureta of Pfizer and third place was Ricky Bactol, Educational Media Technician from the Philippine Children's Medical Center. It was a very successful event with close to 500 participants in all, the largest contingency coming from the Chinese General Hospital...see what the President can do!

#### **5th EUROPEAN CONGRESS OF EPILEPTOLOGY by: Dr. Josephine Gutierrez**

The 5th European Congress of Epileptology was held in Palacio de Congresos in Madrid, Spain last October 6-10, 2002. Madrid is a relatively new capital built in the 15th century. It is the elevated - miles above sea level and has a rolling terrain covered with parks, gardens and rotondas, its wide streets lined with grand buildings standing proud because of its sense of history and culture. The Spaniards are a beautiful people and they love to dress well and enjoy themselves. A regular Spanish day starts normally at 9 am, lunch is at 2 p.m. and siesta is observed all over the city (including shops). Dinner is usually at 9 p.m. and things are still going around until the late hours of the night.

The congress was well attended, mostly by doctors from the European continent. Our members; Dr. Felicidad Soto, Dr. Evelyn Madriaga, Dr. Bimbo Diaz, Dr. Josephine Gutierrez and Dr. Gloria Balmogera were fortunate

enough to have been given the opportunity to attend the congress. Convention topics mainly focused on recent developments pertaining to epileptogenesis, new treatment modalities for refractory epilepsies, and the role of genes in the development, clinical manifestations, response to drugs and prognosis of various epilepsies. In the mornings, two main sessions were held in two big conference halls and in the afternoons and evenings, one can choose from among about 7 function rooms for less formal Discussion Groups featuring special topics of interest/controversy. These were jumpstarted by short lectures from 3-4 lecturers followed by a lengthy free-for-all question and answer session. A special feature of the Congress was the Tapas seminars held during the typical Spanish cocktail hour (6-9 pm), tackling topics pertaining to advances in treatment.

A Chairman's Symposium chaired by Dr. Martin Brodie, entitled "Epilepsy into the New Millennium" inspired excitement and optimism among the audience. It featured eight speakers who summarized cutting edge researches, comprehensive meta-analysis and future directions on research on topics that showed great promise for understanding and use in the future like Anti-Epileptic Drug Development, Pharmacogenomics, Epileptogenesis, Unclassified Pediatric Encephalopathies, Brain Imaging in Epilepsy, Neural Stimulation, Targeted Surgery and Gene Implantation Therapy and Neuroimplantation.

The plenary session on the second day was a symposium featuring comprehensive meta-analysis of new and emerging treatment modalities for epilepsy. There was a brief summary of the roles of new antiepileptic drugs. This was followed by a report on the existing worldwide experience and results with vagal nerve stimulation in refractory epilepsy. There was also a lecture on Gamma knife surgery and its role in epileptology. The theoretical basis and limited experience with Transcranial Magnetic Stimulation for Epilepsy was also presented.

On the last day, plenary sessions dealt with fever, genes and epilepsy. The International League against Epilepsy is currently setting up the criteria for what we term as "mesial temporal sclerosis": the natural course of which begins from a febrile illness in childhood and triggers a sequence of changes within the neural networks occurring during a "latent" period leading to the development of difficult-to-control epilepsy in later life. Hence, the popularity of the operational knowledge of epilepsy being a chronic progressive process and not just a static condition or a disease.

#### **Excerpts from Mr. Miguel Nepumuceno's Introduction...**

My only child was diagnosed with epilepsy at 2 months. Amanda is now 18 years old, a lovely angel with the mental age equivalent of a pre-school child – a special needs child. She cannot fend for herself nor attend regular school, is greatly dependent for her basic daily needs and may require dedicated care for the rest of her life. It is the rights of persons such as Amanda and those similarly situated we will be discussing in this forum.

Some months back, I viewed a movie entitled – "The Boys Next Door". The story revolves around the misadventures of a caregiver and four mentally challenged people attempting to live independently outside an institution. One of these four is a character named Lucien P. Singer, whose mental capacity described as between that of a five-year old and an oyster, testifies before the State Senate. As the character Lucien, he is unable to say anything intelligible. However, with artistic license and film magic, his thoughts come to life in words by playwright Tom Griffin and portrayed by actor Courtney B. Vance: "I have the mental capacity somewhere between that of a five-year old and an oyster, and if I could talk, what I would say is this – societies will be judged by civilization with the way it treats the weakest of its citizens. I am one of those weakest citizens and so are all with special needs."

That's the line as I remember; its delivery struck quite an impression in me. Among other things, it encouraged me to be part of the layman's group Friends of PLAE and, in an ambitious scale attempt to address the grander question – "How are we as a society, treating the weakest of our citizens?"

As with all things in society, everything seems to begin with one's self. The greeting – "Peace on Earth, Goodwill to Men" has always fascinated me. With peace taken in the context of the song "Let There Be Peace On Earth", whose next line goes "and let it begin with me", it tells us that only with peace within ourselves and a desire to help our weaker and less fortunate brethren can we even attempt to achieve God's will on earth. (ed.)

This experience I had with a prestigious school (I need not mention the name) where my son, Mark, was enrolled for almost ten years as a special student. The school is really for normal kids – from Toddlers to Prep, all the way to High School. But it also accepts students classified as having "special needs" – like slow learners, autistics, and mentally retarded, including those with Down Syndrome. It was through the recommendation of a developmental psychologist who had evaluated Mark's learning capacities that he was enrolled in this school in 1991.

During all those years, I never had any cause to complain. Whenever Mark would have a seizure, the teacher-in-charge, with the assistance of others in the school, would rush him to the Cardinal Santos Medical Center. This happened about 4 – 5 times during the years Mark was studying there. Mark was not the only one given this attention but all the other afflicted kids as well.

However, things did not remain rosy. During the first day of school in June 2000, I was dismayed to find out – when I fetched Mark in the afternoon – that his classroom had been transferred to the 2nd floor of the building which had a steep staircase made of iron that could be slippery when wet. I made representation with the school authorities and asked why the classroom had been switched from the ground to the 2nd floor. They could not give me any good reason for this. I could not understand why they assigned the disabled students upstairs while the normal kids were on the ground floor. I was concerned about Mark. What if a seizure would occur while he was in his new classroom?

I was assured, though, that there would always be a teacher who would assist Mark get to his classroom. But whenever I would check with Mark, he would say that although sometimes there were teachers who assisted him, more often than not, no one accompanied him as he climbed or descended the stairs. That although sometimes there were teachers who assisted him, more often than not, no one accompanied him as he climbed or descended the stairs. In instances when no one was there to accompany him, especially if this was during dismissal time, he would allow the other kids to go down first. Then he would go down slowly while holding onto the handrail.

This went on for the entire month of June, 2000... Until October, Mark returned to school. His classroom was still upstairs. I again pleaded with the school authorities to transfer this to the ground floor. If it could not be done immediately, perhaps this could be effected by the 2nd semester – which was also in October. Further, I told them that nobody was helping Mark negotiate the stairs. Once, when I fetched him, I noticed that his pants were wet. He said he had peed. He was shy to ask somebody in the classroom to accompany him downstairs to pee. Yes, the toilet was in the ground floor!

The only reason the authorities could give regarding why they could not transfer the classroom was that it would be hard to do so at that point in the school year – or words to that effect which I found to be a very lame excuse. I nastily thought that maybe they were doing it so we could move to another school. True enough, when Mark was already studying at Teacher Mom, he confided that one of his teachers in his former school had told him to find another school. Maybe they were already fed up attending to his emergency needs.

Going back to where I had left off, I went to DECS and inquired if they had a list of schools that admitted children with special needs, and told them the reason for my inquiry. To my surprise and dismay, the DECS official whom I talked to encouraged me to look for another school if that was the situation. DECS also went to the extent of checking the school's permit and found that it did not have a permit to accept disabled students. The DECS officials told me they would investigate the matter. I don't know if this was ever done.

Last June, I went to Mark's former school to get his year book. To my surprise, the disabled students were back in their former classroom in the ground floor. (ed.)

**Rose Marie Cruz**

#### **MY SAN SERVULO EXPERIENCE By Conrad C. Nievera, Jr., MD**

I had the privilege of being awarded a full scholarship to the Advanced International Residential Course on epilepsy sponsored by the ILAE and NATO with the theme: 'Bridging Basic with Clinical Epileptology'. This was held from July 21 to August 4, 2002 at the International School of Neurological Sciences, Venice International University in San Servolo Island, Venice, Italy. The criteria for the award included submission of an original research paper on epilepsy. My qualifying work was entitled "Treatment Outcome of Seizures Associated with Intracranial Cavernous Angiomas".

My 36 classmates were a hodgepodge of basic and clinical scientists, either MDs and/or PhDs, from different countries. Most of them were from Europe. Our tutors, who were about half our number, could be aptly described as the "Who's Who" in the field of epileptology (Guilano Avanzini, Marco De Curtis, Jerome Engel, Solomon Moshe, Fernando Lopes Da Silva, Peter Wolf, Amel Mrabet, to name a few).

The course was a 2-week intensive workshop in an intimate, classroom-like, yet still very informal, setting. The first week was composed of didactic lectures on the basic and clinical aspects of epilepsy, including, but not limited to such topics as bench research techniques, genetics, diagnostics, treatment and even information technology (the latter I found particularly exciting). The second week was composed of practical exercises and application of theory including poster sessions, journal clubs and computer simulations. The highlight of the course was the individual public presentation of original research proposals of international grant-quality, which we were required to make during our stay. The tutors were our advisers, as well as critics. My proposal was entitled "The Use of CDP-choline as a Neuroprotectant in a Novel Model of Electrographic Status Epilepticus"

Not everything was study for us though. In-between sessions, we would have football matches, sight-seeing in Venice and the surrounding islands, shopping, food sampling, art and opera viewing, gondola rides and at the

end of the course, a dance party (with lots of wine and grappa!). I will particularly never forget the daily breakfasts held under the trees and facing the lagoon and mainland Venice.

To this day, the "San Servolo Islanders", as we call ourselves, still keep in touch through our e-mail group. Not only do we continue our scientific discussions, but also strengthen friendship ties that have developed in this unique, practically isolated and beautiful island that straddles the Grand Canal and Adriatic Sea.

### PLAE GOES TO JAPAN

The Philippine League Against Epilepsy recently participated in the 4th Asian and Oceanian Epilepsy Congress (AOEC) held in Karuizawa, Nagano, Japan from September 11-14, 2002. Members of the Philippine delegation were Dr. Leonor Cabral-Lim, PLAE president; Dr. Josephine Casanova-Gutierrez, "Out of the Shadows" Campaign Director; Dr. Carlos Chua of the PNA Board of Governors, and our country's two recipients of the ILAE/Dainippon Fellowship Grant, Dr. Hazel Paragua (UP-PGH) and Dr. Neil Ambasing (DLSU-EAC). Dr. Paragua presented her paper entitled, "The Neurologic, Obstetric and Pediatric Significance of Maternal Seizures", while Dr. Ambasing presented his research on "A Survey of Practices in Epilepsy Management among Physicians in Cavite, Philippines". The delegates joined around 800 other epileptologists and neurologists in the workshops and regional meetings held during the four-day congress. The AOEC was also attended by officers of the ILAE and the International Bureau of Epilepsy (IBE), the sister organization of ILAE concerned with the social aspects of epilepsy.

The ILAE Executive Committee clearly desires to strengthen the regional organizations and allow more medical practitioners within the region to avail of quality medical education on epilepsy, the way it has done in Europe. Among the new policies that support this move are: 1) the development of an Epilepsy Academy in the Asian-Oceanian region, similar to EUREPA, 2) complete ILAE support and endorsement of the regional congresses, 3) official ILAE representations to the main offices of pharmaceutical companies in Europe and in the US to ensure pharmaceutical support during congresses, and the 4) provision of an ILAE management team (finance, marketing, etc) which would coordinate with the host organization and the government in organizing the regional congresses. The test case for this will be the next Asian-Oceanian Congress on Epilepsy in 2004 which will be held in Bangkok.

### EPILEPSY IN ASIA WORKSHOP In Shizuoka, Japan

Dr. Josephine Casanova-Gutierrez represented the country in a workshop on "Epilepsy In Asia" held at the National Epilepsy Center in Shizuoka, Japan from Sept. 15-17, 2002 right after the 4th Asian-Oceanian Epilepsy Congress. The workshop was organized by the ILAE Commission on Asian and Oceanian Affairs (CAOA). 15 junior medical consultants from various Asian countries who were recipients of the ILAE bursary fund for researches contributed to the Congress were invited to attend the workshop.

After a half day tour of the National Epilepsy Center each delegate gave a 15 minute presentation about the state of epilepsy in their respective countries. Eleven representatives from several Asian countries which included Korea, Nepal, Indonesia, Mongolia, China, India, Singapore, Malaysia and the Philippines attended the workshop. The workshop was chaired by senior Asian epileptologists, Dr. Masakazu Seino (Japan) - founder of the Asian-Oceanian Epilepsy Organization and former director of the National Epilepsy Center in Japan, Dr. Kazuichi Yagi (Japan) - incumbent director of the National Epilepsy Center, Dr. Chong Tin Tan (Malaysia) - Chairman of the ILAE Commission on Asian and Oceanian Affairs.

### DATES TO REMEMBER

<b>November 20</b>	5:30-7:00 pm PLAE Annual Business Meeting Kris Room, Oasis Hotel, San Fernando, La Union 7:00 pm PLAE-PNA Epilepsy Council Satellite Dinner Symposium <b>Clinical Dilemmas In Epilepsy Management</b> "Oh my, it's not in the books!?" Convention Hall Oasis Hotel San Fernando, La Union
<b>November 30</b>	Deadline of PLAE-Abbott Essay Writing Contest
<b>2003 September 5-6</b>	2nd National Epilepsy Congress, Manila