EPI-Focus

Newsletter of the IBE European Regional Executive Committee (EREC) Issue 11

Message from the Chair

Dear Friends

Welcome to the new issue of EPI-Focus: IBE's newsletter dedicated specifically to its European chapters. This is also my first EPI-Focus as Vice-President Europe and Chair of the European Regional Executive Committee (EREC) and I am delighted that so many of you have shared information about your activities for this issue.

I would like to draw your attention to the short introductions that the new EREC members have written on their specific areas of focus on the committee. There is also a message from the IBE President, Martin Brodie, about IBE's EpilepsyNext programme. A new strategic direction for IBE and one in which we hope to connect with the next generation of young epilepsy leaders.

We have contributions from all corners of Europe. From the west in Ireland, to the south-east in Turkey and the north in Denmark. This shows us that a great variety of projects and other activities are taking place to help improve the quality of life of people with epilepsy throughout the whole of Europe.

EPI-Focus is here for you to tell us, and each other, about the fantastic work you are doing. Tell us about your achievements, but also if things didn't work out the way you had planned. We can use this forum to share our experiences and to connect with our fellow European members to offer advice and assistance. Happy reading!

I would like to take this opportunity to wish you and your families a happy, peaceful and healthy 2018. May the stars shine bright for us all, and for people with epilepsy who need us to be their voice.

Caroline

Kind regards,

Caroline

IN THIS ISSUE

EREC Officers

Chair:	Caroline Morton, Netherlands
Vice chair:	Natela Okujava, Georgia
Secretary:	Shirley Maxwell, Scotland
Members:	Francesca Sofia, Italy, Ljubica Vrba, Slovenia, Margaretha Andersson, Sweden
Ex officio:	Martin Brodie, President; Mary Secco, Secretary General; Anthony Zimba, Treasurer.

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EREC
European
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IBE

PUTTING EPILEPSY IN THE PICTURE

New guide to educate with few words

The kick-off meeting of the EPIPICTO project, a European Erasmus+ project that will develop a pictorial guide for adults with epilepsy with reading difficulties, was held in Malta from 24th to 25th November 2017. The project is an activity initiated through the IBE European Regional Executive Committee and comprises five partner organisations from Austria, Germany, Malta, the Netherlands and Scotland. Representatives from the partner organisations met with people affected by epilepsy living in Malta, and with other stakeholders, to discuss what this guide should include.

The EU literacy report (2012) showed that up to 20% of European adults have poor literacy skills, and from experience many people living in rural areas have little or no access to education. In view of the recent influx of migrants into Europe, who might not speak the language of the country in which they settle, it is estimated that this percentage may be higher and can have a significant impact on people's quality of care and quality of life.

Poor literacy skills lead to poor health-seeking behaviour and contributes to the enduring stigma of epilepsy. This project aims to meet this unmet need. The aim of the guide is to share information about what epilepsy is, and what it is not.

The guide will allow for easy knowledge transfer on facts about epilepsy. It is envisaged that this will also help adults with epilepsy to improve their health-seeking behaviour, contribute to an improved quality of life and in turn contribute towards a reduction of stigma based on misinformation and ignorance. The contents will explain what epilepsy is and what it is not (dispelling myths), medication and treatment options, epilepsy first aid, how to reduce seizure frequency, and information for families.

The guide, which received €60,000 in funding, will provide education on epilepsy for people in Europe living with epilepsy who have a poor literary standard or who, as immigrants, struggle with a foreign language. It will also provide a tool for those working in the field to support these people. We expect that the format of the guide will be readily adaptable for roll out in other regions of the world where similar situations are present.

The two-year project ends in November 2019. The final 6-page illustrated folder will then be featured on the EPIPICTO website, that is currently being created, through open source, and also available on the IBE website. A limited number of hardcopies will also be available.

FURTHER INFORMATION

EPIPICTO Management Committee
epipicto@gmail.com.

FINANCE

Funding has been provided by Erasmus+ for the development of this guide.

PHOTO

Members of the EPIPICTO management committee and staff of Caritas Malta Epilepsy Association (CMEA). Left to right: Noel Portelli, CMEA; Robin Pinkston, CMEA; Michael Alexa, Malta; Caroline Morton-Gallagher, Netherlands; Shirley Maxwell, Scotland; Thomas Porschen, Germany; and Janet Mifsud and Caroline Attard, CMEA.

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MEET THE TEAM!

CAROLINE MORTON-GALLAGHER: CHAIR

Since my instalment as Vice-President Europe and Chair of the European Executive Committee (EREC), I have been representing the interests of the IBE Chapters in Europe at various stakeholder meetings at the European Medicines Agency.

I have also been appointed as a member of the Joint Task Force (JTF) of the Epilepsy Alliance Europe, and several teleconferences have already taken place. The EREC has had its first videoconference in November, which served to define the roles and focus areas for each EREC member. One of the main discussion points was the proposal to organise an activity in Europe for young adults affected by epilepsy. Plans will be worked on further with information to follow at a later date.

EREC is committed to engaging to its European members to hear what you have to say. If you are disappointed that your organisation's activities are not mentioned in this issue of EPI-Focus then I encourage you to write and tell us know what you have been doing and we will include this in our next issue.Get in touch, we want to hear from you!

NATELA OJUJAVA: VICE CHAIR

I was elected Vice Chair of the European Executive Committee (EREC). Election results were approved at the IBE General Assembly during the International Epilepsy Congress in Barcelona in September 2017. The first meeting of the newly elected EREC also took place in Barcelona. Since then we have video conferences on a regular basis. On the first video conference we defined the roles and priorities for the EREC members. My special activities will be devoted to raising awareness about IBE among Post -Soviet countries, activation of existing chapters and involvement of new chapters from this region. Together with my colleagues in EREC, we are working on organizing an event for young adults with epilepsy and planning more activities to connect with the chapters in Europe. We want to stay in touch with you and to hear any opinion and ideas. Let EPI-Focus be our platform for discussion!

SHIRLEY MAXWELL - SECRETARY

In these challenging times, it is more crucial than ever that IBE Chapters work together to ensure that the voice of epilepsy is heard and acted on by policy and decision makers, and that the needs of people with epilepsy throughout Europe are recognised and addressed.

Social media has transformed the way we communicate and connect. Facebook, Twitter, You Tube and other media channels create vital opportunities for sharing and learning, create communities, and extend networks of support to more people with epilepsy than ever before. But I believe there is still value in bringing people with epilepsy together. I'm looking forward to working with EREC to develop attractive and affordable meeting opportunities for the epilepsy community, and in particular for younger people with epilepsy, that will build relationships and harness the knowledge, skills and experience we share to find new ways of working towards our common goal of making life better for people with epilepsy in Europe.

LJUBICA VRBA: MEMBER

Our new EREC committee will continue the effort in improving the lives of people with epilepsy and persons who care for them across Europe. It is important for IBE Chapters to work together so that their efforts will be recognized by politicians and other important public persons. It is very evident that people now connect and communicate using social media such as Facebook, Instagram, Twitter. However, we in EREC believe that, in the European epilepsy community, there is still a place for EPI-Focus- the magazine where IBE Chapters from all over Europe can share their ideas, plans and activities. In this way, we can get to know each other better and share our experiences and ideas. I will try to continue working on EPI-Focus in the future and warmly invite all European IBE Chapters to participate by sending us your news. We are open to all communication - short or long articles, photos, posters, ideas and short comments or anything else that you would like to share with other associations in Europe.

FRANCESCA SOFIA: MEMBER

As yet, epilepsy is a neglected disease. It became evident to me since I, as mother of a child with epilepsy, took my first steps into the field. People do not know (and do not hear) enough about it; people with epilepsy often experience discrimination; epilepsy research is underfunded; it is not possible to foresee when more effective treatments will become available to the many who live with drug resistant epilepsy. How can we change this situation? With union, I believe. If we really want to champion the cause of epilepsy we need to keep growing strong and united under the umbrella of IBE. That's why I accepted to take on the challenge of "Chapter expansion" by encouraging and supporting prospective members to join forces. In doing so, I will try and reach out to local patient organizations through the European ILAE Chapters as well as through National Neurological Alliances. However, all chapters are encouraged to bring to my attention any information they have on epilepsy organisations in their countries that are not IBE members yet. There is strength in union!

MARGARETHA ANDERSSON: MEMBER

My name is Margaretha Andersson but everyone calls me Maggan!

I live on the west coast of Sweden near Gothenburg and I´m active in our local chapter as Chair. I´m also Chair of the Swedish Epilepsy Association.

I had epilepsy but am now medication- and seizure-free for more than 15 years.

I have been active in epilepsy work in Sweden for more then 20 years and in EREC for the last four years. This term I´m a co-opted member of the committee and I´m looking forward to working with the new committee. My role will be that of Treasurer and I think it will be very interesting.

Caroline and I are also delegated as the admins for our Facebook page - IBE Europe - which we hope you will visit to get news and other information from us.

With a wish to meet you all - Maggan

LETTER FROM THE PRESIDENT

Dear Friends

I am writing to you as the new President of IBE to wish you well and to encourage you to work together with myself and our new EREC committee in helping to improve the lives of people with epilepsy and all who care for them across Europe. I would also ask you to pass the word to colleagues and friends in European countries that don't yet have an IBE chapter to join our organisation. I want to meet as many as you as possible and get to know what is happening in your country. We can all learn from each other. Let me know, too, what you are planning for International Epilepsy Day on Monday 12th February 2018.

What have I been doing since taking up my presidency at the Barcelona Congress at the beginning of September? Not surprisingly, I have been very, very busy getting to know everybody in my new team. We have also set up 3 commissions with membership from across the world (including Europe!) on research, education and e-solutions. They are currently planning their 2 year programmes. All activities will be highlighted in EPI Focus in due course.

The biggest new development has been the rolling out of "EpilepsyNext: IBE focus on youth". Building confidence, recognising ability and supporting capacity in young people is an important plank of IBE's work. The 4 elements currently included in the programme are "The TEA Room", "Young Adult Summits", "Leadership Training Programmes" and "My Story". All IBE regions are encouraged to undertake at least one of these projects each year. All funds raised for this programme in a region will be spent in that region. The IBE Management Team will support these activities as much as possible.

So, what, then, do these 4 modules consist of? "The TEA room" is based on the already successful platform for teenagers with epilepsy (http//www.thetearoom.org.uk), which currently hosts more than 500 young people with epilepsy from 18 countries around the world. This gives them the opportunity of discussing issues relevant to them-not just their epilepsy, but also their day to day activities and interests. Our plan is to extend its remit by raising money to provide education and training opportunities for some of the young users of the platform. Can you help?

The second project is the "Leadership Training Programme", which will be provided through a range of themed workshops with a limited number of participants. The goal is to equip ambitious young people with epilepsy to become leaders by providing a range of learning modules geared at improving their skills. Training will be by experienced professionals working in the field. The age range is likely to be between 18 and 30 years. Bursaries will be provided to assist with travel and accommodation costs. These can be a stand-alone event or part of a congress. Can you help?

The third element of EpilepsyNext are the "Young Adult Summits", which follow the model of a successful event organised by the IBE North American Regional Committee in 2014. The summit provides a forum for young adults to network with each other and share personal stories of their epilepsy, both as medical and social conditions. Some summits will be associated with regional conferences allowing active involvement of their committees and local chapters. Indeed, such an event in being planned in September 2018 at the 10th Latin American Epilepsy Congress in Costa Rica. Others will be stand-alone events, as is (hopefully!) being planned for sometime next year in Europe. Can you help?

The 4th element of EpilepsyNext is called "My Story" and focuses on inspirational personal stories creating human connections and emotional resonances. A series of videos is planned similar to those that came out of the North American Young Adult Summit, which can be viewed at epilepsy.org. To help develop this activity, we plan to hold a series of communication workshops. Many people have powerful and positive personal narratives that can inspire others. Their stories will tell others that a person is more than their condition. Can you help?

As you can see, IBE is ready to embark on a range of exciting new initiatives, for which we need as much support and involvement from members of our chapters in Europe as possible over the 4 years of my presidency, and beyond. Please help!

Warmest regards,

Martin
President, International Bureau for Epilepsy

POLITICAL VICTORY IN DENMARK: Parliament to review epilepsy plan

Following the Danish Epilepsy Association's detection of problems in epilepsy care, it was decided to implement a review of health and social efforts in Denmark for people with epilepsy. The National Board of Health must now prepare the review with the involvement of the relevant authorities and associations. Of particular interest is the fact that the review must gear its effort around the patient, focusing on the challenges and opportunities in diagnosis and treatment, as well as rehabilitation in a collaborative effort of the various authorities.

Lone Nørager Kristensen, President of the Danish Epilepsy Association, says: "This is the best news for a long time. We see this review as the first step towards a solid lift of epilepsy efforts in general. The selected focus points fit well with the reality we hear from patients and their relatives. Epilepsy plans should be better and more coherent than today. Thank you so much to the politicians who have listened and acted.“

The first step was a conference entitled "A better life with epilepsy" in December 2017, with the Danish Epilepsy Association, Danish Epilepsy Society (medical) and Danish Epilepsy Hospital Filadelfia presenting their common proposal for a boost in epilepsy efforts in debate with politicians. The review must be completed by mid 2018. Politicians will then decide on how to follow up.

NEWS FROM TURKEY

Mrs Ebru Öztürks reports on recent activities of the Turkish Epilepsy Association

The IBE chapter in Turkey has been encouraging the implementation of new regulations to improve the quality of life of people with epilepsy and to recognise those people with uncontrolled seizures as having a disability. Those whose seizures are not controlled will be accepted as having special medical entitlements. The new regulations will also help those whose seizures are controlled and have, to date, found it difficult to find employment.

KOSGEB is a government enterprise that is charged with assisting small and medium sized enterprises (SMEs) to develop and grow their products with more added value and to ensure that their work and brands were in line with international best practices and standard. Our association has been able to benefit from the services provided by KOSGEB by participating in a free course to learn how to create and govern a lay association. Those who successfully complete the course and submit a project that is acceptable to KOSGEB will have some of their running costs reimbursed by the government enterprise. We are now involved in developing a project and, if successful, the project will be run by people with epilepsy, thereby providing employment and increasing self-esteem.

The association spent five days in Ankara in July, meeting with political parties to talk about driving regulations and the need to support people with disabilities. Our association was also one of five associations invited to meet with the Ministry of the Family and Social Policies. We had the opportunity to talk about our project with a number of Ministers.

Last October, five students who study medicine at Arel Universty told us that they would prepare their dissertation on the topic of epilepsy. I talked with them from the perspective of someone who now lives a healthy life following surgery and they also heard from the perspective of a neurologist. They made their presentation, which was then published at the university. I hope many students have learned from this.

Photos: *Top: Meeting with Ministry of the Family and Social Policies.*
Centre: Mrs Öztürks (white top) with students from Arel University.
Bottom: Mrs Öztürks meets a member of parliament in Ankara.

Epilepsy Care Management in Austria

Report by Michael Alexa

In Austria, the prevalence of epilepsy is between 0.6% and 0.8%, meaning that about 70,000 people in Austria have had a diagnosis of epilepsy. In Austria there are about 600 neurologists which means that each neurologist will care for around 120 people with epilepsy. While the prevalence rate for epilepsy is around 0.6%, a total of 2.5% of the population i.e. 200,000 people[1 page 32], will have a neurological disorder. One of the main problems is the fact that as people begin to live longer, more people will be diagnosed with stroke, Parkinson, Alzheimer, etc. This brings a huge problem for the health insurance system in future![2]

Epilepsy stigma

Although there are a high number of neurologists and there are several epilepsy treatement centres (e.g. AKH in Vienna, CDK in Salzburg, Graz, Innsbruck or Klagenfurt), epilepsy still carries stigma – even in Austria.

One personal example: 28 years ago, when I applied for my job, I told my boss about my epilepsy during my interview. I must have made a good impression because I was asked to come back to convince the "big boss" to hire me! He asked me if working on the computer would cause a seizure – and I explained to him that it would never happen! He was afraid, because I was the first person with epilepsy the company had hired. But, I was very lucky!

In Austria today stigma and discimination remain a big problem for people with disabilities when trying to find employment. This means that it's a priority issue for politicians. But when you check the programs of the different political parties, you find you find out that only two of the five major parties have a policy for people with disabilities[3]. In Austria we had an unemployment rate of 5.6% in August 2017[4]. When you check the unemployment rate for people with disabilities, you find that it was 8.6% in the same period[5] - 54% higher than the general rate!

The social security system

In Austria, social security systems cover all medical costs – from medications to medical consultations (other than private consultations) and, where appropriate, epilepsy surgery. To cover all these costs, a percentage of salary is deducted from employees and employers also make a payment. Austria has about 20 different social security systems – e.g. each of the nine federal states has its own system. During the elections in October 2017, social security systems, and the amount collected by these systems, was on the political agenda. It will be a huge task for the new government.

The facilities for people with epilepsy are very comprehensive. They include:

- Medical prescriptions, covering even newer drugs. These can be prescribed by the general practitioner except those that need approval by an epileptologist.
- Vagus Nerve stimulation devices.
- Epilepsy surgery in specialised clinics.

The cost of medication

The annual report 2015 of the social insurance industry shows income of €17.119 billion against expenditure of €17.088 billion, leaving a profit of €31 million. Some of this income comes from insured people themselves through prescription fees, and some treatment costs - although these are means tested against income and pension levels[6].

If you look at total costs of neuro-psychiatric diseases in EU and EEA countries, you find a total cost of €798 billion every year – more than the cost for cancer. But, of the total costs only 37% are direct costs. Non medical costs amount to 23% and indirect costs (loss of productivity) amount to 40%[7].

Epilepsy Association of Austria

The Epilepsy Association of Austria started in 1998 as a loose cooperation network of the different self-help-groups in Austria in 1998. My first contact with the Epilepsy Association of Austria was in 1991 at the general assembly in St. Pölten. The Epilepsy Association of Austria was founded later – it was created in conjunction with the first DACH (D German – A Austrian – CH Swiss) league meeting. The last DACH meeting took place this year in Vienna.

The Epilepsy Association of Austria asked me to be their IBE representative because of my knowledge of the English language. My first European conference was 1994, in Veldhoven (Netherlands), followed by participation at my first international epilepsy congress in 1995 in Sydney (Australia). Since then, I haven't missed any international or European congress and prepare written reports on each one, for publication in our newsletter. The association has its own website www.epilepsie.at[8], which provides information on group meetings as well as information on a range of issues - pregnancy, sport, drivers' license, information about disability passes and so on. The Epilepsy Association of Austria is also part of the Erasmus project Epipicto, which you can read about in this issue of EPI Focus.

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7. *Olesen J et al: The economic cost of brain disorders in Europe; European Journal of Neurology 2012, 19:155-162; Grundlage der Studie waren 27 EU-Staaten (ohne Kroatien) sowie zusätzlich die Schweiz, Norwegen und Island*
8. *www.epilepsie.at*

EPILEPSY IRELAND RECOGNISES SPECIAL VOLUNTEERS

Brenda Quigg

Epilepsy first crossed Brenda Quigg's path eight years ago, but she didn't recognise the early symptoms and it was only after her first tonic clonic seizure that she was diagnosed.

The diagnosis had a huge impact on her life and she was confronted by the realisation that awareness of epilepsy and health services for people with epilepsy in her community are not always ideal. However, Brenda's positive outlook soon shone through and she decided to take action.

In late 2014 she organised a cycle for epilepsy. Within just a few months after much hard work, more than 250 cyclists took to the start line on a cold February morning to mark International Epilepsy Day. The event raised €15,000 and, just as important, there wasn't a person in her home country who didn't know about it. In 2016, the event was back again with over 400 people taking part and an incredible €35,000 raised.

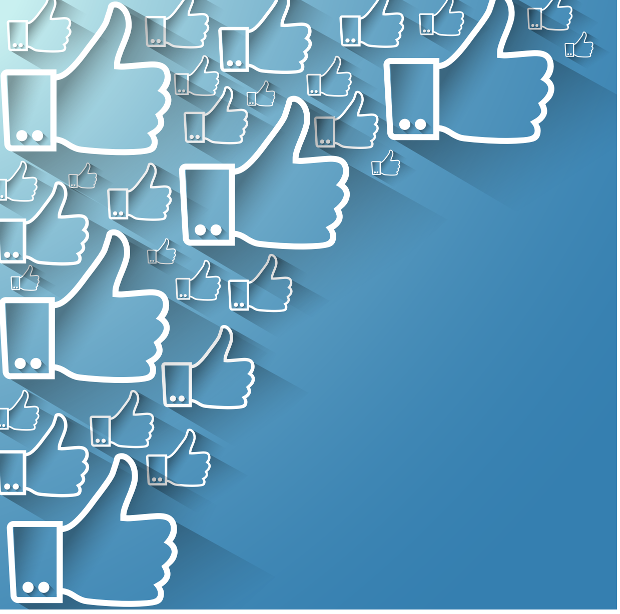
Karen Keely

Karen Keely was diagnosed with epilepsy as a child and was put on the drug sodium valproate to treat her seizures. Today we know that it should not be taken by women of childbearing age, because of the risks to the foetus in the womb of Foetal Valproate or Foetal Anti Convulsant Syndrome (FACS for short). However, Karen was never fully advised of the risks and continued to be prescribed valproate throughout her three pregnancies and all three of her sons – Harry, Lee and Lorcan have been affected by FACS.

The consequences of sodium valproate have dominated her life. Her sons have all had repeated medical, surgical and clinical interventions and two require lifelong care. Despite all the difficulties and challenges that this has brought, and the battles she has had to endure for her family, Karen has devoted herself to raising awareness among other Irish women with epilepsy of the risks of valproate and fighting for recognition and justice for the families affected.

Karen pictured with Epilepsy Ireland CEO, Peter Murphy

Karen has set up the Irish branch of OACS - Organisation for Anti-Convulsant Syndrome. She also brought about the formation of the FACS Forum, a group of organisations, including Epilepsy Ireland, who have come together to help deliver on Karen's campaigning. She is a true epilepsy advocate dedicated totally not only for her own boys but for all the mothers and children who are similarly affected or at risk.



EREC is looking for YOU!

EREC is looking to engage and connect with the European IBE Chapters as much as possible.

One of the ways we want to achieve this is through our newly-formed IBE Europe Facebook group. Information can be posted in any language and we hope to use this social media channel as a means of informal and easy contact with our Chapters.

We will regularly post information which we think you will find of interest. But at the same time, we also encourage **YOU** to let us know what you are doing. If you have a question for other European IBE Chapters, then this is the place to post it!

Join our online community IBE Europe at:
https://www.facebook.com/groups/304754713360308/

International Epilepsy Day

Monday, 12 Feb 2018

THIS *is* ME

SHARE YOUR PHOTO WITH THE **#EPILEPSYDAY** HASHTAG TO RAISE AWARENESS

EPILEPSY.ORG