



EPI FOCUS



Newsletter of the IBE European Regional Committee

Issue 2-2014

Happy Christmas and Best Wishes for New Year 2015

*Frohe Weihnachten und
einen Guten Rutsch ins
Neue Jahr!*

Michael Alexa (Austria) Vice Chair

**Καλά Χριστούγεννα
& Ευτυχισμένος ο
Καινούργιος Χρόνος**

Tata Vassou (Greece) Chair

**Vesele božične praznike in
srečno novo leto!**

Ljubica Vrba (Slovenia) Secretary

**En God Jul och
Gott Nytt År**

Maggan Anderson (Sweden) Member

A Cantie Yule an a Guid New Year

Shirley Maxwell (Scotland) Member

Il-Milied u S-Sena Tajba!

Janet Mifsud (Malta) VP Europe





Message from the Chair

Dear Friends

As I write to you, we are preparing for that special time of year when we celebrate Christmas, reach the end of another year, and begin to prepare for the rest.

The Committee met in Athens in June and at that time we began looking at ideas for future activities. The responses of associations to the Members Survey gave us excellent material and your views were closely discussed and considered. So, again, I would like to thank all the Members who took the time, not only to complete the survey questions, but to also provide comments and suggestions. It is very important that we know your views, so that we can work to meet your aspirations.

The biggest activity in 2015, not only in Europe but also across the whole world, will be the launch of International Epilepsy Day. This is a great initiative and will give global focus to epilepsy around the world. It is important that we are working with our colleagues in the International League Against Epilepsy because this provides a medical

prospective as well as the focus we can give on the social aspects of epilepsy. I hope that all IBE Members in Europe will participate in this and I look forward to hearing about events at national level.

Early in the New Year we will bring you news about the next Epilepsy & Society Conference, which will take place in 2016 in Prague. Early planning is in hand and all is looking good.

But for now, it just leaves me to wish you and your loved ones a Happy and a Healthy New Year. As we say in Greece:

Καλά Χριστούγεννα & Ευτυχισμένος ο Καινούργιος Χρόνος

With best wishes to all
Anastasia Vassou

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Happiness Laughter Fellowship and Solidarity!

Susanne Lund writes about a successful Swedish summer camp

they do, they will be taken care of by experienced leaders. The parents need to be at ease knowing that their young people will be in good hands. No parents are allowed at the camp, but the leaders stay in contact, if needed. The underlying aim is to encourage the young people to be independent and to rely in their own abilities.

A colourful bouquet of activities was offered, both indoors and outdoors; for example team activities to increase self-esteem and build confidence, painting, playing ball, conversations, games, disco and dance, etc.

A wonderful part of the camp is that every participant has to write something positive about each person in the group. At the end of the camp every individual will have a heavy pile of notes in their bag, as they head back home, with appreciative words written about them.

- That is really a boost for self-confidence! Why don't we use this very nice simple way of sharing positive images, in the family, at work, in the epilepsy movement and elsewhere in life?, says Susanne Lund, Chief Executive of the Swedish Epilepsy Association.

Young people with epilepsy are of major focus within the Swedish Epilepsy Association. For a 15th year the Swedish Epilepsy Association organised a well-attended summer camp - or "Summer-camp" as the youngsters themselves call it - for young people with epilepsy.

Due to external funding of one million Swedish krona, received annually for a period of three years, the association was able to welcome an increased number of participants this year.

- We are happy not to have to refuse anyone who needs to get away, to share experiences and to meet other young

people who have seizures, says Margaretha Andersson, Vice President of the Swedish Epilepsy Association.

As many of the young people have severe epilepsy, the plans and preparations are worked on very carefully by the youth section in Sweden, with Mrs Anna Eksell having chief responsibility for this. It is about being a step forward - to have everything under control, to offer nice challenges with a lot of activities and with staff on hand to ensure safety.

A vital part of the camp is to have fun, to be safe and relaxed with no fear of having seizures. If seizures occur, and



Definition of Epilepsy 2014:

A perspective for patients and caregivers, prepared by ILAE

Seizures and epilepsy are not the same. An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. Epilepsy is a disease characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. Translation: a seizure is an event and epilepsy is the disease involving recurrent unprovoked seizures.

The above definitions were created in a document generated by a task force of the International League Against Epilepsy (ILAE) in 2005. The definitions were conceptual, (theoretical) and not sufficiently detailed to indicate in individual cases whether a person did or did not have epilepsy.

Therefore, the ILAE commissioned a second task force to develop a practical (operational) definition of epilepsy, designed for use by doctors and patients.

The results of several years of deliberations on this issue have now been published (Fisher RS et al. A practical clinical definition of epilepsy, *Epilepsia* 2014; 55:475-482) and adopted as a position of the ILAE.

A commonly used definition of epilepsy heretofore has been two unprovoked seizures more than 24 hours apart. This definition has many positive features, but also a few limitations. This definition does not allow the possibility of "outgrowing" epilepsy. Inclusion of the word "provoked" seems to imply that people who have photosensitive seizures provoked by flashing lights or patterns do not have epilepsy; whereas, most people think that they do.

Some individuals, who have had only one unprovoked seizure, have other risk factors that make it very likely that they will have another seizure. Many clinicians consider and treat such individuals as though they have epilepsy after one seizure.

Finally, some people can have what is called an epilepsy syndrome and these individuals should meet the definition for having epilepsy even after just one seizure. You cannot have an epilepsy syndrome but not have epilepsy. The new definition of epilepsy addresses each of these points. A person is considered to have epilepsy if they meet any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome

Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.

In the definition, epilepsy is now called a disease, rather than a disorder. This was a decision of the Executive Committees of the ILAE and the International Bureau for Epilepsy. Even though epilepsy is a heterogeneous condition, so is cancer or heart disease, and those are called diseases.

The word "disease" better connotes the seriousness of epilepsy to the public. **Item 1** of the revised definition is the same as the old definition of epilepsy. **Item 2** allows a condition to be considered epilepsy after one seizure if there is a high risk of having another seizure. Often, the risk will not precisely be known and so the old definition will be employed, i.e., waiting for a second seizure before diagnosing epilepsy.

Item 3 refers to epilepsy syndromes such as benign epilepsy with central-temporal spikes, previously known as benign rolandic epilepsy, which is usually outgrown by age 16 and always by age 21. If a person is past the age of the syndrome, then epilepsy is resolved. If a person has been seizure-free for at least 10 years with the most recent 5 years off all anti-seizure medications, then their epilepsy also may be considered resolved. Being resolved does not guarantee that epilepsy will not return, but it means the chances are small and the person has a right to consider that she or he is free from epilepsy. This is a big potential benefit of the new definition.

What will change as the result of this new definition? Although revision of the definition has generated some controversy, it is likely that real-world changes will be fairly minor. Some people will be able to

say their epilepsy is resolved. Others may encounter the problems and stigma of being told that they have epilepsy after one seizure in some circumstances, rather than after two seizures.

The definition might stimulate research on how likely another seizure is after a first seizure in various clinical circumstances.

Governments and regulatory agencies, people who do therapeutic trials for epilepsy, insurance companies and other third-party payers might have to adjust some of their definitions.

One reason changes will be small is that individuals with one seizure and a high risk for another are currently practically thought of as having epilepsy by many treating physicians. This process simply formalizes that thinking.

Making a diagnosis of epilepsy is not the same as deciding to treat. Some seizures are minor; some patients choose to avoid the side effects of medications. Treatment decisions will be individualized between a person with epilepsy and a physician. Sometimes, information is incomplete; for example, a possible seizure may not have been observed. In these conditions it can be impossible to confidently diagnose epilepsy using any definition. Clinicians will apply best judgment when faced with such incomplete information and often will wait for future developments.

This practical definition is designed for clinical use. Researchers, statistically-minded epidemiologists and other specialized groups may choose to use the older definition or a definition of their own devising. Doing so is perfectly allowable, so long as it is clear what definition is being used.

In the process of developing the revised definition of epilepsy, consensus was reached by forging opinions of 19 co-authors of the publication, while accounting for criticisms by five anonymous journal reviewers and over 300 public commenters on the ILAE website. The revised definition is not perfect. It will become more useful over time as we gain better information on seizure recurrence risks. But for now, the new definition better reflects the way clinicians think about epilepsy.

EPILEPSY: A chronic, life-long, non-communicable Disease

Report by Mike Glynn,
IBE Immediate Past President,
CEO of Epilepsy Ireland and a
member of the ILAE Definitions
Task Force

All over the world, at least 30% of people with epilepsy continue to have seizures on an ongoing basis. This figure can rise to as high as 90% in some developing countries. For these people there can be no question that epilepsy represents an acute, chronic and life-threatening disease. Some of the people fortunate enough to have gained control of their seizures give back a huge amount as volunteers and staff members to help those whose epilepsy remains drug-resistant and not controlled. These people form the very backbone of IBE member associations around the world.

However, many of the up to 70% people with epilepsy, whose epilepsy is controlled, are very happy to move on with their lives, forget about their epilepsy and refer to it as just a small "disorder" which upset their lives for a while. In fact, Wikipedia currently suggests that "disorder" may refer to randomness, civil disorder or disease.

The "mistaken belief that epilepsy is a benign condition" (Hanna et al 2002) is almost certainly what led to SUDEP being hidden for 80 years, even though it is now recognised as a leading cause of deaths in people with epilepsy.

Using mild terms, such as "disorder", to describe epilepsy undoubtedly contributes to this notion that it is benign. The renowned American public relations practitioner Lynda Resnick said that "when people affected by epilepsy are reluctant to expose their condition, the public remains in the dark about it –the tragic irony that has made patient care and raising funds for research more than challenging" (Resnick, 2009). Resnick also made the point that "epilepsy is a disease in the shadows" and this is why it has not gained the same prominence as other diseases (Resnick, 2009). Would prostate and breast cancer and heart traumas

receive the same attention if those who suffered from them refused to allow them to be called diseases but insisted they were just "disorders"? Definitely not.

The general public does not recognise epilepsy as a serious problem (Engel, 2010). As long as this situation continues, the search for cures for epilepsy to ensure that nobody has to live a life curtailed by seizures, will be stymied through lack of proper funding for research and care, and through a lack of support from the public. According to Reynolds and Rodin (2009) there is a great unresolved debate about whether epilepsy should be viewed as a separate symptom of underlying brain disease or as one or more idiopathic diseases or syndromes. However there is no debate amongst epileptologists about whether or not epilepsy is a disease: only what type of disease or diseases it is.

This debate has continued in some form from the time when the ancient Greeks called epilepsy the sacred disease even while Hippocrates held the view that it was a brain disease. As early as the 3rd century Galen classified epilepsy into three categories of disease (Reynolds & Rodin, 2009). These attempts to achieve a better form of classification of epilepsy as a disease continue to this day.

The new ILAE Definition of Epilepsy states that "Epilepsy is a disease of the brain" (Fisher et al 2014). This is a very important step forward in ensuring that legislators, public health officials, media



people and funders see epilepsy for what it is: a major serious health issue which can destroy lives.

The epilepsy community should now begin to build on this new start to create a future where no person's life is blighted by this chronic disease.

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International Epilepsy Day

In the European Parliament

As IBE Members across Europe, begin to plan for the first International Epilepsy Day on 9th February, IBE is also busy preparing for this great day. Associations across the globe, the 98 countries in which IBE is represented, will be using this world day for epilepsy to raise awareness about epilepsy, to promote events for better legislation for people with epilepsy, and to raise funds to finance their initiatives and member programmes.

Already in place are arrangements for an exhibition in the European Parliament, that will tell the lives of people living with epi-

lepsy from all regions of the world. There stories are compelling and recount great achievements as well as major difficulties.

The event is being hosted by Brian Hayes MEP, President of the European Advocates for Epilepsy Group and EU Commissioner for Health and Consumer Affairs, Mr Vytenis Andriukaitis (Lithuania) has accepted the invitation to perform the official opening of the exhibition at a reception in the parliament in Strasbourg on Tuesday 10th February.



Louise Weiss Building, European Parliament, Strasbourg

Breaking news!

Epilepsy to be highlighted in key WHO meeting

It has just been announced that a dedicated agenda item on epilepsy will be included during the 136th session of the WHO Executive Board meeting to be held in Geneva, 26 January–3 February 2015. The agenda item is entitled ‘*Global burden of epilepsy and need for a coordinated action at the country level to address its health, social and public knowledge implications*’. IBE President Thanos Covanis and ILAE President Emilio Perucca have stated that the inclusion of epilepsy in such a prestigious agenda ‘*could have important implications for the prioritization of epilepsy care programmes worldwide, particularly in low-income countries. ... (we) are liaising with the WHO office to ensure that we exploit this opportunity at best.*’

We will keep you informed of developments!

Epilepsy Connections Mainstreaming Project 2009—2014



AIMS

To support adults with epilepsy to return to education, training, paid or voluntary work, try out new interests, make new friendships and achieve greater independence.

PROCESS

To provide people with the confidence they needed to build their skills and knowledge to achieve their goals.

STEP 1

8 week induction phase which included:

- epilepsy awareness and self-management training
- sessions on memory, confidence building, assertiveness and maintaining good health.



STEP 2

Social and leisure opportunities encouraged new interests, promoted healthy living, reduced isolation and built confidence. These included the opportunity to attend Epilepsy Action's Conferences in Newcastle, and to attend art, drama, gardening and a walking group.



STEP 3

Sessions on employment rights and preparing for work carried out on a group basis to allow friendships to develop.

STEP 4

Progress to further education courses at college or to training placements, or support to find paid employment or voluntary work.

OUTCOMES

- 14% achieved paid employment
- 7% actively seeking employment
- 31% went on to study at college or went into training
- 12% went on to voluntary work
- 20% completed the course but were unable to progress due to health reasons or personal circumstances
- 16% did not complete the course.

STATISTICS (84 Adults)

Male 67%, Female 33%
Ages: 40+ = 46%
25–39 = 29%
16–24 = 25%

74% of people taking part had been unemployed for at least 36 months when they enrolled.



European Funded Projects on Epilepsy: a focus on DESIRE

In this series of articles, beginning in this issue of EPIfocus, attention will be given to various EU funded projects that are looking at research on epilepsy.

A mailing list is being set up of those patient and other epilepsy organizations interested to receive regular updates and a newsletter on DESIRE.

For more information on DESIRE contact Prof Janet Mifsud, University of Malta, member of the DESIRE WP7, Dissemination and Exploitation on janet.mifsud@um.edu.mt

Photo: DESIRE consortium at the Kickoff meeting, San Servolo, Venice



DESIRE, <http://epilepsydesireproject.eu/> is the acronym for the FP7 funded project (Grant Agreement no: 602531), entitled Development and Epilepsy: strategies for Innovative Research to Improve Diagnosis, Prevention and Treatment in Children with Difficult to Treat Epilepsy.

DESIRE kicked off in October 2014 and will last 5 years, involves 25 partners in 11 countries, more than 250 researchers and 19 clinical centres involved in the clinical trial. It is co-ordinated by Prof. Renzo Guerrini, Dipartimento di Neuroscienze, Università degli Studi di Firenze, Italy.

DESIRE will focus on epileptogenic developmental disorders EDD, i.e. early onset epilepsies whose origin is closely related to developmental brain processes.

A major cause of EDD are malformations of cortical development (MCD), either macroscopic or subtle. EDD are often manifested as epileptic encephalopathies (EE), i.e. conditions in which epileptic activity itself may contribute to severe cognitive and behavioral impairments. EDD are the most frequent drug-resistant pediatric epilepsies carrying a lifelong perspective of disability and reduced quality of life.

Although EDD collectively represent a major medical and socio-economic burden, their molecular diagnosis, pathogenic mechanisms (PM) and rationale treatment are poorly understood.

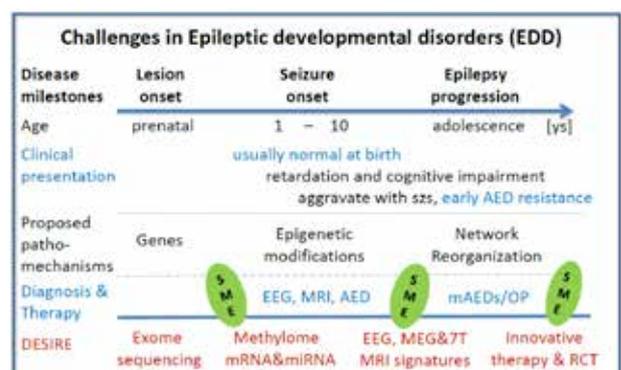
The specific objectives of DESIRE are to advance the state of the art with respect to:

1. The genetic and epigenetic causes and PM of EDD, particularly epileptogenic MCD, to elucidate molecular networks and disrupted protein complexes and search for common

bases for these apparently heterogeneous disorders.

2. The diagnostic tools (biomarkers) and protocols through the study of a unique and well-characterized cohort of children to provide standardized diagnosis for patient stratification and research across Europe.
3. Treatment of EDD using randomized, multidisciplinary clinical protocols and testing preclinical strategies in experimental models to also address novel preventative strategies.

The workplan spans from clinical observation, to whole exome studies, cellular and animal models and basic research, identification of biomarkers and improvement of diagnostic methods, and back to the clinical trials and assessment of innovative, targeted treatment strategies. The consortium partners have an outstanding track record in genetics, basic neurophysiology, neuropathology and clinical research. Specialized expertise will be made available by the SMEs involved to develop novel diagnostic tools for tailored treatment approaches.





WELL DONE!

Epilepsy Connections' Glasgow Fieldwork Team, Gayle Weir and Katherine Harvey were presented with the Lord Provost's Award for Community Service at a ceremony at Glasgow City Chambers on 4 December 2014.

"I'm delighted that, in making this important civic award, Glasgow recognises the impact that epilepsy can have and the work that we do to support people affected by it. I am immensely proud of Gayle and Katherine, and of all our staff and volunteers, but we view ourselves as part of a much bigger team working for people with epilepsy, of which all IBE members are part and we look forward to working with you in the New Year to make life better for people with epilepsy and their families," Shirley Maxwell, CEO Epilepsy Connections and Member of the EREC told us.



NEWS FROM SLOVENIA

Report by Ljubica Vrba

I would like to tell you about two of the programs that the Slovenian chapter of ILAE has organised and that we consider as very important.

We put great emphasis on educating the general public as well as other institutions about epilepsy. Either through an invitation or on our own initiative, we visit kindergartens, primary and secondary schools and provide lectures for teachers.

We also present talks to university faculties including social work, journalism and sports departments, so that the students will know more about epilepsy when they will start out on their careers. We visit institutions for persons with special needs, residential homes etc. and on these occasions we are not only teaching about epilepsy but also have open discussion about their concerns in dealing with persons with epilepsy in everyday life.

On all previous European Epilepsy Days we prepared a press conference, which were always well attended, and as a consequence we had quite a number of articles spoken and written about epilepsy in newspapers, on televisions and on radio stations all over Slovenia.



In various places in Slovenia we organized open public lectures for local people. We invited their also nurses, teachers, medical doctors, employers, and pharmacists. The purpose is to spread knowledge about epilepsy and thereby to reduce prejudices against this disease and to improve the quality of life of persons with epilepsy.

Another important program is accompanying persons with epilepsy when they go for presurgical investigations and surgical procedures in epilepsy centers abroad. Slovenia has only about two million inhabitants and we haven't developed surgical procedures for epilepsy in our country.

Health insurance companies enable this to be done abroad, mostly in centres for epilepsy in Germany and in France. Persons with epilepsy and their relatives often don't speak a foreign language. Our organisation has developed a project to help them. We find volunteers- usually students of medicine- to accompany persons with epilepsy and assist them with interpretation in the hospital and also to provide organisational and emotional support.

This is very useful also for epileptologists in epilepsy centers because they can get clear details on all the important information about seizures and other relevant data which they need. The program has been ongoing for several years and each year we organize help for about 20 persons.



Istanbul Congress Bursaries

IMPORTANT MESSAGE!



To assist those wishing to apply for a Bursary to attend the 31st International Epilepsy Congress in Istanbul next year, but who do not wish to submit an Abstract, special arrangements have been put in place on the congress website.

This arrangement will allow applicants to apply online through the congress website. Unlike the procedure used for previous congresses, application papers for IBE Bursaries will NOT be circulated as a separate action.

So, don't miss your opportunity to find support to be with IBE in Istanbul next September.

The closing date for Bursary applications is 27th February 2015.

For further information on the application process and procedures go to:

www.epilepsyistanbul2015.org



European Regional Executive Committee meets in Athens

The European Regional Committee met in Athens over two days in June, to discuss ongoing activities and to plan for the future.

Suggestions included:

- Collaboration amongst a group of member associations on projects of mutual interest;
- A workshop for Members to take place in Istanbul at the time of the congress next September.

The meeting also discussed the Members Survey that had been completed earlier in the year. It was noted that thanks were due to all those members who had taken the time to

complete the questionnaire, which gave valuable information to EREC that would help in drafting its future plans. Common barriers to participation in IBE activities (including surveys) are language and resources; these themes cropped up throughout the feedback. In the international survey one member suggested IBE produces a pictorial guide to epilepsy. This would overcome language and illiteracy issues and could therefore be used not only in Europe but worldwide as well. It was agreed to pursue this idea.

Image: Maggan Anderson and Ljubica Vrba at the Acropolis Museum. Photo: Michael Alexa.

2nd African Conference Cape Town, South Africa

Michael Alexa shares his diary

Finally I made it! When I put my feet on the grounds of Cape Town, South Africa, I realized that I've finally visited all 5 continents on the earth. But if I had known, what lay ahead of me I would have even be more excited. As usual, I planned a few days before the conference to visit the conference city. After visiting the Waterfront, next stop was Table Mountain. Unfortunately, as soon as I arrived at the valley station, I found out that was too windy and cablecar to the top wasn't running – I'll do that next time!

A planned visit to Robben Island - the island where Nelson Mandela was emprisoned for so long - also met with disappointment as it was closed on that day. As compensation I went on a cruise through the harbour of Cape Town. We saw Table Mountain, the soccer stadium – and of course dolphins. What a wonderful day!

In the afternoon I went to Muizenberg, which is very well known for its huge waves – and the sharks as well. On my way back I started to talk with a man as I wasn't sure whether I was on the right paath. He started to “interview” me – and it turned out that he's a journalist working for the radio station in Muizenberg. He asked me if I would like to take part in his show the next Saturday – during the conference. But let me come back to that.

Of course an organized trip tour to Cape of Good Hope had to be part of my visit as well. The trip was incredible as we saw not only Cape Point but we also visited a penguin farm.

Wednesday May 21 – Opening Ceremony

During the congres opening ceremony a lot of facts were presented. And again, epilepsy was compared with HIV. The number of HIV patients in Africa decreased by 43 % between 2005 and 2010. On the other hand epilepsy stigma remains.

Thursday May 22

One of the findings of the conference is that the number of neurologists remains too low. In Africa there is a median of 0.03 neurologists per 100,000 compared to Europe where the figure is 4.84 neurologists per 100,000. Africa is the third largest growing region in the world – and epilepsy is the second most common neurological decease in Africa! Only a few epilepsy drugs are available in Africa – mainly the older drugs. Newer medicines are rarely available and are too expensive. Strengthening epilepsy organisations in Africa will require capacity building. The Africa Disability Alliance (ADA), which is a technical agency established to facilitate the implementation of the Continental Plan of Action (CPOA) for persons with disabilities – the UN Convention on Rights for Persons with Disabilities in Africa can play an important role.

Another important issue is that other deceases, such as malaria,



HIV and other parasitic deceases, are very common in Africa. Studies on drug interaction are needed; which brings us back to the lack of neurologists and scientists to undertake this work.



The treatment gap is very high in Africa, at about 75% in low income countries and about 50% in middle income countries. What are reasons for the treatment gap?

- Population knowledge
- Care seeking behavior
- Access to healthcare
- Knowledge/skills of primary health care
- Access to AEDs
- Knowledge of people with epilepsy and their families

Friday May 23

The day began with a meeting of the IBE African Regional Committee and I was pleased to be able to attend together with other representatives from Europe and Asia. It was a fruitful discussion and the committee agreed on an ambitious plan of activities for the future.

Later that day we heard more about the great work being done in Africa including EEG, neuroimaging, epileptic encephalopathy, and genetic issues.

To show how international the conference was, I want to highlight two presentations: one from Laos the other from Argentina. In Laos they have similar issues to Africa – advocacy and awareness do not exist. On the other hand Laos is setting up a special Outpatients Departments for epilepsy in the hospital. They want

to reduce the treatment gap by 25%, reduce stigma by 60%, and achieve an adherence to treatment level of 70% . If this test is successful, it will be expanded countrywide.

In population of Buenos Aires is 15.6 million of whom 78,000 have epilepsy. But the lack of health insurance is high (36%) and a high percentage of people with epilepsy go to public hospitals. Therefore a master plan has been created. An epilepsy care network has been built, with antiepileptic drugs being provided, the population is being educated and primary health care workers are being trained with support from the Argentine Neurological Society and the Argentinian League Against Epilepsy.

Saturday May 24

Saturday began for IBE President Dr Covanis and me with a trip to the radio station in Muizenberg, where we were expected by the journalist I'd met on the train. We were involved in a radio talk show for one hour and were asked all the relevant questions about epilepsy. Dr Covanis covered the medical aspects and I told them my personal story.

Back at the conference another exiting issue was brought to the table: the importance of traditional healers in Africa. As medications and the neurologists aren't available, especially in rural areas, traditional healers (TH) play an important role. The doctors and the TH work together but need to collaborate more, as the TH have a better relationship to the patients. Education of the TH is also vital as some have poor understanding of medical facts about epilepsy; believing, for example, that epilepsy can be transmitted via saliva of lizards. In some countries, including Cameroon, epilepsy is linked to insanity and witchcraft.

After the Conference

During my stay in Cape Town I organized a trip around the garden route. It was a great trip. First stop: Mossel Bay! After about 8 hours drive on the bus I arrived, more or less in the middle of the night, at the bus stop. Fortunately a friendly South African took me to my hotel. The next day I took a daytrip to the Cango Caves which were very impressive. Massive stalactites and stalagmites all over the cave. A definite must see! On the way back we made a stop at an Ostrich farm, where I ate my first Ostrich steak. Then my driver brought me to the Wildlife Ranch in Oudtshoorn, where I was able to see the Big Five up close. Simply wonderful.

Next day I moved on to Plettenburg Bay, which is a lovely resort. I relaxed and enjoyed a lovely dinner next to the sea in a wonderful restaurant. The day after I travelled to Kneysna – the Monte Carlo of South Africa. I didn't have too much time to visit because a sign grabbed my attention: Epilepsy South Africa. There I met Anne Fredericks – an incredible woman! They've achieved a lot in Kneysna already: they provide employment for people with epilepsy and they also provide accommodation. They also have an incredible view to the ocean!

Last but not least I visited Plettenburg Bay I went first to Monkey Island where there are 14 different kinds of apes. Right opposite you find Birds of Prey. So many different kinds of birds! On my way back home to the hotel I visited the townships of Plettenburg Bay. My driver told me that new houses have been built by the government and the old houses have to be demolished by their owners as soon as they move into their new homes. But unfortunately I think it won't happen, as there are so many poor people living in South Africa, for whom the "old houses" would still be an improvement.

What a wonderful holiday!

