EPI Focus

Newsletter of the IBE European Regional Committee
Issue 1-2011

Celebrating European Epilepsy Day in Strasbourg

The 1st EED, which took place on the 14th February 2011, was a great success. To make it even more effective, it was decided to have a session at the European Parliament in Strasbourg, France. The session was a huge success, as we were supported by several MEPs. Mostly we've got to thank Gay Mitchell (Ireland) - without his support AND advertising throughout the European Parliament it wouldn't have been possible.

Through an address list, provided by the IBE, all the member states were able to contact their MEPs personally. The answers were different – one country met four out of five MEPs personally, another one only two out of 17 MEPs.

We all met together on the 14th February for an evening dinner. Gay Mitchell also joined us for dinner, for which we are very proud. IBE members from a lot of countries came to Strasbourg – Austria, France, Germany, Netherlands, UK, Ireland, Croatia, Czech Republic, Sweden, Switzerland, Italy, Malta, Greece, Bulgaria, Scotland, and Hungary.

As the parliamentarian session usually starts on Tuesday, the event at the European parliament took place on the 15th February 2011. All of us thought that we were at an airport – the security controlled everybody and everything! After security checks were passed, the participants had time to meet THEIR parliamentarians and to talk to them personally.

During lunchtime the main event took place. Everybody, whom I was talking to, was very impressed about the personal stories given by the speakers Hanna and David, who talked about her personal experience. But everyone was also impressed by the facts given by the neurologists.

After lunch we had a little time to look around the European Parliament. It's so huge – and very impressive! We've also had the possibility to join the parliamentarian session, which takes place – more or less – the whole day long!

After that we moved to the exhibition area, where the reception for the 1st EED was officially opened by Edward McMillan-Scott – Vice President of the European Parliament. Mr McMillan-Scott cancelled another session to be able to join us! At this reception there has also been the possibility to talk to parliamentarians from our own countries.

The end of the evening – which I unfortunately couldn't join since my flight home was on the evening of 15th February was marked by a dinner. I am sure that everybody enjoyed it.

As I've already said, the event at the European Parliament was a huge success – and I hope that it helps to raise awareness throughout Europe!

Michael Alexa

Vice Chair, European Regional Executive Committee

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EUROPEAN EPILEPSY DAY

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A History of Epilepsy in Europe

Part Two of a series of articles written by Dr Athanasios Covanis, Chair, IBE European Regional Executive Committee

Hippocrates described 'aura' and seizures, which in a later era were called Grand Mal. He noticed that age and the menses predispose to seizures and that injury of the left side of the head cause seizures to the right side of the body. This is probably the first description of seizures secondarily generalised. He recommended physical treatments and stated that if the disease became chronic, it was incurable. He also suggested that drilling (trepanation) the brain opposite to the side of the focal seizures could have a curable effect (possibly the first suggestion to surgical intervention).

The ideas of Hippocrates dominated our knowledge for about two thousand years. The description of an epileptic seizure in the New Testament (Mark 9.17) as devils entering a boys body is well known. This belief does not appeared to have been fully abandoned yet and exorcism is still used by some para-religous groups e.g. in Greece.

The scientific approach to epileptic seizures started in the seventeen and eighteen centuries. The first worker to pay attention to minor attacks was Hughling Jackson who described in detail the focal seizures of his wife. This Jacksonian approach was continued and further established by the work of Penfield and Jasper (*Penfield W and Jasper H: Epilepsy and the functional anatomy of the brain. Little, Brown, Boston; 1954*) and Lennox (*Epilepsy and related disorders. Little, Brown, Boston; 1960*), who performed systematic studies on functional localisation of the seizures in the brain.

In 1920s, Hans Berger, a German psychiatrist, developed the human electroencephalography, and its gradual application to epilepsy revealed the presence of electrical discharges related to different seizure types. The EEG has greatly contributed to locating the seizure discharges that contribute very much to the possibilities of surgical treatments, which have become more widely available recently in parallel with the developments in structural and functional neuroimaging. This progress has developed in parallel with the gradual development of effective drug treatment for epileptic seizures, since the introduction of phenobarbitone in 1912.

The introduction of Carbamazepine and Valproic Acid in early 60's and 70's, respectively, has greatly contributed to better seizure control and quality of life of the person with epilepsy. The last two decades have witnessed the accelerating process of drug discovery based on a much greater understanding of the electroclinical activities of the brain, and the genetic specific effectiveness or resistance of anti-epileptic drugs will further improve control and quality of life. In Europe almost all newly developed anti-epileptic drugs are available for the treatment of seizures and this is provided free of charge for the person with epilepsy. Yet even in Europe there are social barriers in terms of education, employment and life-style.

In 1993 the Maastricht Treaty (Article 129) established for the first time that the EU has a competence in the area of public health. Article 129 stipulates that health protection requirements shall form a constituent part of the EU's other policies, such as education, employment, social affairs, environment and communication. This aspect was further strengthened by the Amsterdam Treaty which entered into force on May 1, 1999.

The EUCARE white paper on epilepsy was accompanied by the 'Call to Action' which summarises the key areas in the white paper, clarifies the recommendations to make them understandable for politicians and decision makers; provides a few simple but

Working with Glasgow's Black & Minority Ethnic Communities

to improve quality of life for people living with epilepsy

Nine percent (9%) of Glasgow's population of 1,179,350 people are from Black and Minority Ethnic (BME) communities. The largest community is Pakistani (2.1% of the population, or 17,964 people), followed by the Chinese community (0.6% or 4,912 people). Since 2000, more than 11,000 asylum seekers and refugees have arrived in Glasgow, further diversifying and enriching the life and culture of Scotland's biggest and most vibrant city.

Epilepsy Connections' research into perceptions of epilepsy among local BME communities found that although understanding of epilepsy and seizures is generally good, difficulties with language and communicating cultural values means that there is a low uptake of information and support services that could enable people living with epilepsy in BME communities to optimise their wellbeing.

Multicultural Project Worker Zareen Iqbal connects with BME community groups to raise awareness of epilepsy, improve access to epilepsy information and support services amongst BME communities and reduce the myths and stigma that still surround epilepsy.

Zareen's poster presentation about her work at the 12th European Conference on Epilepsy and Society attracted a great deal of interest from delegates interested in finding out how best to engage with BME communities and the organisations that work with them, and how to develop and deliver culturally-appropriate information and support services.

"As Europe's population shifts and diversifies it is important for everyone who provides epilepsy-related information and support to be aware of the cultural implications of having epilepsy and of the barriers that people with epilepsy from BME communities can face when accessing services", explains Zareen, "Understanding that these issues exist is a starting point for developing inclusive, accessible services".

For more information about Zareen's work go to Epilepsy Connections' website at www.epilepsyconnections.org.uk

Epilepsy Connections is a Scottish charity providing information and support to people with epilepsy, their families and friends, and those with whom they live and work.

A History of Epilepsy in Europe - continued from previous page

powerful messages; and forms the basis for media communications.

In October 1998, over 100 leaders of European professional and lay bodies, WHO representatives and health experts from governments and universities met in Heidelberg, Germany and unanimously agreed the following declaration:

- Six million people in Europe currently have epilepsy. Fifteen million will have epilepsy at some time of their lives
- Epilepsy has profound physical and social consequences.
- Children, adolescents and the elderly are especially afflicted by non-detection and under-treatment.
- With appropriate treatment, over tree quarters of people with epilepsy could lead normal lives free of seizures.
- Epilepsy costs the countries of Europe over 20 billion ECU every year, an amount that could be significantly reduced with effective action.

They called the governments of Europe, the European Union, and all health care providers to join them in taking strong and decisive action to meet the objectives of the Global Campaign against Epilepsy launched by the ILAE/IBE/WHO.

Recently, during the opening ceremony of the 12th Epilepsy and Society Conference in Porto, Dr Matthijs Muijen a WHO Regional Advisor for Mental Health and Brain Disorders gave a short presentation on the occasion of the launch of the European Regional Report on Thursday August 26th. The report is an ILAE/IBE/WHO Global Campaing Against Epilepsy initiative. The launch was chaired by Hanneke de Boer, Mike Glynn and Dr. Muijen in the presence of all stakeholders in the European Region. Dr Muijen commented "we are very excited about this report, we believe that the recommendations will help countries to develop activities to compact stigma, restore dignity and reduce the treatment gap for people with epilepsy in Europe. The report is an advocacy tool and an instrument for dialogue with governments, healthcare providers, consumer associations, non-governmental organizations, academic institutions and development partners"

LET'S INTRODUCE OURSELVES

Lithuanian Association for Integration of People with Epilepsy (LESIA)

Lithuania – one of the Baltic countries, has 3.3 million inhabitants, of whom 24,000 people have epilepsy. Under historical circumstances, it happened that epilepsy, until the restoration of Lithuanian Independence, was attributed to mental diseases, and people with epilepsy were under psychiatrists care. This put a stigma on people with epilepsy and, as a result, our society still has a mistrustful view of people with epilepsy and tries to avoid them and their problems.

Lithuanian Association for Integration of People with Epilepsy (LESIA) was founded at the end of 2004 and joined with associations of people with epilepsy in 6 regions of Lithuania. The main objectives of LESIA is to represent and to protect the rights of people with epilepsy, which are still being violated, - e.g. people with epilepsy do not have access to medical rehabilitation, higher education, or equal participation in labour market.

Considering these circumstances, LESIA has started to look for the ways to help people with epilepsy solve their psychological problems; to recreate their biopsychosocial functions; to motivate them for education and work. Various methods have been created and adapted, which have now been in use since 2006.

LESIA and its members provide social (psychosocial) rehabilitation for people with epilepsy. Bethel Epilepsy Centre (Germany) was and is giving invaluable support for us in creating the methods of social rehabilitation, giving us MOSES – education program for people with epilepsy and their relatives, and helping us to train the instructors of this program. Social rehabilitation consists of psychological therapy, improvement of memory and attention concentration, theatre and music therapy, occupational therapy. Social rehabilitation helps people with epilepsy to get ready for professional rehabilitation, to better integrate into society.

A very important part of LESIA activities is education for society. In 2008 and 2009 we lead a public campaign "Me the same as you". Before this campaign we undertook research, with 1,000 adult respondents and 1,000 children respondents, which had shown that the general public has very little knowledge about epilepsy or how to help people during seizures.

The campaign reached various media sources – television, radio, publications in newspapers, brochures, and so on.

We are putting a lot of effort in to fighting for the rights of people with epilepsy. We have offered amendments for the Law on social integration of the disabled (2004) and part of this have already been accepted. We are going to continue solving juristical problems.

We would like to communicate with analogical national organizations of people with epilepsy. Maybe there are some who would be interested in our modest work? It would be very nice to hear from you. The wish to carry out common projects in the areas of social rehabilitation or solving juristical problems in the light of the Convention of the Disabled would be very welcomed.

Breaking News!

Ljubljana to host
13th European Conference on Epilepsy & Society
More details available soon

European Epilepsy Day in Malta

The launch of the European Epilepsy Day in Malta was welcomed heartily. Making epilepsy an agenda issue of the day contributed a great deal to the ILAE/IBE/WHO Global Campaign Against Epilepsy "Out of the Shadows"

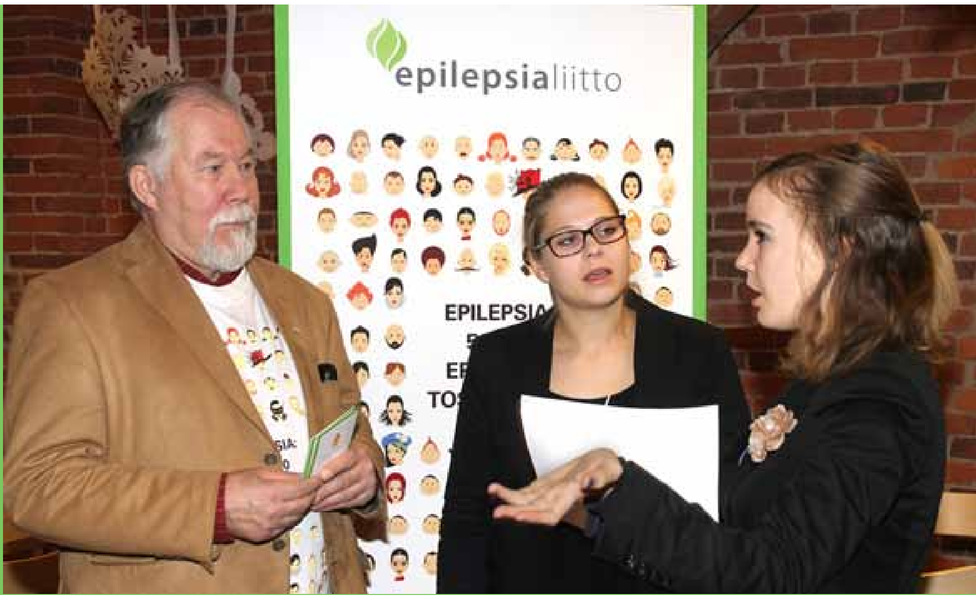
The Caritas Malta Epilepsy Association (CMEA) issued press releases and relevant articles in various newspapers to mark the day. The President of the Association, Mario Dimech, gave an interview on one of Malta's leading TV stations during the prime time news bulletin. This interview got great reviews from several people who contacted the association.

One of the main activities held on this occasion was an "Epilepsy Day On Campus" organised by the medical pharmacy and dental students in conjunction with CMEA. The Parliamentary Assistant to the Minister of Health attended this initiative and was very interested to know more about the work being done both locally and internationally regarding epilepsy. In addition to boosting the profile of this activity, the presence of distinct personalities helped enormously to improve the services given to people with epilepsy and, obviously, their families. It also helps to increase awareness. Needless to say we look forward to celebrating next year's European Epilepsy Day with earnest.

European Epilepsy Day at the Youth Parliament

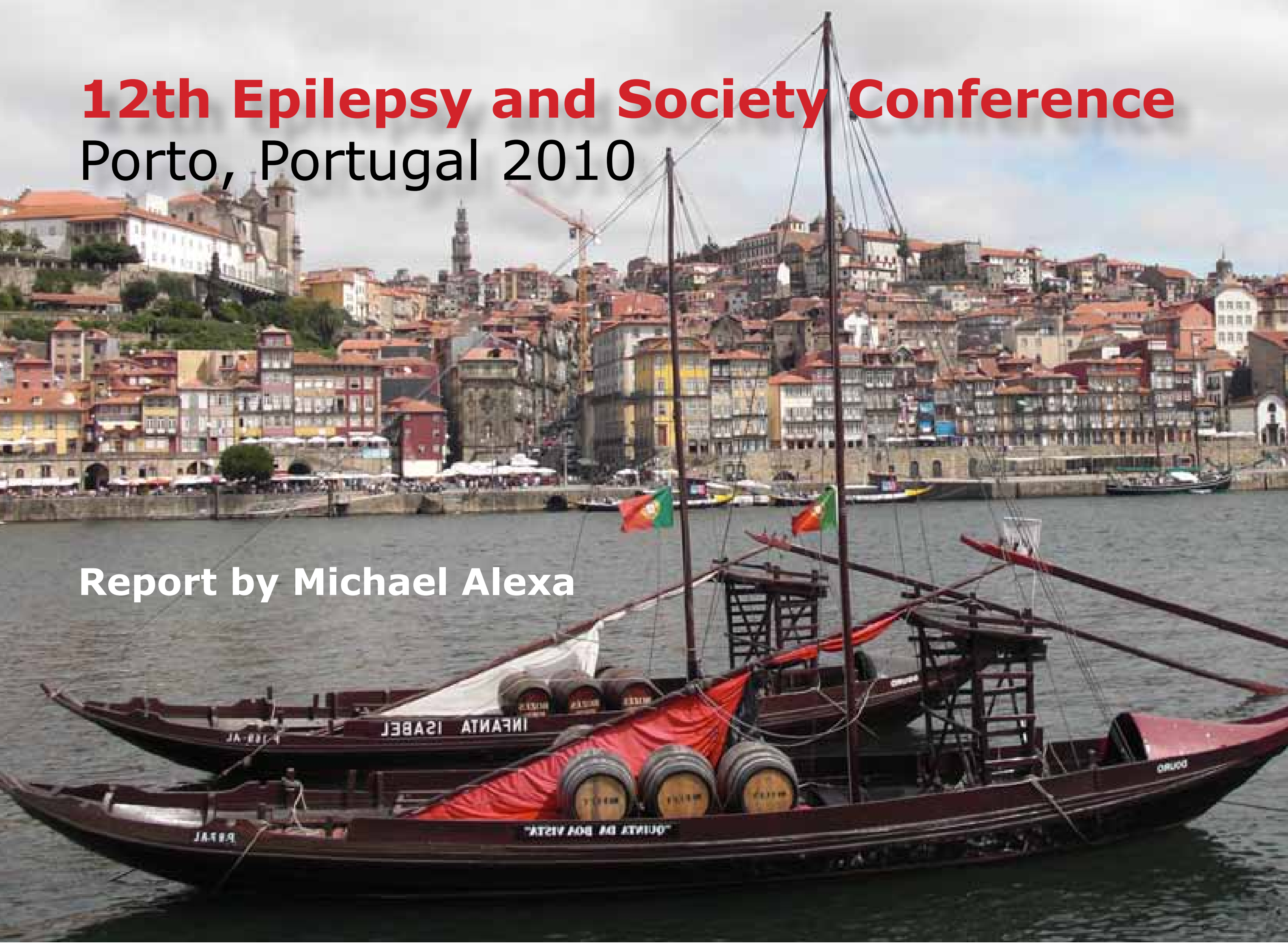
Strasbourg was not the only parliament to celebrate EED!

On European Epilepsy Day, 14th February 2011, Seppo Sarkkula (member of the IBE European Regional Executive Committee) visited the 10 Year Jubilee Session of European Youth Parliament in Helsinki. The photo shows Seppo discussing epilepsy with two members of the European Youth Parliament from Switzerland.



12th Epilepsy and Society Conference

Porto, Portugal 2010



Report by Michael Alexa

The history of Porto began back in 2008. At that time, during the 11th Congress in Marseille (France), for the first time a karaoke evening took place - well organized by young people from Norway, Sweden and Finland. Even then I was sure that this can't remain a single event. The history found a continuation in 2009. By that time I was elected vice chairman of EREC (European Regional Epilepsy Commission) of the IBE.

Our first meeting was held during the congress in Budapest - so we had only about 1 year to complete preparations. The EREC called on all member organizations to send suggestions for topics for the next meeting. We tried to accommodate all possible proposals. So 2009 was filled with conference calls, which helped us to prepare a lot. We also met in Dublin for face to face discussion. At this meeting, I argued that the karaoke event in Marseille should be repeated! The proposal was taken up and implemented. The participants of the karaoke event in Porto have also found that it was a very nice evening - after the opening ceremony.

The "serious side of life" – the Congress - started the next day with the presentation of the European Report of the Global Campaign Against Epilepsy. It is always surprising how many different systems are existing in Europe, although everyone is talking about a "united" Europe. Therefore one of the recommendations of the European report, to collect information about existing legislation then adapt the WHO recommendations, should be followed. Another recommendation is making epilepsy surgery available across Europe.

Next, Ley Sander (UK) gave an impressive talk about ethics in epilepsy - duties, obligations and making the right decisions when dealing with others.

In the following session, Victoria Dimech (Malta) focussed on the social aspects of epilepsy, while José Lopes Lima (Portugal) took care of the medical aspects. Victoria Dimech mentioned such as the fact that passerby-by who witness a seizure can still find it intimidating, if they don't know how they deal with the attack. Therefore education has to begin in school so that children lose their fear of epilepsy - children today are tomorrow's adults! For the parents who experience a seizure for the first time, this can lead to trauma because they feel helpless and can't protect their child. Of course this has effects on the child's development: because the parents try to hide the child's problems and in all probability the child will attend regular school. A child can feel excluded in a normal school, so the affected child feels differently, it feels not good enough. In adulthood this feeling continues - no alcohol, no disco (especially not if you are photo sensitive), no driver's license, and family and work problems. So it remains once again that education is one of the most important issues that ALL countries must be deal with – even in Austria.

The latest development was brought to us - after lunch - again by Ley Sander (UK): deep brain stimulation (DBS). The big difference to the vagus nerve stimulation (VNS) is that the DBS is placed to stimulate "on-site". The big advantage of this device is that you can provide another possibility to patients who are suffering long term from epilepsy to become seizure free. The study that was carried out after the implant operation showed that patients are very satisfied or satisfied with treatment for the most part – and they would recommend treatment. A noticeable increase in the quality of life of affected patients is also

shown. At the same time, the frequency of seizures fell significantly! Nex up were discussion groups:

Driving licenses: Regarding license regulations it has to be said that in the EU – as well as in the USA - there are different rules in different countries on whether or not a person with epilepsy can obtain a driving licence. There is no difference whether the person is applying for a Class I (car, motorcycle) or class II (truck) driver's license. It should be noted that the rules are even stricter than for Class II license than for the Class I.

The Family: As mentioned above, the initial diagnosis of epilepsy can be a bomb for the family! How can I deal with it? How much should I adjust my life? The social network is crucial. Family support is crucial. At the same time it must be "patronizing". Striking that balance is very difficult.

Living with Epilepsy: Several studies which looked at families were presented from Denmark, which dealt with living conditions for people with epilepsy. The studies covered the period 2007 to 2009 and are used in advocacy work. At the same time, the studies are also used to determine the future needs of people with epilepsy

Opportunity for a better life: In Scotland there is a project to enable people with epilepsy to complete an education, in order to have a better chance on the labor market. This will happen because the person with epilepsy has the opportunity to expand their horizons - which includes education, training and paid or voluntary work. This also improves their mental well-being; they get more confidence and be more autonomous and independent.

After the break the moment of truth came for me. I was asked to give a lecture - about personal development opportunities. I've did nothing other than tell my life story - and that really impressed everyone present. Sarkkula Seppo (Finland) and I reported on the problems involved in setting up an epilepsy association.

The evening social event took place in a world famous port cellar. I wanted to take a bottle for my parents – but it was removed by customs in Santiago de Compostela (Spain) ... But that's another story!

The next day began with a breakfast seminar. This was particularly poignant with three people affected by epilepsy telling life stories. Each of these stories was terrific: Julie Joseph (GB), Monica Warbroek (NL) and Alexander van Huffel (NL) impressed the participants present with their openness and bravery in living with epilepsy.

Then there was a lecture by Covanis Thanos (Greece) on photosensitive epilepsy and seizures. I have to say – unfortunately - that in this matter I can talk from my own experience as I also suffer from photosensitivity. Therefore for me discos - and flickering lights - are always off limits, otherwise a seizure is the consequence. Photosensitivity occurs in 5-10% of young adults with epilepsy - it should therefore not be underestimated.

Graham Harding gave us an insight into how to prevent photosensitive seizures. As you may remember in Japan in 1997, when people - with or without epilepsy – watched a POKEMON episode on television, there was an avalanche of seizures. This was related to the frequency in which the image was refreshed.

When you see between 16 and 20 or more than 65 pictures per second, then the probability of having an epileptic seizure is very high. In the POKEMON incident there was a continuous change from red to blue very quickly for 4 seconds. Of the 560 confirmed epileptic seizures, 76% had NO background - BEFORE POKEMON! In Europe, a frequency of 25 pictures per second, in the U.S. this is 30 pictures per second - is regarded as safe with very low incidence of seizures. Computers are also usually safe, but you should still be careful about what you watch. Since I suffer myself from photosensitivity, I've got used to keeping a lamp lit while watching TV - which seems to help.

After a coffee break, we had the plenary session on how to influence politics. The first speaker was Gay Mitchell - a Member of the European Parliament (MEP) from Ireland – who gave an impressive speech. In this speech he gave advice on how to influence European policy. A step in this direction is the creation of the European Epilepsy and I am sure you have already read about that.

After Gay Mitchell we had Tarun Dua's insight into the work of the WHO. The WHO has had epilepsy on its agenda since the launch of the Global Campaign Against Epilepsy (GCAE) in 1997. The GCAE was established by ILAE, ILAE and the WHO.

In the last discussion group I was impressed by Judith Bekes (Hungary). She took the word literally and group discussion involved participants actively taking part in the discussion by answering the questions she presented. Thus, the different experiences from different countries came to light, which was very informative. The issues they discussed ranged from stress management techniques to who or what controls the lives of people with epilepsy?

The final session was devoted to youth. Stine Strømsø (Norway) gave an impressive presentation on this topic. She referred to the Youth Camp to be held in Norway. At this camp, which is organized by youth for youth, not just with young people from Norway taking part but also from Sweden and Finland. The cooperation of the youth associations in the Nordic countries works extremely well. I would like to see something similar for the German speaking countries.

As I - as usual – combined the congress with some holidays. This time, on the road to Porto, I had a brief stopover in Majorca. If I am now asked why Mallorca - it's because there is NO direct link from Vienna to Porto - I must either go through Lisbon or even change at Mallorca! Therefore I decided to combine the pleasant with the useful!