

INTERNATIONAL EPILEPSY NEWS

ISSUE 4 - 2017

**HEARING ON SODIUM
VALBROATE**

**INTERNATIONAL
EPILEPSY DAY 2018**

EPILEPSYNEXT
Focus on Youth

INTERNATIONAL EPILEPSY NEWS

ISSUE 4 - 2017

FROM THE EDITOR

With the change of guard of the IBE board and other committees at the General Assembly in September, now is also a good time to introduce a new look to the newsletter. It's daunting to face a 20-page blank canvas, casting around for inspiration and then finally deciding on a new cover design, font face and layout style that one hopes will be liked by the readers. So, here it is unveiled - I hope you like it!

While just two months have passed since the 32nd International Epilepsy Congress in Barcelona, it's been a very busy time and you can read what we've been up to in this issue of the magazine.

EpilepsyNEXT has been further developed and will be embraced by the regional committees who are considering activities at a regional level that will come under its banner.

Also underway are preparations for International Epilepsy Day, which takes place on Monday 12th February. We've had a great response to our photo competition but we would love to see more entries to the Under-12s category before the close date of 31st December.

Other important stories are the report from the EMA public hearing on sodium valproate, a shocking story from Malawi, and a call for those of you in the US, Italy or Belgium to help with a survey on epilepsy support dogs.

To find out more about these and other stories, just flick through the pages and enjoy.

Ann Little
Editor



CONTENTS

7
SUPPORT DOGS
Help with a survey on epilepsy support dogs



6
ONE MINUTE EXPLANATION
Norwegian series of epilepsy videos with fast lessons



4
WHAT'S THE PROBLEM?
EMA Public Hearing on sodium valproate use in women



16
EPIPICTO PROJECT
EU funded guide without words



17
YOUTH ADULT SUMMIT
EpilepsyNext programme in Costa Rica

8
WORLD DAY FOR EPILEPSY
Our plans for International Epilepsy Day

15
MOB ASSAULT
The brutal reality of living with epilepsy in Malawi

10
HEALTHCARE POST BREXIT
The future of health care in the EU

EDITOR: Ann Little

REGIONAL SUB-EDITORS:

Jacob Mugumbate, Hassan Hosny, Caroline Morton, Tomás Mesa, Phil Gattone, Satish Jain, Phil Gattone

ADVISORS: Martin Brodie, Mary Secco, Anthony Zimba



International Epilepsy News is published by the International Bureau for Epilepsy, 7 Priory Office Park, Dublin A94 FN26, Ireland. www.ibe-epilepsy.org.

All rights, including moral rights, reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, without the prior permission in writing from the publisher. The Editor reserves the

right to edit content for reasons of space or clarity. The views expressed in this magazine are not those of the publisher. Articles covering medical aspects of epilepsy are not intended to be taken as advice; they are not intended to replace medical care.

PRESIDENT'S MESSAGE

DEAR FRIENDS

I took over the presidency of IBE during the 32nd International Epilepsy Congress in Barcelona in early September, when I chaired our Management Committee meeting for the first time. This kick started me down my 4-year journey in the job and highlighted the many challenges ahead.

During this congress, we held a joint meeting with our 3 newly established Commissions on Research (chaired by Kheng-Seang Lim from Malaysia), Education (chaired by Margarete Pfäfflin from Germany) and E-solutions (chaired by Najib Kissani from Morocco). All other invited commission members from around the world have agreed to help with these activities. Our 7 regional vice presidents also attended this session to help ensure cohesion across IBE's global agenda. All 3 Commissions have now started their work and I will report on their progress in due course.

One of the most pressing issues that arose in Barcelona was the importance of attracting new chapters to IBE and ensuring good contact and ongoing dialogue with the existing ones. We currently have 98 full and 38 associate chapters in 100 countries. Opportunities for interaction are now many and it is increasingly easy to develop conversations with people with epilepsy, their families and those working with them and for them around the world. Personal stories, either good or bad, can help us to identify problems and provide solutions.

A meeting of the IBE Management Committee took place in Glasgow, Scotland on 6th October to move our global agenda rapidly forward following up on the broad-ranging discussions undertaken in Barcelona. Focus will be made on regional programmes headed by our vice presidents and their teams, who will report quarterly to the Management Committee. We plan to concentrate particularly on issues relevant to young people with epilepsy via the EpilepsyNext programme, which is discussed in greater detail in this issue of International Epilepsy News. This consists of 4 modules ("The Tea room", "Leadership Training", Young Adult Summit" and "My Story"), and will provide a target for our fundraising activities during my presidency. Another idea was to consider co-opting a young person (under the age of 30 years) as a member of each of our regional committees. The hope too is to link IBE's Promising Strategies programme with our youth projects.

Epilepsy Alliance Europe will be co-chaired for the next 4 years by myself and Philippe Ryvlin, representing ILAE. The other IBE members are Caroline Morton, Janet Mifsud and Francesca Sofia. This ongoing programme focuses on our interaction with the European Union. It is planned also for ILAE and IBE to hold a research workshop in Brussels in partnership with the European Brain Council in



the spring of 2018. The eventual goal is to develop a global alliance for epilepsy research with many partners.

In parallel to these activities IBE and ILAE are working with the World Health Organization (WHO) to put together a Global Epilepsy Report, which will be translated into 5 languages and distributed to all WHO member states. This publication will provide IBE chapters with the opportunity of lobbying their Minister of Health to improve services for people with epilepsy in their country.

To conclude, despite being only 3 months into my presidency, I am greatly encouraged by the energy and enthusiasm shown by everybody working within the IBE family geared at improving the lives of people with epilepsy and those that care for them. There is much to do but, with your help, we will go forward together to "make a difference".

Martin Brodie

President, IBE



PUBLIC HEARING ON SODIUM VALPROATE

IBE participated in a Public Hearing on Sodium Valproate, hosted by the European Medicines Agency (EMA), in London on 26 September 2017. The hearing was organised to review the prescription of medicines containing sodium valproate for women and girls who are of childbearing age. The goal was to listen to different views and experiences concerning its use. This is part of an ongoing safety review by the EMA to reduce the risks of sodium valproate in pregnancy. The aim is to see what can be done to prevent or minimise harm to unborn babies exposed to the drug in the womb.

A review was held by the EMA in 2013, which included consultation with people with epilepsy and other stakeholders. Following this, the EMA recommended widespread restrictions to the prescription of sodium valproate for young women. The product information was updated and educational materials were developed for healthcare professionals and people with epilepsy. These included a guide for prescribers, a patient booklet, an 'acknowledgment of risk' form and a letter to better inform healthcare professionals. However, recent research carried out in France suggested that the people at risk were not receiving the information. A follow-up review by the EMA was initiated and the decision was taken to organise a public hearing.

The hearing was attended by 65 stakeholders, of which 28 were people with epilepsy and their representatives, including the International Bureau for Epilepsy. The President of IBE, Professor Martin Brodie,

contributed a statement and the Vice-President Europe, Mrs Caroline Morton-Gallagher, attended the hearing on behalf of our European Chapters.


Sodium valproate is widely regarded as the drug of choice for idiopathic generalized epilepsies (epilepsies with a genetic basis) and is also frequently prescribed for focal epilepsies, with or without secondary generalization. It has been licensed for use in EU countries since 1967. Valproate has been recognised as interfering with the development of the foetus and causing birth defects (teratogenic) for many years, as have other antiepileptic drugs. Recent information suggest, however, that at high dose it may occasionally reduce the cognitive development of exposed infants and may be associated with autistic spectrum disorders.

Uncontrolled epilepsy, particularly in young people, carries a risk of sudden unexpected death (SUDEP). Therefore, leaving seizures, especially tonic-clonic seizures, uncontrolled is not an acceptable option. Sometimes, sodium valproate has proved to be the only effective treatment. IBE accepts the need to restrict its use in young women, but would support its prescription as drug of last choice, if all other therapeutic approaches had proven unsuccessful in a severely affected individual. In addition, there are many women who do not have a pregnancy in their life plan. All women with epilepsy should have the option of taking sodium valproate after careful, accurate and sensitive explanation and weighing

up the risks and the benefits. Sodium valproate is considered an effective and well-tested antiepileptic drug, which should not be discarded as a therapeutic choice for every young woman. In addition, the risks of sodium valproate withdrawal should be discussed with women already established on the drug and any proposed changes to the treatment plan should be discussed with their doctors.

There was agreement that some improved information resources had been developed in a number of EU member states. However, these were not reaching the right people at the right time. The distribution and use of these materials, as well as the acceptance of the need for change, had not happened as had been hoped. In addition, risk minimisation has not always been apparent. Other ways to implement change should also be considered, besides an improvement in communication and knowledge. The consensus was that the status quo was not acceptable, and it was clear that things could, and should, be done better.

IBE emphasised the need for improved public information and health education, advancing advocacy and the exchange of international best practice. The EMA should establish a well-organised and professional education campaign, in all EU languages, to ensure that as wide an audience as possible is reached. This could consist of well laid out booklets containing frequently asked questions. These should be distributed to patients, relatives and health care profes-



Report by: Caroline Morton-Gallagher and Martin Brodie

sionals through all appropriate outlets, and made available also online. Such material could also be distributed through IBE channels. Martin Brodie concluded with the message that clear and accurate presentation of the scientific data should be made available, without emotion and bias, to the public and all relevant healthcare professionals. IBE appreciated the opportunity to participate in the public hearing in order to represent the wider epilepsy community.

Following on from the public hearing, a stakeholders meeting was organised at the EMA in London on 13 October. Caroline Morton-Gallagher attended on behalf of IBE. This follow-up meeting focused on how to further reduce exposure to sodium valproate during pregnancy. The goal is to better protect the unborn baby and improve the information for women of childbearing age about the risks in pregnancy.

It was recommended that all women and girls prescribed long-term sodium valproate should have regular (at least annual) face-to-face reviews with their doctor. Personal communication and trust with healthcare professionals should be the basis of the dialogue. Positive messages and explanations should be part of this communication. It was agreed that personalised, age-appropriate and clear information is important to reach women at different stages of their lives. This should also include conversations with relevant health professionals, including specialist epilepsy nurses and dispensing pharmacists. Follow-up information in take home print format should follow the

three stages of the woman's life:

- first prescription,
- when planning a pregnancy
- in the case of an unplanned pregnancy.

Counselling should be given during the first trimester of unintended pregnancies and advice should also be provided in cases of termination.

There was strong support for a visible reminder (warning symbol) of the risks on the outer packaging of medicines containing sodium valproate, as well as on blister packing. Every time valproate is dispensed, it should be supplied in appropriate packaging accompanied by a patient information leaflet. There was concern that this might mean young women would stop taking their antiepileptic medication, without consulting their doctor. These warning symbols should, therefore, be accompanied by text to ensure a message was clear that they should consult their doctor if concerned.

The importance of alerts and prompts (red flag warnings) in prescribing and dispensing software was also discussed. It was also suggested that professionals follow regular professional educational programmes on pharmacovigilance issues. This ensures they are updated on the latest scientific data concerning the risk-benefit ratio.

Awareness of the risks of sodium valproate in pregnant women is vital and this was agreed by all participants. Consistency of information is crucial, especially in the representation of these risks. Patient organisations can play a key role in this activity!

MORE FROM EMA



DIGITAL MEDIA AND HEALTH

The European Medicines Agency (EMA) has created a topic group *Digital Media and Health* to look at the challenges and opportunities of using social media in medicine development, evaluation, surveillance and information. The intention is to use social media to enhance communication, offer new opportunities for interaction and to ensure that information distributed through social media channels meets the needs of its audience.

The topic group has three streams: social media (led by Caroline Morton-Gallagher), m-health and real world evidence. The social media stream will look at best practice in the use of social media in organisations. The aim is to advise the EMA in the development of their social media strategy.



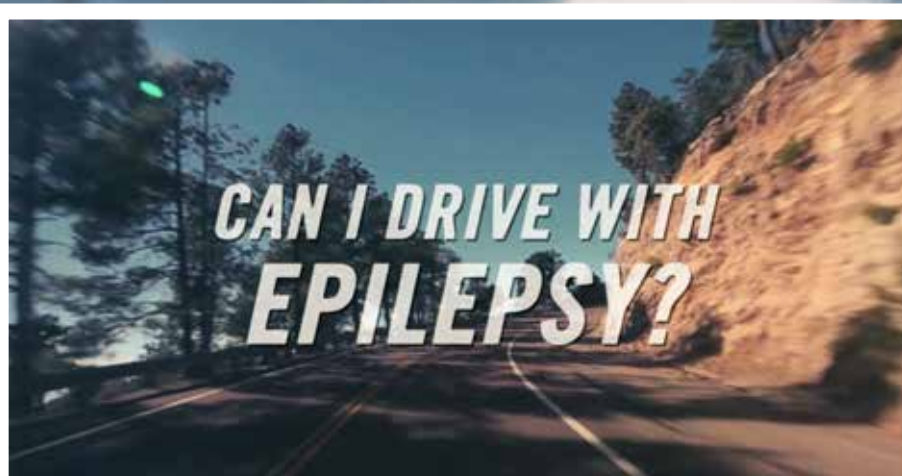
IMPROVING PACKAGE INFO

The EMA has published an action plan to improve the information package for patients and healthcare professionals that accompanies every medicine authorised in the EU and explains how it should be used and prescribed. This follows a report published by the European Commission in March 2017 which concluded that there is a need to improve how information on medicines is conveyed to patients and healthcare professionals.

One of the key areas of this plan is to explore how electronic or digital means can be used to improve accessibility to medicines' information by patients and healthcare professionals.



EPILEPSY LESSON IN A MINUTE



The one-minute epilepsy lesson? Is this possible? Well, the Norwegian Epilepsy Association has proven that, not only is it possible to teach someone a little about epilepsy in the space of one short minute - it is also possible to do so in a very entertaining way!

It all began with a bit of research to find out what were the most frequently asked questions about epilepsy on web searches. The top 16 were then selected to comprise a series of short videos uploaded to YouTube and available on social media. Each short video represents one question and answer and have been produced both in Norwegian and English.

On Monday 13th November the Norwegian Association launched the project by publishing news of the series on its webpage www.epilepsi.no and on Facebook.

First up, and released on 19th November, was "What is epilepsy?": <https://www.youtube.com/watch?v=eZgo5ELcfMg>

with a second video "What is an epileptic seizure?" launched on the same day:

<https://www.youtube.com/watch?v=hFNY-WRrVoQg>

A further six one-minute lessons were made available during November:

- Is epilepsy dangerous?
- Will I ever get well?
- How is epilepsy diagnosed?
- How is epilepsy treated?
- How to choose the right medicine
- How to handle a seizure.

The second eight videos will be released in January 2018 and will cover the following topics:

- Is epilepsy just about seizures?
- Can I exercise?
- What can trigger a seizure?
- Is it OK to drink alcohol?
- Can I drive with epilepsy?
- Is it safe to be alone?
- Is it safe to swim?
- Can we have children?

Each of the videos is being uploaded to the YouTube channel of the Norwegian Epilepsy Association: <https://www.youtube.com/user/NorskEpilepsiforbund> in line with a planned launch schedule and the association has high hopes that they will be successful.

This is not surprising, following the success that the association had with an earlier video that was successfully shown at a number of film festivals around the world. "Thea" is a short film in a series that shows the life of children with epilepsy. The films, which show what life is like for families who have a child with epilepsy, were made by a couple who are film producers and have a child with epilepsy. Watch it on this link: <https://youtu.be/bi5AUP1qyc>

Having seen a few of the short one minute videos, I have no doubt that they will be equally well received.

The photos shown above are from the video titled "Can I drive with epilepsy?" that will be launched in January.

SURVEY ON SEIZURE ALERT DOGS

For some people with epilepsy, a dog really is man's best friend. The EPIDOG Project now wants to find out just what makes seizure alert dogs so special



It has long been accepted that dogs often have an extra sense, predicting an event before it happens. This has been used to great effect in seizure dogs, whether we are referring to seizure alert dogs or seizure response dogs. A seizure alert dog can predict a seizure before it happens in a human, while the seizure response dog will react once the seizure has begun.

Dogs can be trained to serve people with epilepsy in a number of ways. They can learn how to attract help by barking to summon help when a seizure starts; they may be able to set off an alarm; move dangerous items out of the way; or place themselves between the person having a seizure and an object that might impose danger.

But, above and beyond their ability to react to a seizure, these dogs also act as constant devoted companions for the person they assist, improving their quality of life in so many ways and providing a sense of security for those who care for them.

Just what makes some dogs more suitable to act as seizure dogs than others is something that is not fully understood.

Keenly interested in the topic, Ana Martos,

a PhD student from Ghent University in Belgium, is working on a project to examine the behaviour of epilepsy alert dogs in Belgium, Italy and the USA.

The research project is being carried out under the supervision of Prof Veerle De Herdt (Department of Neurology, Ghent University Hospital) and Prof Christel Moons (Department of Ethology, Faculty of Veterinary Medicine) to look at how dogs can detect when a seizure is about to occur and how they react to the situation.

Now at the first stage of the project the research team is building an international database of alerting dogs, and for that purpose they will be using a questionnaire for people with epilepsy and dog training organisations. The questionnaires can be accessed through the project website.

The study has been approved by the Ethics Committees from Ghent University Hospital (Belgium), Dartmouth-Hitchcock Medical Center (US) and the Fondazione Istituto Neurologico Nazionale C. Mondino (Italy).

The study is part of a four-year PhD research project looking at the reliability of canine seizure alerting behaviour and the

senses that a dog may use when perceiving an imminent seizure. For the latter, the research team will focus on olfaction (sense of smell). Should dogs rely on olfaction and on specific odour molecules when perceiving upcoming seizures, the identification of such a cue will be helpful to further optimize training methods for seizure alert dogs.

Since patients will not be contacted directly to take part in the survey, IBE is pleased to assist in alerting people to this interesting project. At the present time, the questionnaire is restricted to responses from people in Belgium, Italy and the USA but there are hopes to expand it to more countries in the future.

If you are interested in taking part, or know someone who has a seizure alert dog who might be persuaded to get involved, you can find the survey questionnaire on the project website:

<http://www.epidogsproject.net/>

RESOURCES

for International Epilepsy Day

International Epilepsy Day

Monday, 12 Feb 2018



Monday, 12 Feb 2018

International Epilepsy Day



THIS
is ME

SHARE YOUR PHOTO WITH THE #EPILEPSYDAY
HASHTAG TO RAISE AWARENESS

EPILEPSY.ORG

THIS
IS ME



SHARE YOUR PHOTO WITH
THE #EPILEPSYDAY
HASHTAG TO RAISE
AWARENESS

Have you visited the International Epilepsy Day website resource page yet? There you will find a range of support documents that are free to download and use to support your International Epilepsy Day campaign activities.

This year we have produced, not one but, two different posters to promote #EpilepsyDay. As in previous years, we can provide you with a version of the poster in your language - you just need to provide us with the translated text and we can take it from there. If you would like to personalise the poster for your organisation, we can also add in your logo, if you send that to us in a good quality resolution.

You will find Information and First Aid postcards, as well as graphics for use on social media on the site.

We also invite you to use the hashtag #EpilepsyDay to share your photos in our This Is Me! event to encourage people with epilepsy, and those who care for them, to talk about what epilepsy means to them. Every story is unique and shines a different light on what it is like to live with a personal diagnosis of epilepsy or with someone close to you who has epilepsy.

Of course, International Epilepsy Day is a day for everyone to promote awareness about epilepsy, to advocate for improved services for people with epilepsy, or to raise funds to support a local epilepsy association in its work. The International Epilepsy Day website - epilepsy.org - provides a platform for you to advertise your plans for the day. If you send the details, we can spread the word.

We are also busy, in the background, building a gallery to host the amazing photos that have been entered in the Life is Beautiful photography competition. You will see on the next page that the closing date for entries is now rapidly approaching. The response to this year's competition has been fantastic and, already, we have received more than 1,000 photos. It will be a daunting task for the judging panel to make its selection of winning entries!

Monday 12th February is coming close. Are you ready?



Do you know a young photographer?

HURRY - CLOSING SOON!

Life is Beautiful Photography Competition
with a separate **junior category** for those under 12 years of age.

Total Prize Fund: US\$2,000

Closing date: 31st December 2017

Find out more at www.epilepsy.org

Entries should be submitted to ibeexecdir@eircom.net.
No entry form required - just provide us with your name, address, age (if under 12-years),
a title for your photo and details of where it was taken.

THE FUTURE OF HEALTH

What will happen when Britain takes a hike?

On Tuesday 21st November, the EU announced that the European Medicines Agency (EMA) would be relocating from London to Amsterdam. The move will happen as soon as possible, even before the end of the Brexit talks, and will be irrevocable irrespective of how those talks might finally pan out.

Several EU cities vied to be chosen as the new location and the hard-fought battle to decide which city would be selected indicated just how coveted a prize this was. The EMA employs more than 900 people, the majority of whom are highly educated with executive level status. Add to that the extensive number of meetings that take place at EMA on a daily basis, with participants travelling from all over the EU to attend (most requiring hotel rooms), and it's easy to see the economic benefits that attach.

Almost as soon as the announcement was made, a regular flight serving Antwerp (Belgium) and London City Airport (located close to the current EMA building) was cancelled with immediate effect. Others may follow.

However, the move of the EMA away from London is just the tip of the iceberg in relation to the changes (and problems) that Brexit will inflict on a wide range of healthcare issues that will adversely affect patients, people with a chronic disorder or disease and, even more so, those whose condition is rare and/or complex.

Healthcare is not an EU competence and national governments, to a great extent, decide their own budgets and programmes. Nevertheless, although there are national policies pertinent to each country, there are a number of systems, programmes and arrangements in place that operate across the EU, through Directives that govern the rights of European citizens.

The UK Brexit Health Alliance which was created by the UK national health service (NHS) to safeguard the interests of UK patients, as well as healthcare and research

during the Brexit negotiations, is looking at some of these issues. The alliance is comprised of the NHS itself as well as medical research, industry, patients and public-health sectors.

At the present time, there is a range of reciprocal programmes that involve all 28 (soon to be 27) member states that provides the same healthcare services, with the same rules and conditions applying, both to people from other EU state and to national citizens. This care can be provided during either a temporary or a permanent stay in another EU country:

- The European Health Insurance Card is for those on a temporary stay, and is usually carried by holiday-makers in case they should need emergency care.
- The S1 system is used by those on a long-term stay - for example the hundreds of thousands of Northern Europeans who retire to the sunnier climes of Spain, Greece, the south of France or Italy. A high number of these are UK pensioners who retire to the Spanish 'Costas'.
- The S2 system is for those travelling specifically to receive medical treatment - for instance where specialist treatment is not available in their home country.

Post-Brexit what will be the implications and how will those UK and EU citizens currently using one of these systems be affected? Could patients be denied the access to the best specialised treatments available? Will treatment costs that are currently covered by one of these systems cease - with patients having to pay personally for any treatment they avail of abroad or face the cost of taking out expensive private health insurance to cover medical fees? At the present time, 25 million visits are made from another EU country to the UK each year for treatment. In the other direction, the flow of traffic is even higher, with 53 million visits made from the UK to

one of the other 27 member states!

Returning to the EMA, in addition to the economic benefits enjoyed

by the country that hosts the agency, there are other issues to be considered. The EMA is responsible for licencing all medicines available for sale across the EU, both for both human and animal health, and ensuring their safety.

Without doubt, EU citizens will see the cost of medicines, produced either entirely or partially in the UK, become more expensive to purchase

The move of the agency is likely to be disruptive and will undoubtedly lead to delays in the processing of medicine licencing. We need also to bear in mind that the production sequence of a medication can span two or more EU states. According to Elisabetta Zanon, Secretary of the Brexit Health Alliance:

- More than 2,600 final medical products have some stage of their manufacturing process based in the UK.
- Forty-five (45) million medicine packs are supplied each month from the UK to other EU countries and 37 million packs are supplied from the other 27 EU member states to the UK each month.



IN THE EU



The bus used by pro-Brexit politicians to encourage Britons to vote to leave the EU

- Fifty per cent (50%) of medical devices approvals are conducted by the UK.

According to Elisabetta Zanon, apart from the disruption and capacity issues that will likely arise during the EMA move and settling down in Amsterdam, post-Brexit trade barriers and the divergence in regulatory systems between the UK and the rest of the EU could lead to delays for patients in being able to access new and innovative therapies. In addition, some medicines or medical devices may become unavailable, at least in some EU countries. Without doubt, EU citizens will see the cost of medicines produced either entirely or partially in the UK become more expensive to purchase.

One of the most important aspects of collaboration in health issues among EU member states has been in the field of clinical research, under the various EU funding programmes. The UK has been a very active partner in a significant number of these collaborations, often acting as the lead partner. Indeed, 25% of the top 100 prescriptions in the world at present were discovered and developed in the UK.

The UK also co-ordinates the highest number of EU patient registries and, across Europe, has the highest number of Phase I clinical trials and ranks close to the top

in Phase II and Phase III trials. Post-Brexit, we could see a divergence in regulations governing clinical trials that would make it unwieldy or unworkable to run trials that involve EU patient participation and impact on the translation of research into practice. It is likely that these trials and, perhaps, their collaborators will move to another EU state.

In what must be a cruel twist of fate, the day on which the EU announced the 24 European Reference Networks that had been successfully selected to form the first block of ERNs on rare and complex neurological diseases, one quarter of which are led by UK centres, was also the day on which Britain voted to leave the EU! A total of 40 UK centres are involved in these 24 ERNs, with some centres involved in more than one network. EPICare, the ERN on rare and complex epilepsies, is led by Prof Helen Cross OBE in London. Given that, in legal terms, only EU or EEA member states can participate in the ERNs, this is likely to lead to yet another headache in the disentangling of the UK from EU activities.

There is no doubt that Brexit will impact negatively on healthcare in the EU. It is likely that medicines produced in the UK will become more expensive due to tariffs once the free trade agreement is terminated. The access to specialist care under the

current reciprocal healthcare systems will mean that patients will no longer be able to travel to the UK for treatment under the regulations that now apply. This will particularly impact on Irish citizens for whom the UK is the next door neighbour and where language is not a barrier.

For researchers, both those based in the UK and in the EU, the loss is profound on both sides. The current vibrant, successful, collaboration between the greatest brains in Europe to develop new and innovative medical treatments will surely be diminished. And that will affect everyone.

One of the biggest messages made by the pro-Brexit camp during the referendum was that the British people wanted their country back, believing that EU membership had robbed the country of its liberty and freedom. Now that the ties are being loosened and the UK is due to be set adrift from the EU by March 2019, will there be disappointment among those who sought to regain their independence, only to find that life outside the EU may not be what they expected? Whatever comes to pass, the one surety is that the health service for both those in the EU and for UK citizens alike will not be the same post-Brexit. But, how different? Only time will tell.

EPILEPSY? DON'T PANIC AND NOTHING TO DO WITH THE MOUTH!

A bit like a bus - you wait for ages and then two come along at the same time. So it is with high class epilepsy awareness videos that manage to teach and tickle our funny bones at the same time. Elsewhere in this magazine you may have read about the one-minute epilepsy FAQs videos produced by the Norwegian Epilepsy Association.

This time, it's the turn of Společnost E, the Czech Epilepsy Association that has joined forces with BARD PR to produce two entertaining spot videos that demonstrate what to do when someone has a seizure and, more importantly, what not to do. The videos are in Czech but with English subtitles.

"A lot of people think that something has to be put in the mouth to avoid the tongue being bitten during a seizure. That's unless you want to lose your fingers or have the person end up with false teeth," says Alena Červenková, Director of Společnost E, the association that has been helping people with epilepsy for 26 years.

So how do you keep it right when it comes

to someone? Be calm and do three basic things:

1. Remove any dangerous objects nearby to prevent the person being injured.
2. Stay close, but do not prevent the person from moving.
3. Afterwards, make sure that the person is breathing and turn them on their side, the so-called recovery position.

"Sometimes it looks terrifying, the person may foam at the mouth, they may fall to the ground ... but, just as often, a seizure can be inconspicuous. Maybe I just stare at the table in front of me when I have a seizure. I'm not surprised that people think that a person having a seizure is just drunk or mentally ill. He just does not know what's going on," says Lenka, who had her first seizure at the age of 12.

"Many people also do not know when to call an ambulance. Generally, if we see a seizure for the first time or if it lasts longer than 5 minutes, then you should call for an ambulance. And, of course, if there

are complications. Perhaps injuries," adds Alena Červenková.

The new campaign seeks to eliminate unnecessary fears about epilepsy. Společnost E has come up with a campaign in which it tries to give the most important pieces of information to the public, with more than a slight exaggeration using pleasant humour - a campaign that leaves you smiling. The creative concept and production of the campaign is collaboration with BARD PR, directed by Miro Mráz and shot by Filip Knoll. The actors were Tereza Dočkalová, Šimon Krupa, Veronika Lazorčáková and Petr Buchta. Well done to all!

You can watch both videos on YouTube using the links below:

Video 1:

https://www.youtube.com/watch?v=cjIAd-EqG_X4

Video 2:

<https://www.youtube.com/watch?v=oZLZ-viH76zg>





INTRODUCING THE COMMISSIONS

Three new topic Commissions have been created by IBE President, Martin Brodie, to address topics of particular relevance to people with epilepsy. The e-Solutions commission will look at the opportunities that electronic communications now afford in bringing healthcare and advice to those living in remote areas or with limited access to services. The Research and Education commissions will focus on the social aspects of these important issues. With a broad global membership, the commissions are well-positioned to consider a programme of activities that will address their particular topic, cognisant of regional diversity and healthcare and social welfare provision at a local level.



EDUCATION

Chair:

Margarete Pfäfflin, Germany

Members:

Marina Clarke, South Africa
Arlette Honein, Lebanon
Janet Mifsud, Malta
Patricia Braga, Uruguay
Hidemoto Kubota, Japan
Graeme Ambler, New Zealand
Avirmed Tovvudorj, Mongolia



e-SOLUTIONS

Chair:

Najib Kissani, Morocco

Members

Harmiena Riphagen, Namibia
Alicia Bogacz, Uruguay
Yuan-Fu Tseng, Taiwan
Eliashiv Dawn, USA
Cigdem Ozkara, Turkey
Victor Patterson, UK
Graeme Shears, Australia
Hasan Aziz, Pakistan



RESEARCH

Chair:

Kheng Seang Lim, Malaysia

Members

Farah Abassi, Iran
Anchor Hung, Hong Kong
Manjari Tripathi, India
Khaled El Zamel, Qatar
Rosemary Panelli, Australia
Jana Jones, USA
Laura Guilhoto, Brazil

CALLING ALL CHAPTERS IN SOUTH EAST ASIA AND WESTERN PACIFIC REGIONS

Is there a young member of your association who has been a shining light for others and who is deserving of recognition?

Early in 2018, the Regional Committees in South East Asia and Western Pacific will be calling for nominations for the IBE Golden Light Awards, to be presented in Bali in 2018 at the time of the 12th Asian & Oceanian Epilepsy Congress. The awards were first introduced in 2004, with the title 'Outstanding Person with Epilepsy Award' and have been presented at each Asian Oceanian Epilepsy Congress since then.

The title of the award was changed to Golden Light Awards in 2016, to recognise the fact that people with epilepsy do not have to be defined by their condition and

embracing the call of the International Bureau for Epilepsy 'bringing epilepsy out of the shadows and into the light'.

All people living with epilepsy, parents, family members or their carers are eligible to be nominated for this award. However, for 2018, it is proposed to focus the awards on young people and to combine the award with a learning activity under the newly launched EpilepsyNext program.

Each chapter member of the South East Asia and Western Pacific Regions is entitled to nominate a recipient for the award. The nominating procedure can be determined by the chapter, which may have a process or activity already in place by which to choose a person to receive the award. If

not, it is then suggested that guidelines might include:

- Contribution to community service
- Longstanding support for people living with epilepsy
- Individual achievement (personal, professional, educational, sporting, creative)
- Long standing advocate for epilepsy (community, political, media)
- Distinguished service to a local epilepsy support organization.

We will have more information on the awards, the nomination and conferring process, and the Epilepsy Next activity in the next issue of IE News.

GOLDEN LIGHT AWARDS BALI 2018



WITCHCRAFT MURDERS IN MALAWI

Malawi is one of the smallest and least developed nations in the world with a population is just over 18 million. It has a history of human rights issues, some still ongoing as reported by international observers as recently as 2017. Human rights issues include corruption within security forces, lack of adequate legal protection of women from sexual abuse and harassment, very high maternal mortality rate, and abuse related to accusations of witchcraft. Homosexuality was outlawed in 2010.

In recent months, lynch mob attacks have left a number of people dead in some parts of Malawi and now the problem has spread to Blantyre, the second largest city in Malawi and its unofficial capital. According to Reuters, the situation has become so serious that the Malawian President, Peter Mutharika, has been visiting parts of the country affected by the vampire scare, to try to prevent further deaths. The United Nations and the US embassy have blacklisted several parts of Malawi as danger zones for staff and visitors and the UN pulled staff out of two districts in the south of the country.

The reason for the recent killings is a belief by some people that the victims were blood-sucking vampires. To those living in more developed and economically healthy nations, this may seem as incredible. However, in one of the poorest countries in the world, where the belief in witchcraft is still widespread, mob rule can be more easily incited to believe that there are bloodsucking vampires at large.

One of the recent victims in Blantyre was Abdul Matola, a young 19-year old who had epilepsy. Abdul had a seizure while on his way home from a nearby hospital and, while he rested to recover, was set upon by a marauding group who suspected him of being a blood-sucker and decided to carry out a citizen arrest. They brought him to a police checkpoint but, dissatisfied in the delay by the police in taking him to the main Police Station, they began throwing stones at the police officers manning the checkpoint.

The mob then chased the police officers from the scene, dragged the young out of a makeshift cell where the police had held him and set him on fire. Distressing images of his charred body were printed in some news reports that were posted online.

In response to the horrific attack of the young man, the International Bureau for

Death of a person with epilepsy in Chileka, Malawi

On 17 October 2017, Abdul Matola (a 19-year-old) who had epilepsy was burnt to death because he was suspected of being a vampire or bloodsucker. Eight more people died in related incidences. Abdul had a seizure and whilst he rested to recover people suspected him to be a bloodsucker. A mob dragged him to the nearby satellite police station, but police officers were overpowered. As a result the mob burnt Abdul to death. A young life was lost, and many more could be lost in future if the community is not educated about epilepsy. Epilepsy is a neurological condition treatable with medication, and people with epilepsy are not vampires, bloodsuckers or witches.

We support the petition set by the Federation of Disability Organisations in Malawi (FEDOMA) and the National Epilepsy Association of Malawi (NEAM) calling upon the government of Malawi to urgently develop and implement national plan for epilepsy management that includes:

- Epilepsy awareness campaign,
- Making treatment and anti-epilepsy medicines available,
- Changing laws that do not protect people with epilepsy, and
- Fully investigate incidences of violence including Abdul's death.

We thank the government for the efforts already in place to stop the killings and to bring justice but we want to stress that a long-term solution is desirable. **We call upon interested individuals and organisations to support this petition with statements and letters** that FEDOMA/NEAM will deliver to the authorities. Finally yet importantly, we extend our condolences to the families and friends affected by the ruthless killings.



Professor Martin J Brodie, President, International Bureau for Epilepsy

Jacob Mugumbate, Chairperson, IBE African Region

Action Amos, FEDOMA, Executive Director

Francina Gondwe, National Epilepsy Association, Director

Epilepsy, and a number of IBE chapters in Africa, signed a petition that has been forwarded to the government of Malawi urging it to develop and implement a national plan for epilepsy management. IBE has had a chapter in Malawi for a number of years.



PUTTING EPILEPSY IN THE PICTURE

NEW EUROPEAN GUIDE TO EDUCATE WITHOUT WORDS

The kick-off meeting of the EPIPICTO project, a European Erasmus+ project to develop a pictorial guide for adults with epilepsy with reading difficulties, was held in Malta from 24-25 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. Representative 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 contribute 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 initial aim of the pictorial guide, which received €60,000 in funding, is to ensure that people with epilepsy living in Europe who have a poor literacy standard or those immigrants who find the foreign language barrier an issue in learning about epilepsy or helping others to understand the disease. However, the format of the guide will be readily adaptable to be rolled out in other regions of the world, where illiteracy rates are considerably higher than in Europe.

The two-year project will end 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 for download from 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; Janet Mifsud, CMEA, and Caroline Attard, CMEA.



Co-funded by the
Erasmus+ Programme
of the European Union

Project 2017-1-MT01-KA204-026946



YOUNG ADULTS SUMMIT IN COSTA RICA

One of the first activities to be held in the Latin American region under the banner of the new IBE EpilepsyNext program for youth, will be a Young Adult Summit in Costa Rica. The event will run over a period of three days in tandem with the Latin American Epilepsy Congress, taking place in San Jose at the end of September 2018.

Plans are now being put in place and an exciting schedule of activities are being developed, based on the very successful Young Adults Summit that took place in Washington DC, organised by the IBE North American Regional Committee in 2014. The North American event, gathered 20 young adults from Canada, Jamaica, Puerto Rico and the USA and led to the development of a media project that already has generated compelling videos highlighting the personal stories of triumph over diversity in young adults with epilepsy.

Two years later, its success, which led to the reMARKable videos, is evident in the continued active engagement of the young people in the project. The excellent videos can be viewed on the International Epilepsy Day website - epilepsy.org.

Following IBE's desire to further develop the successful Young Adult programme in each IBE region, the event in Latin America will be adapted from the original, to suit local requirements. Targeting a general audience aged 30 years and younger, as well as people affected by epilepsy (patients, family, friends, work colleagues), the objectives of the campaign will be:

- to educate through inspiration
- to show that epilepsy is not a barrier to success
- to give an accurate representation of epilepsy
- to educate society and to end stigma
- to empower people to feel comfortable talking about their epilepsy

Each chapter in the region will support the travel of one young person from their country to attend the summit in Costa Rica, with a maximum of 20 participants being accepted. The Latin American Regional Committee will receive some financial support from IBE towards some of the costs of accommodation and other expenses.

Details will be available to the chapters in the region in early 2018. Given the ongoing success of the North American project, there is every confidence that the Latin American summit will rise to equal heights.



As we put in place our plans for 2018,
we take this opportunity to thank you for your support
throughout 2017.

We look forward to our continued collaboration
in making a difference for people with epilepsy
as we begin a New Year.



International
Epilepsy Day

Monday 12th February 2018

