EPI-Focus

Newsletter of the IBE European Regional Executive Committee (EREC)
Issue 13

FOCUS ON SLOVENIA

Message from the Chair

Dear Friends

Preparing this message, I was looking through previous issues of EPI-Focus and the short introductions of us, newly elected EREC members in issue number 11. Something caught the eye. It was Maggan's introduction which she started with: "My name is Margaretha Andersson but everyone calls me Maggan!" and her picture, reflecting her joy, strength and charm shines from the journal page. And I remember the video conference calls of our group, where Maggan appeared sometimes with a glass of wine, bringing so much positive energy, new ideas and courage for changing things and starting new projects.

So, I find it very difficult to start my first message from the chair with the words: "Rest in peace, Maggan."

In this issue you will find stories from all over the Europe: from Norway, Spain, Germany, Austria, Malta, Ireland, Slovenia and Georgia. The stories are as different as the countries, but all are beautiful and focused on different needs of the epilepsy community.

EPI-Focus lets us share our experiences and tell our stories to each other and this is great! I hope you will enjoy this issue and perhaps send us your news and stories for the next issue!

Kind regards

Natela Okujava

IN THIS ISSUE

EREC Officers

Chair: Natela Okujava, Georgia
Secretary: Shirley Maxwell, Scotland
Members: Francesca Sofia, Italy, Ljubica Vrba, Slovenia,
Ex officio: Martin Brodie, President; Mary Secco, Secretary General; Anthony Zimba, Treasurer.

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EPI-Focus layout and design: Ann Little

IBE International Bureau for Epilepsy

MEMORIES OF MAGGAN

It was with great shock and sadness that the European Regional Executive Committee (EREC)learned of the passing of its much loved member - Maggan Andersson. Maggan passed away on 28th December, following a short illness.

Maggan first became involved with IBE when she was elected a member of EREC in 2013 and had been working with the committee until shortly before her passing. She had great energy and was a wonderful ambassador for IBE at the European Medicines Agency (EMA), attending a number of meetings as an IBE representative. She also travelled to the European Parliament as part of the IBE delegation at the time of European Epilepsy Day and, more recently, International Epilepsy Day.

Her outgoing friendly personality made her a wonderful colleague, always easy to work with and always happy to talk about how to improve the situation for people living with epilepsy.

At a national level, Maggan worked with the Swedish Epilepsy Association and was its President when her final illness was diagnosed.

Maggan will be missed by all who knew her, but remembered with great fondness. Here, her friends at EREC share their memories of a fun-loving colleague.

Maggan, was such a lovely and outcoming person, passionate in whatever she did, yet always with a smile on her face and living life to the full. She was an excellent ambassador for EREC and IBE and keen to share her personal experience with all she met - whether they were MEPs, EMA officials or other patient organisations.

She will be greatly missed and her ‘joie de vivre’ is something we should all try to duplicate.

I remember with great fondness attending European Epilepsy Day in Strasbourg in 2014 with Maggan and the rest of the term. Her energy was positively contagious.

Janet Mifsud, formed member of EREC

What can I say about Maggan? Maggan was a shining ray of light, full of life and someone who made the most out of life. She shone a positive light on difficult issues, always focussing on possibilities rather than the negative.

Maggan was not afraid to voice her opinions, and I appreciated her candour.

She made me smile, she made me laugh. I will miss her.

Rest in peace Maggan.

Caroline Morton, former Chair of EREC

Maggan lived life to the full and with great joy and energy. She had strong views, was always willing to share them. She enjoyed discussing and debating ideas.

Maggan was an energetic, thoughtful and knowledgeable advocate for epilepsy and the epilepsy community is the poorer for her loss. It was a privilege and a pleasure to know and work with her, and I will miss her.

Shirley Maxwell, member of EREC

CONFERENCE IN GEORGIA

Report by Natela Okujava MD, PhD, IBE Vice President Europe, Associate Professor Tbilisi State Medical University, and Head of SEIN-SKUH Epilepsy and Sleep Centre

IBE president Prof Martin Brodie visited Tbilisi from 26 to 29 October last year. He was invited by the IBE Chapter in Georgia to participate in its international conference and to meet with local chapter members.

On October 26 a full day conference: "Chronic Neurological Disorders - e-Health approach", was held at Tbilisi State Medical University (TSMU). The conference was devoted to finalising the project "First Georgian Digital Cognitive Behavioral Therapy for Insomnia Project" and launching of a new international project on automatic detection of epileptiform EEG abnormalities. The conference was organised under the auspices of the Shota Rustaveli National Science Foundation, Tbilisi State Medical University and the IBE chapter in Georgia – "Epilepsy and Environment Association".

Leading scientists from the Netherlands and Austria participated in this international event. The conference was also attended by the President of the Ukraine Epilepsy Association, Dr Olga Mostovaya. The Rector of Tbilisi State Medical Universit, Professor Zurab Vadachkoria, opened the Conference and welcomed participants. Welcome speeches were made by Deputy Director of the Rustaveli National Science Foundation, Mrs. Nino Gachechiladze; and Prof Martin Brodie (UK); and Dr Al de Weerd (SEIN, Netherlands). Prof Natela Okujava presented a brief overview of research projects on sleep disorders and epilepsy.

Two major issues were discussed during the full day conference: the role of e-health in sleep disorders and e-health in diagnostics and management of epilepsy. Presentations were given by leading experts in this scientific field: Prof Martin Brodie, Prof Annemieke van Straten, Dr Al de Weerd, Dr Tilmann Kluge, Prof Natela Okujava, and Dr Alex Tsereteli. The conference was attended by neurologists, psychologists, psychiatrists, basic scientists, AIT specialists, medical students and residents. Multidisciplinary approaches to sleep and epilepsy research was of special importance and interest for all participants and led to lively discussion.

On October 27, Prof Martin Brodie met with the executive committee of the Georgian Chapter and President of the Ukraine Epilepsy Association, Dr Olga Mostovaya. Major problems of epilepsy care and the needs of people with epilepsy in Georgia and Ukraine, activities of local chapters at national and international level, and challenges and ways of raising chapter engagement were discussed during this full day meeting.

We hope that this visit will contribute to the scaling up of epilepsy care in Georgia, facilitate better understanding of local needs and, consequently, support more effective collaboration between local chapters and IBE.

Photos:

Main: Prof. Zurab Vadachkoria, Prof Natela Okujava, Prof Martin Brodie, Dr Al de Weerd (SEIN), Mrs Nino Gachechiledze Deputy Director, Rustaveli National Science Foundation Georgia

Below left: Delegates at the meeting

Below right: Media interview with Prof Okujava

Bon appétit!

Norwegian Center for Epilepsy launches new Ketogenic Diet Cookbook

Since the mid-90s, the National Center for Epilepsy has been treating children with the ketogenic diet. Because pediatricians noticed a great positive effect in this group, the hospital started to treat adults with the ketogenic diet, as well. From recently published research on this topic, we know that the ketogenic diet has a moderate effect on adults with focal epilepsy. Even though it was proven to have just a moderate effect, people report on improved life quality, better sleep and faster recovery after having a seizure. Some adults say their lives have changed since beginning to use the ketogenic diet!

Therefore, two patients and a nutritionist from the National Center for Epilepsy contacted the Norwegian Epilepsy Association with the request for more recipes, or even a cookbook, tailor-made for the diet!

Following the ketogenic diet is demanding and it is hard to maintain the lifestyle over a long period. A cookbook would be encouraging and a practical tool in the everyday life of those using the strict diet, the patients argued.

Jørn Mandla Sibeko, Assistant General Secretary of the Norwegian Epilepsy Association, took on the challenge. He was granted funds from a foundation, which enabled the project. A cooking class was held with patients from the hospital, and the menu from the class was the beginning of the now completed cookbook.

"We want to make it easier for patients to follow through with their treatment. Hopefully this book contributes to sustaining the patients love of food," says Jørn.

Because the ketogenic diet has tons of fat and only a little carbohydrate, the ingredients must be measured exactly. All the recipes in the book have a ketogenic ratio which specifies the ratio between fat, protein and carbohydrate. The book is inspired – with photos of garnished dishes, easy to follow recipes, and a cooking vocabulary. The recipes include recipes for dishes using avocado, legumes, fatty sauces, meat, poultry and fish.

Main photo: The cookbook cover

Above: : Jørn Sibeko from the Norwegian Epilepsy Association, Magnhild Kverneland from the National Centre for Epilepsy and chef Svein Harald Iversen

Below: Avocado salad, a colourful recipe from the book

Epilepsy Ireland volunteers recognised at National Epilepsy Conference

Mags Cummins and Una Long pictured with Community Resource Officer Niamh Jones

Cork Parents Support Group

The first award went to a very special group of people who have highlighted over the years the multitude of different ways in which people can volunteer with Epilepsy Ireland.

On March 14th 2007, the Cork Parents Support Group came together for the first time. A group of mums and dads, they joined forces because their child had been diagnosed with epilepsy and they wanted to meet others in a similar situation.

Many have come and gone from the group over the past 11 years, often as their child's epilepsy improves, but others have stayed involved so that they can help other parents who join the group and who are often starting out on their epilepsy journey.

Mags Cummins and Una Long, who accepted the award on behalf of the group, are two of the original pioneers who continue to be dedicated members to this day.

The group has contributed immensely to fundraising work over the years from coffee mornings, quizzes, raffles, launching a CD, cycles, cake sales, participating in the marathons and assisting with Flag Days and Rose Week.

The parents have also brought in their extended families, friends and work colleagues to raise funds to support Epilepsy Ireland services.

However the award is not just about fundraising, it's also for the time they have given up so generously to help organise events, to speak out about epilepsy at events and participating in media interviews.

Above all, the award is for supporting each other and sharing experiences. It is about being there for each other when there were tears and when there were moments of great joy like when children become seizure free or pass their exams.

Volunteers have extraordinary determination and Epilepsy Ireland was delighted to present Mags and Una with an award for all the work put in over the years to lessen the impact of epilepsy in Cork and beyond.

Michael Earley, Finola Earley, Mark Earley, Sarah Earley and Hector LLoyd

Mark Earley

In April 2017, Mark was given devastating news that turned his life upside down. While attending a wedding in Australia he received a call that his wife of just under two years, Liane had passed away as result of a seizure in her sleep. Mark and Liane had plans to build a family, travel the world, live in Galway and grow old together.

Mark turned to writing and fundraising to help him grieve. His blog 'There are Words' is an open and honest account of what life is like without his dearly missed wife and best friend.

His fundraising efforts, since Liane died, have been nothing short of extraordinary. In 18 months Mark has raised over €50,000 for Epilepsy Ireland through various events including quizzes, music events and comedy nights. He is an active member of the Leinster Open Sea Swimming Association who organised the first 'Liane Deasy Memorial Swim' in August 2018, which saw over 250 people take part.

As well as his incredible fundraising, Mark's has helped raise awareness of Sudden Unexpected Death in Epilepsy (SUDEP) by writing about his loss in the national press and speaking recently on Irish national radio.

There was no doubt Mark was an extremely worthy recipient of the volunteer award, for all he had done to support Epilepsy Ireland and to honour his wife Liane's memory.

EPILEPSY IRELAND LAUNCHES NEW WEBSITE

Epilepsy Ireland has launched a redesign of its website (epilepsy.ie). The new site is intended for people with epilepsy and their carers as well as professionals and the general public.

It features an innovative design to accommodate new features such as special sections for parents, women, children and teenagers.

Epilepsy Ireland has also released a new and expanded version of the Epilepsy Management App on android. The app includes features such as reminders for medication, appointments and a seizure diary.

FEDE

SPANISH EPILEPSY FEDERATION

Report by José Luis Domínguez

Research Conference

The Spanish Epilepsy Federation has undertaken awareness raising and public education activities through two major events that it organised during 2018.

The first activity was an Epilepsy Research Conference, which it organised for the first time in May on the occasion of Spanish National Day for Epilepsy.

People with epilepsy and their families have been voicing concern on the need for two major issues to be addressed:

1. The need for increased research to improve treatment
2. The need to undertake activities to end the stigma the can prevent people with epilepsy from living normal lives.

To address these concerns, the Spanish Epilepsy Federation (FEDE), which represents 20 associations throughout Spain with more than 3,200 members, launched the 'Face Epilepsy' national campaign during the conference.

The Research Conference aims to shed light on the difference types of research being carried out at the national level, both in applied technology research to improve the lives of patients and research in basic science of the brain.

The conference was divided into two sessions: the morning session, which focused on medical research, during which six research projects, currently underway in Barcelona, Seville, Albacete, Madrid, Valencia and Vizcaya were presented.

The afternoon session focused, in turn, on presentations of technological devices that improve the quality of life of the patient, such as vagus nerve stimulation or seizure alert devices.

Patients Lecture at National Neurology Congress

FEDE also represented patient associations at the 70th Annual Meeting of the Spanish Society of Neurology, at the 25th Annual Congress of the Spanish Society of Neurological Nursing and at the 1st International Congress of Neurological Nursing.

José Luis Domínguez, president of FEDE, represented the different lay epilepsy associations and put their demands on the table. Apart from being a control body for administration and laboratories in the face of possible shortages of medicines, Domínguez stated that patient associations are also the societal voice to "inform and raise awareness about the need to promote research."

Patient associations are a growing in number. "In recent years there has been a rebound in the number of active associations, they are more professional, they have more training and information and they know about the need to be internationally focussed," explains the president of FEDE. But in spite of this, "we still do not have guaranteed economic resources, we lack social visibility and, most importantly, we have not secured a generational change".

Trinidad Ruiz Escudero, lawyer and member of the legal and social section of the Epilepsy Association of the Valencian Community (ALCE), considers the participation of associations in national events to be vital "not only because we want to control seizures, but also because we seek to make epilepsy a socially understood and accepted disease, which allows people with epilepsy their social, educational and work integration and an adequate quality of life ".

I Feria de Investigación en Epilepsia

23 de Mayo de 2018
Auditorio ONCE Madrid

¿Cuál es el futuro de la investigación en epilepsia?

Descubre los nuevos dispositivos que alertan sobre las crisis y mejoran la calidad de vida de las personas con epilepsia y sus familias

Regístrate en la web fedeepilepsia.org para participar de forma gratuita.

Más información en presidente@fedeepilepsia.org o en el teléfono de atención 655 91 84 45.

MICHAEL ALEXA REPORTS

Weekend in Vorarlberg, Austria - May 2018

This meeting was for relaxing. From all over Austria people with epilepsy, their partners and even children, arrived in Vorarlberg, which is a distance from Vienna, for a relaxing weekend. We visited some beautiful places, including the island of Mainau in the middle of the "Bodensee". We also managed to ascend the "Pfänder" mountain in Bregenz with wonderful views from the top! A big plus was the wonderful sunshine we enjoyed all weekend. Of course we used the meeting to talk about the latest developments in the epilepsy community.

German General Assembly, Berlin - June 8-10

The General Assembly of the German epilepsy association took place from June 8 to June 10 in Berlin. I was delighted to attend with my friend Janette Menia and we had the opportunity to meet with a lot of old friends as well as making some new ones.

The most important lessons from this meeting were:

- How can we attract the young people? Is our public awareness campaign reaching them?
- Do we have to change/intensify internet campaigning? Are all the associations on Facebook, YouTube, Twitter, Instagram and Snapchat? How are those internet giants dealing with the data they collect from us?

Another important issue raised was peer counselling for people with epilepsy. People living with a disability can help others like them to achieve a "normal" life. It's very important that people with epilepsy are being treated with respect by their counsellors – on an equal level. To maintain high quality, peer counsellors have to participate in continuing education. In Germany peer counselling is a huge success story and has been offered since 1994 - which is terrific!

12th Asian Oceanian Epilepsy Congress, Bali - June 28 to July 1

Before the conference, Janette and I enjoyed a visit to Taiwan, with the help of Shaw Yu Wu who organised all our tickets and travel. During our stay, we visited a number of places including Hualien and the Taroko Vally; Kaohshiung and Taichung. And, of course, we had the chance to tour Taipei itself.

Then on to Bali for the congress. We had some days to enjoy the hotel pool and the sandy beach that was just five minutes' walk away. We also used the hotel shuttle bus to go shopping in the city centre and a private cab to drive us around the island. We visited temples and saw rice fields.

One of the key questions from the conference was whether epilepsy diagnosis is correct. Have patients really been diagnosed with epilepsy and treated properly? Are the episodes epileptic seizures or not? Have all possible ways of diagnoses been taken into account – EEG, MRI etc.

Another important issue is epilepsy surgery if treatment with medication fails. It takes considerable time to assess a patient's suitability for surgery but can be very successful. More than a third (38 %) of the people with epilepsy on whom surgery is performed become seizure-free. Surgery can reduce (or end) seizures but it is a very costly exercise. There are also more affordable measures such as VNS, DBS. RNS, tVNS etc. All those methods can also be used as an alternative adjunctive therapy but, of course, there are advantages and disadvantages.

Also discussed throughout the conference was the question of genetics. In the last few years the number of genes identified that can cause epilepsy has risen dramatically. But there are problems: interaction between genes, which haven't been investigated as yet. Another problem is data - who has access to the results of the investigation. It was interesting to hear that the first 'epilepsy' gene was discovered many years ago. It took 20 years for a medication to be developed to address it!

At the conference, a new method of treatment was discussed: using biomarkers to see whether or not treatment is effective! A biomarker has to be easily accessible (e.g. use of blood, urine or saliva tests). The biomarker can help the doctor to find out if the diagnosis is correct. This new way can lead to a lot of new treatments: If the biomarker shows the treatment chosen is not effective, then the treatment can be changed rapidly.

Another "new treatment" is the use of marijuana/THC for epilepsy. During the conference it was announced that the FDA had legalized its use for the treatment of epilepsy. It can be expected that the EMA (European Medical Agency) will follow in due course. Of course there is also another opinion: that medical marijuana is not as safe as it seems and has a lot of interactions with other commonly used medicines.

The Epilepsy and Society Symposium took place on the last day of the conference. It was a great pleasure to take part in this great event. A lot of initiatives from the IBE were introduced but, more importantly, Indonesia and the whole region presented themselves! We heard the moving testamonies of people with epilepsy – all of whom had one thing in common: they have already achieved a lot in their lives – even in resource poor countries. It was so impressive to listen to their stories. One patient from China collected 150 stories from all over China and raised the money to print the book that was produced.

I also learned that Indonesia consists of 17,000 islands and not all have a doctor or hospital. Indonesia has more than 270 million inhabitants. This means that, based on a statistic of 1% of the population, 2.7 million people with epilepsy live in Indonesia. But a lot has already been achieved – and they continue on working. Especially when fighting against the beliefs concerning epilepsy. Some people still believe that it has been caused by the sins of ancestors or by a black magic jinn. Another huge problem is the traditional healer - many people with epilepsy go to the traditional healers first, before they visit a doctor.

National Epilepsy Day in Germany

On October 5, 2018, our central event for National Epilepsy Day took place in the Brothers of Charity Trier Hospital with the theme "Epilepsy - and now?".

The focus was on people who have been newly diagnosed with epilepsy and whose lives have often been completely turned upside down. The audience was able to exchange views with experts and experienced self-helpers in two panel discussions.

The patroness of National Epilepsy Day was the Federal Minister of Justice, Dr Katarina Barley. The Mayor of Trier, Wolfram Leibe, accepted an epilepsy resolution from self-help associations in Germany calling for the nationwide development of financially secure epilepsy counselling centers.

Picture: Wolfram Leibe (Lord Mayor of Trier), Dr Katarina Barley (Federal Minister of Justice), Stefan Conrad (Chairman of the German Epilepsy Association), Prof Matthias Maschke (Hospital of the Brothers of Charity Trier)

Photo acknowledgement: Brüderkrankenhaus Trier (Hospital of the Brothers of Charity Trier)

Focus on Slovenia

Ljubica Vrba tells us about some of the work and initiatives of the Slovenian League Against Epilepsy

The Slovenian League Against Epilepsy is a professional-humanitarian non-governmental organization which consists of medical and paramedical professionals working in a field of epilepsy (medical doctors, clinical psychologists, social workers, nurses and others) and people with epilepsy, their relatives and friends. Our association is a member of ILAE and IBE (because we are small). It was launched in 1991, when Slovenia became an independent state.

Slovenia is a small country in the Central Europe and Mediterranean region with two million inhabitants. Until 1991, it was one of the republics of the former Yugoslavia. It is bordered by Italy, Austria, Hungary, and Croatia. The capital is Ljubljana. Since 2004, Slovenia has been a member of the European Union.

For people with epilepsy, almost all antiepileptic drugs are available, as well as vagus nerve stimulation and, for children, the ketogenic diet is also used. Slovenia is too small to have its own epilepsy surgery unit but our health insurance covers procedures abroad. Our neurological department sends children and adults to epilepsy centers abroad, mostly in Germany and France but also in the Czech Republic and Italy for intensive evaluations and surgery.

The main problems affecting epilepsy care is a lack of neurologists with a special knowledge of epilepsy and this results in long waiting lists for check-ups. In the case of adults, we don't have satisfactory comprehensive care (psychiatrist, social worker, occupational therapist,…). People with epilepsy have problems with employment. Because of poor public transport in Slovenia, people without driving licenses have problems in participating in social activities.

The aim of our association is to improve the quality of life of people with epilepsy (e.g. comprehensive management, schooling,

employment, social activities, sport activities…)

The association is involved in education activities for professionals in the field of epilepsy and for people with epilepsy, their friends and the broader general public.

For professionals, we have organized eleven International Practical Epilepsy Schools with experts from France, Germany, Great Britain, Italy, Czech Repbublic, Netherlands and other countries. We organized workshops on genetics, epilepsy and psychiatry, epilepsy and employment, epilepsy and driving, comprehensive care in children with epilepsy, epilepsy and sport, as well as workshops for pharmacists and dentists.

We were also very active in the ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows'.

There are several self-help groups gathering persons with epilepsy, parents, relatives and friends together.

Regularly, we have lectures in kindergartens, schools, homes for elderly people, sheltered workshops, which include also a discussion about proper help to support the involvement of persons with epilepsy in everyday life activities. We organize lectures for groups of parents of children who are recently diagnosed, not only for educational purposes but so that they can hear each others problems and stories and to see that they are not alone in this. Exchanging experiences can be very useful and helpful.

Every year on International Epilepsy Day we organize press conferences to spread knowledge about epilepsy. In different parts of our country we organize lectures for the public. In 2013 we hosted the IBE Epilepsy & Society Conference, which was a very successful and enjoyable event.

Our important and, we believe, also successful activity for persons with epilepsy who are travelling abroad to epilepsy surgical centrs for invasive investigations and surgery is to find a volunteer (mostly medical student) to tavel with them. This volunteer helps with translations in foreign languages between person with epilepsy and medical staff on the hospital ward and with organizing life on the ward.

We hope that with our activities we will improve knowledge about epilepsy in professionals and the general public and in this way also reduce the prejudices and improve the quality of life of people with epilepsy.

Photos:

Main photo: View of Ljubljana city

Top left: Self-help group meeting in Koper

Bottom left: Experts discussion at an International Practical Epilepsy School session

Above: Press conference for International Epilepsy Day.

WINTER CAMP FOR CHILDREN WITH EPILEPSY IN CROATIA

MAKING PROGRESS

Maša Malenica, Monika Kukuruzović, Kristina Kužnik, Snježana Bota, Maja Batista,
Department of Pediatrics, Neuropediatric Department, University Hospital Center "Sestre Milosrdnice", Zagreb

This year we held our traditional Winter Camp for 20 children aged 6-18 years who have active epilepsy. The camp took place on Sljeme Mountain in Zagreb, the capital of Croatia. As members of the Croatian Association for Epilepsy, the camp was supported by the City Office of Zagreb Department of Health.

As always camp staff included two child neurologists, a psychologist, nurses and trained volunteers from the hospital Psychology Department as well as the Education Faculty.

This year teaching sessions focused on helping others during and after a seizure as well as teaching about peer bullying. Of all the sessions organised, the children enjoyed the lessons on survival in the forest and tae-kwon do the most. Their attention was, perhaps, best during the time when volunteers came to read books to them.

Psychologists were excellent in breaking the ice on the first two days, and helping their transition to staying away from parents for a week, as well as focusing on the various workshops.

We emphasized the importance of taking their medications regularly and on managing lifestyle issues. The idea of transition to adult care was introduced to them, and preliminary talks about how transition will work were quite interesting to them.

The impact of the educational sessions was evaluated at the beginning and at the end of the camp through questionnaires. We have noticed that kids who came to the camp for the second time had excellent results in knowledge of epilepsy and were eager to help others. As always, our main message was for them to reach their full potential in life and to feel equal to their peers in every aspect of life.

Epilepsy and Professional Life

a short report by Sina Lang

A seminar on the theme "Epilepsy and Professional Life" took place from the 17th to the 19th of August last at the charming Hotel Lindenhof, which is located in Bielefeld, Germany.

After all of the participants had arrived at the venue, everyone proceeded to have dinner together, after which the speakers introduced themselves. They were Peter Brodisch who is a social worker, a networker for "Epilepsy and Professional Life", and a leader of epilepsy counselling in Munich, and Jochen Röder, a lawyer who specializes in employment law.

The attendees also introduced themselves so that all of us could get a rough idea about whom we would be spending the next two days with!

It was a notably diverse group from all walks of life and of all different age groups. A few, myself included, had an occupational disability or were in the middle of their studies, while others had found employment in sheltered workshops. There were also those who were struggling with the effects of their condition in an otherwise intact professional life.

A lot of different issues and questions were brought up, all of which were promptly collected and written down. We were going to spend the next two days discussing these topics!

Some members of the group arranged to meet up at a small pub afterwards to relax for the remainder of the first evening together.

Come Saturday, the speakers did an outstanding job at finding commonalities in all the different issues and questions, but still managed to address each problem in a nuanced and differentiated way. In order to go into more detail about the individual points and to be able to discuss each participants distinct struggles, the group was split in two.

Any remaining questions could often be addressed during meals or coffee breaks. I was able to draw much benefit from this Saturday alone already. Peter Brodisch was able to help me to formulate a strategy to make my colleagues understand my condition without losing their respect, which was my personal reason to attend this seminar.

Sunday morning, after an abundant breakfast, the last remaining questions were discussed.

Addresses both professional and personal were exchanged before we all parted and made our ways home.

Photo: the old Market Place (Alter Markt) in Bielefeld

Report from Vienna

The second of two conference reports by Michael Alexa

Vienna, my home city… where shall I start? I think I have to start one year ago in Barcelona at the international Epilepsy conference! Why? During the IBE general assembly Richard Holmes announced that for the first time ever a "Patients Day" would be included into the programme!

It has never happened before that the patients received a platform during the European Congress on Epileptology (ECE)! The name "Patients Day" comes as a translation from the German "Patienten Tag"! The "Patienten Tag" has been introduced years ago as part of the German Austrian Swiss League meeting – which takes place every two years! Thomas Porschen from Germany was asked to take the lead in organising it – together with Prof Eugen Trinka – one of the co-chairs of the whole conference! They asked me, if I could help them – and of course I said yes! It was a great opportunity for us! Both of us (Thomas and myself) – together with Janet Mifsud (Malta), Caroline Morton (Netherlands) and Shirley Maxwell (Scotland) were also working on the EPIPICTO project! And the ECE Patients Day gave us the opportunity to introduce it to the public! What a great chance! I'll come back to the patient's day at the end of my report, as it took place on the last day!

One of the topics, which is usually being discussed during such a conference is epilepsy and pregnancy. There are – of course – a lot of risks during a pregnancy! Especially when you take anticonvulsive drugs in addition! There are foetal risks with exposure to antiepileptic drugs causing intrauterine growth restrictions, major cognitial malfunctions, impaired cognitive and behavioural development, as well as foetal risks with uncontrolled seizures, and maternal risks with uncontrolled seizures. Another topic is gaining more and more importance during the last years: epilepsy in the elderly! Did you know that:

- The likelihood of developing epilepsy in a person older than 80 years is three times higher than compared to children?
- The hospitalisation rate for people with epilepsy who are younger than 60 years is three times higher compared to people with chronic epilepsies (52 % versus 15 %)?
- There is a significant public health issue as more people live longer thanks to advanced medical treatment?

As these points show, epilepsy in the elderly will have to be dealt with for many more years to come! The real problem is the lack of studies in older people with epilepsy – in Europe and all over the world! But those are very much needed as the population will become older in the years to come! And – hopefully – we will be able to offer a gene therapy, which can offer the cure of the epilepsy without resective surgery and possible gene correction!

On Monday it was a special day for us! The organisers of the conference gave us the opportunity to present the EPIPICTO poster in the exhibition hall! Janet and I were present at the poster during the breaks and answered all the questions the public had! We also felt very honoured as the organising committee put our poster on the shortlist for the best poster award!

Another topic which gains more and more importance are epilepsy and genes! This time the recent advances and treatment in status epilepticus (SE) showed the huge progress of epigenetics! Epigenetics is about "readability" of the genetic code! It helps to determine whether the gene is ON or OFF! It also helps to produce the proteins needed in the right cell at the right time for the right duration! This could be a great

solution for the treatment of epilepsy – but – as usual – I think that there is a long way to go! The problem is that there is only very limited data available on effects, safety, practical use of "epileptogenic" drugs! It can also be very helpful in creating new antiepileptic drugs to stop the status epilepticus (SE)! As you know, there is a big black hole (= no drugs approved for SE) between the first drugs and the latest ones! More new drugs are desperately needed! We have the same problem like with the epigenetics – we don't have any data for the SE! There are more studies needed desperately!

As we've heard already in Bali, the use of cannabis was allowed in the USA this year! The advantages have been shown in a satellite symposium! Again – I have to say – in my personal opinion – we are still at a very early stage and side effects and pharmacological interaction still has to be examined carefully for the upcoming years! So far it has proven it's effectivity – but it takes a long time for the pharmaceutical industry to get it legally on the market!

Another topic which needs much more work to be done is about the cost of epilepsy! Can you tell me, how much a person with epilepsy is costing the society? To measure the direct costs is not so difficult: the cost of the medicines, doctors, clinics etc, which are used to help the pwe, can be found out easily. What is more important is the fact how high the indirect costs are! As indirect costs have to be mentioned: e.g. the job loss, the loss of productivity, or the worker replacement! To measure those costs is much more difficult – and therefore those costs are – unfortunately – usually estimated! It's also very important to measure them in the reality! But that's very difficult: how do you compare the loss of productivity? Is it only the epilepsy medication – or are there other medications also which can be responsible for that? How do you divide those costs? Or let's take the job loss! That's "easier" to measure! But – you have to know how much the individual has earned before! And that's not easy to know! The level of education is also a major factor! The highest level of education for pwe is in 73 % less than college degree! Compared to the control group, where the number is 42 %! The level of education is also connected with the level of income! People with epilepsy earn a lot less than the control group! That's one of the major issues we have to work on!

Let's finish it off with the Patients Day! We had two sessions on this day: one in English to introduce the EPIPICTO project to the participants and the other one was the Patients day – it was done in German! During the English session we also had the pleasure that IBE president Prof Martin Brodie and IBE executive director Ann Little were present! We also have had some participants from all over the world! All of them were impressed by our work! At the second session (German one) we've had a lot of interesting features! Prof Strelczyk (Germany) was talking about the compliance. Prof Trinka about new treatment alternatives. Dr Unterberger and Dr Feucht (both from Austria) talked about the importance of rescue medication – for children and for adults! Last but not least we introduced our EPIPICTO project to the public! We asked the participants about their thoughts! And we received a lot of positive remarks. It was very successful and all the participants were very pleased about what they've learned. Our stand – in front of the entrance was also visited very often! We also gave them a lot of goodies to take back home which they liked a lot – including our latest issue of our newsletter – ZAK!

The congress was finished off with a "trip on the Danube". The ship "Vindobona" drove us through the Danube channel to the Danube and back again. We enjoyed the evening with "Heurigen music" and a great dinner on board! It was real amazing!

That's all from me right now!!! See you next year in Bangkok – but before in Morocco!!!

Photos:

Top: from left - Thomas Porshen, Janet Mifsud, Shirley Maxwell and Michael Alexa

Bottom: from left - Michael Alexa, Martin Brodie, Shirley Maxwell, Thomas Porschen and Janet Mifsud