A photograph of two young boys with dark hair and skin, laughing joyfully in a field of sunflowers. The boy on the right has his arm around the boy on the left. The sunflowers are bright yellow with dark brown centers, and the background is filled with more sunflowers and green leaves.

INTERNATIONAL EPILEPSY NEWS

ISSUE 1 - 2018

Life is Beautiful

CELEBRATING INTERNATIONAL
EPILEPSY DAY 2018

INTERNATIONAL EPILEPSY NEWS

ISSUE 1 - 2018

FROM THE EDITOR

The year began with final preparations for International Epilepsy Day 2018 and in this issue we include the results of the *Life is Beautiful* photography award. This was a major success with almost 3,000 both beautiful and moving photos from more than 60 countries. We also showcase some of the hundreds of images uploaded to social media on the day - can you find yourself?

In the last issue, we reported on the public consultation that had been organised by the European Medicines Agency on the use of valproate. This issue carries the report published after deliberations.

Janice MacGregor is a special woman - beautiful and talented. Winner of the Ms Canada 2018 beauty pageant, she talks about her determination not to let her epilepsy define who she is. It's an inspiring and spirited story.

This issue also celebrates significant anniversaries of three IBE chapters - two celebrating 20 years of service to people with epilepsy, the third marks its half-century. Do let us know if your chapter is reaching a milestone!

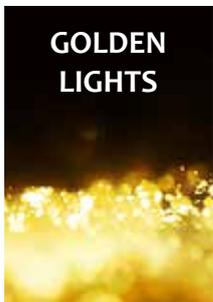
Other stories include a report from the EpiCARE European Reference Network, Golden Lights awards in Bali, the epiXchange conference in Brussels, growth in membership of the European Advocates for Epilepsy group in the European Parliament, and reports from Iran and Malawi.

Happy reading!

Ann Little
Editor



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EpiCARE Reference Network
Annual meeting takes place in London

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PRESIDENT'S MESSAGE



DEAR FRIENDS

For those of us living in the northern hemisphere, it has been a long, cold winter. But spring finally arrived, with rising temperatures and longer evenings and, just like the explosion of growth in nature, so too has there been an explosion of activity in IBE.

This year began with the celebration of International Epilepsy Day around the world and it is heartening to see that, now in just its third year, already the annual day is turning into a major global success. This year, more than 120 countries were involved in activities in some shape or form, each one playing a part in increasing understanding and awareness about epilepsy. Now we look forward to next year's celebration.

As in previous years, International Epilepsy Day was celebrated in the European Parliament with an important breakfast briefing, a closed session of invited Members of the European Parliament, speakers from IBE and ILAE, and relevant stakeholders. In part, this has led to a major initiative of the EU Research Commission, which is holding a one day private meeting in Brussels on 24th May to discuss the need for global alliance on epilepsy research.

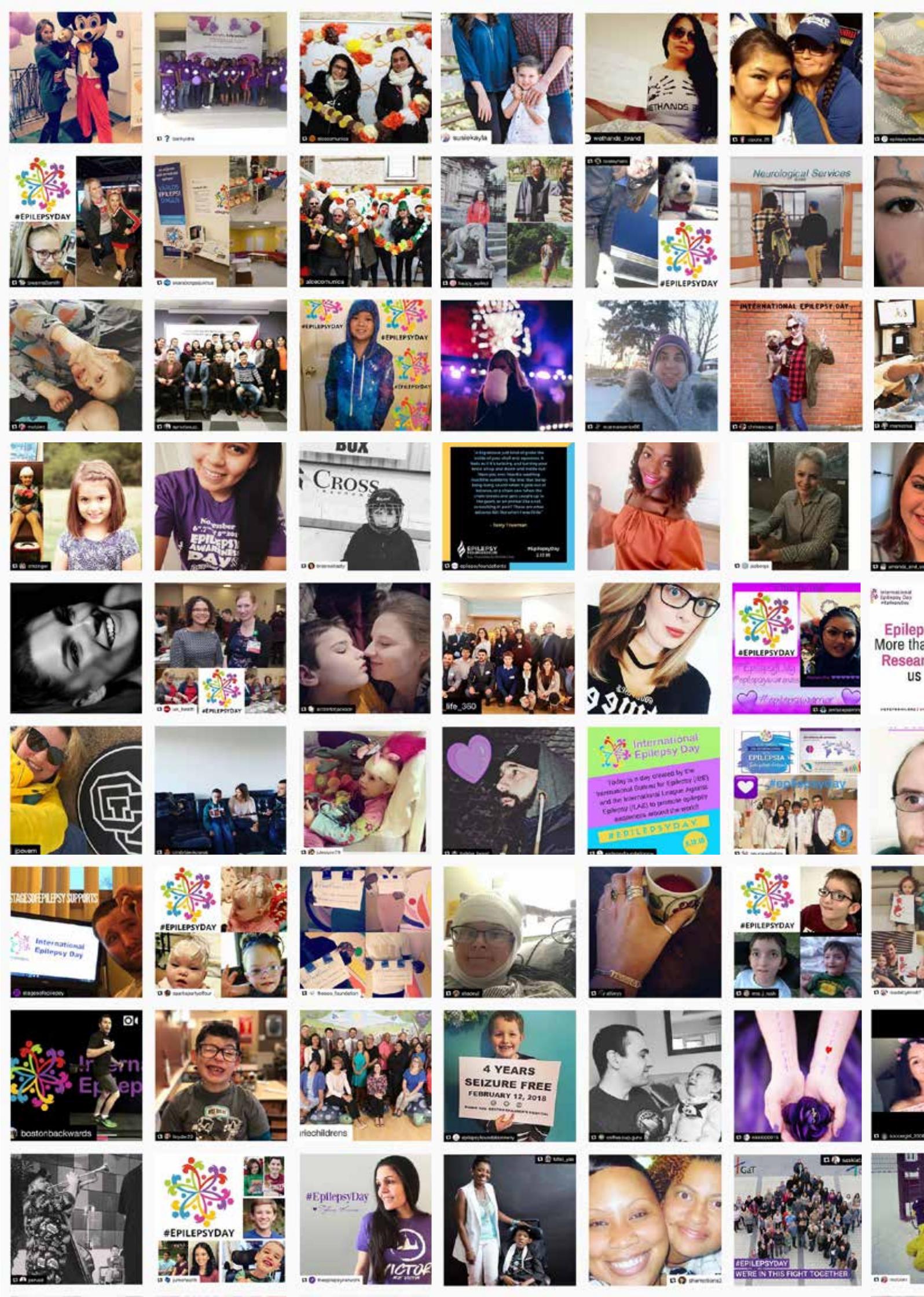
You may recall my invitation to all chapters to consider submitting an article to be published in *Epilepsy & Behavior*, as part of the IBE column in the journal. I am pleased to report that two articles, from our chapters in Canada and South Africa, have already been received and submitted and are due for publication soon. More articles would be welcome – so, if you have something to share about trials and tribulations or successes and celebrations in your chapter, do let me know.

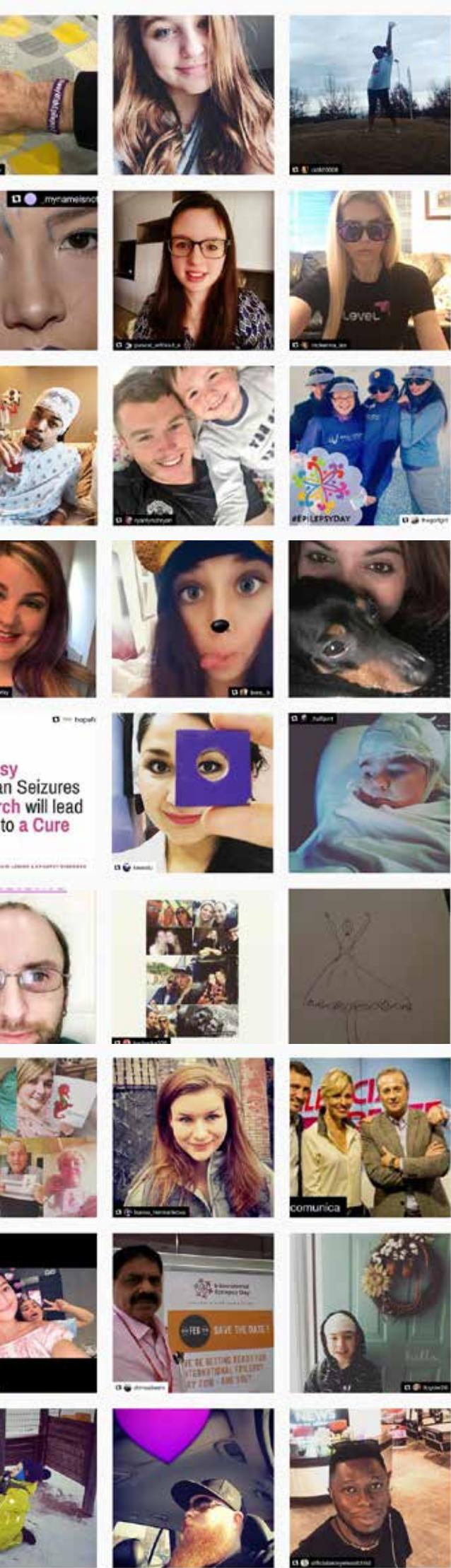
Two activities under the banner of EpilepsyNEXT are in planning – the first is a dedication of the Golden Light awards to young adults. These awards will be presented during the 12th Asian & Oceanian Epilepsy Congress in Bali in late June. The second is a young adults summit that is being organised by the Latin American Regional Committee and will take place in Costa Rica during the Latin American Epilepsy Congress later in the year. As previously reported, I am planning to expand the TEA Room initiative to include education and training opportunities. The paperwork to encourage funding for this endeavor is almost ready.

The next major event, and which I have no doubt will be reported on extensively in the next issue of *IE News*, is the report back by WHO to the World Health Assembly (WHA) this month. At the session, the WHO will be expected to bring WHA up to date on progress and, while there has been some positive outcome to date, a lot still needs to be done. A delegation from both IBE and ILAE will be in Geneva to support the call for an extension of the Resolution on Epilepsy that was approved by the WHA three years ago.

Finally, I would like to let you know that an article on the recent ILAE reclassifications of seizures written for a lay readership, with myself as first author, has been published in *Epileptic Disorders*. You may have received an eZine about this in recent weeks, with a link to the paper. If not, you will find it on the IBE website www.ibe-epilepsy.org.

Martin Brodie
President, IBE





SOCIAL MEDIA

#EpilepsyDay - The Numbers

Thanks to the hundreds of people around the world who took part in our #EpilepsyDay activity. You shared your photos, many moving, some comical and all very much appreciated. The success of the campaign showed just how powerful we can be when we pull together!

8,617 tweets

4,820 participants

50,526,526 impressions!

World Health Organization celebrates the day

The World Health Organization (WHO) were Twitter's top Health Influencer during the period, with 4,320,000 followers. For the second year, the most popular health-related URL in a tweet during the period was WHO's epilepsy factsheet <http://www.who.int/mediacentre/factsheets/fs999/en/>

WHO's factsheet Tweet was shared more than 1,000 times and their Facebook post more than 1,300 times.

WHO also shared a webpage dedicated to International Epilepsy Day focusing on their commitment to reducing the epilepsy treatment gap.

Life is Beautiful Photo Competition

THE RESULTS



1

THE STORY BEHIND THE PHOTO

“Morris took the photo while playing with my phone. For me the picture represents the theme ‘Life is beautiful’ because there’s so much love in it. My daughter Roos (Rose in Dutch) was diagnosed with LGS one month before she turned 2. At that time I was 3 months pregnant with Morris. Roos now is 6 years old and we all have found our way in a life with epilepsy. Roos is, despite of all her seizures, a very happy girl and her own small world is beautiful. She doesn’t judge people, isn’t hateful or intolerant; she’s pure and enjoys her own beautiful world. We have the equipment to make life easier for her (and us); we have a good team of doctors and caregivers and we try to make the best of life, despite of all the unpredictable and stupid seizures. Roos’s little brother, Morris, caught up on her (mentally) when he became one. So, though he is 2 years younger, he is her bigger little brother (or older younger brother).

Roos has lots of seizures every day and she often gets in a non-convulsive status epilepticus. In the picture she’s in it.

For Morris it does not matter who or what Roos is and what she can or cannot do... Roos is just Roos... She is his big sister, he loves her and life is beautiful with her. And he is so right. Life is beautiful with her!”

Iris van der Meer, mother of Morris van de Smaal.

Morris’s photo won First Prize in the under-12 category



2



4



5



3



6

Close to 3,000 photographs were received for the Life is Beautiful photography competition to celebrate International Epilepsy Day 2018. This made it a very difficult task for the judging panel to select the winners. Thanks are due to the members of the panel: Carol d'Souza (India), Heather Davies (Scotland), Carina Jonkers (Netherlands), Jorge Förster (Chile) and Baiqiu Zhang (China) for their wonderful work. We would also like to thank the more than 600 people from 61 countries who submitted stunning photos, some with very personal stories, to the competition.

Winner Adult Category: 1. Oyuncu, Leyla Emektar (Turkey).

Runners Up: 2. Beautiful Mind, Sandipani Chattopadhyay, (India); **3. U Will Like It**, Mithail Afrige Chowdhury, (Bangladesh); **4. Monsoon Splash**, Ata Adnan (Bangladesh); **5. Bond of Memories**, Niraj Gera (India); **6. Harvest**, Peng Yuan (China).

Winner U-12 years Category (opposite): 1. Love makes life Beautiful, Morris van der Smaal (Netherlands).

Runners Up: 2. Beautiful Day, Tiago Terre Neves, 10 years (Portugal); **3. Life is Beautiful**, Amir Mohammad Dehghan, 10 years (Iran); **4. Live the Moment**, Abril Culebras Canas, 12 years (Spain); **5. Little Miracle**, Fatima Yusuf, 10 years (India); **6. Sunset Cows**, Cate Gusentine, 12 years (USA).





EMA REPORT

Important new recommendations for valproate

In September 2017, IBE participated in a Public Hearing on Valproate, hosted by the European Medicines Agency (EMA) in London. The hearing was organised to review the prescription of medicines containing valproate for women and girls who are of childbearing age. The goal was to listen to different views and experiences concerning its use and to see what should be done to prevent or minimise harm to unborn babies exposed to the drug in the womb.

A previous review of valproate had been held by the EMA in 2013, which included consultation with people with epilepsy and other stakeholders. Following this, the EMA

had recommended widespread restrictions to the prescription of valproate for girls and 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 because of concerns that the recommen-

dations from the 2013 review had not been sufficiently effective. The review was carried out by the Pharmacovigilance Risk Assessment Committee (PRAC) of EMA, the committee responsible for the evaluation of safety issues for human medicines. The public hearing was just one element of an extensive review carried out by the PRAC. The committee considered available evidence and consulted with all relevant stakeholders, including women and their children who had been affected by valproate, through written submissions and expert meetings with patient organisations, healthcare professionals and the patients themselves.

MAIN RECOMMENDATIONS ISSUED BY PRAC

- In pregnancy: valproate must not be used. However, it is recognised that, for some women with epilepsy, it may not be possible to stop valproate and treatment may need to continue in pregnancy but with appropriate specialist care
- In female patients: valproate must not be used from the time they become able to have children, unless the conditions of the new pregnancy prevention programme are met - *see programme details on next page*
- The outer packaging of all valproate medicines must include a visual warning about the risks in pregnancy. This may include a symbol or pictogram
- A patient reminder card should be attached to the outer package for pharmacists to discuss with the patient each time the medicine is dispensed
- Pharma companies marketing valproate should provide updated educational materials for healthcare professionals and patients

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 suggests, however, that it may occasionally reduce the cognitive development of exposed infants and may be associated with autistic spectrum disorders.

Speaking at the public hearing last September, IBE President Martin Brodie emphasised the need for improved public information and health education, advancing advocacy and the exchange of international best practice. He stated that 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.

IBE accepts the need to restrict its use in young women, but would support its prescription as drug of last choice, if all other relevant therapeutic approaches had proven unsuccessful. Women and girls who have been prescribed valproate should not stop taking their medicine without consulting their doctor as doing so could result in harm to themselves or to an unborn child.

The PRAC has now issued a series of recommendations. It recommends strengthening restrictions on the use of valproate in at risk patients and has introduced new measures that require appropriate counselling.

However, PRAC also reported that it was clear that for some women, such as those with particular forms of epilepsy, valproate was the only appropriate treatment and could be life-saving. Uncontrolled epilepsy, particularly in young people, carries a risk of sudden unexpected death (SUDEP).

The committee is also calling on pharmaceutical companies marketing the medicines to undertake further research on the nature and extent of the risks posed by valproate and to monitor its ongoing use and long-term effects of those who have been affected by its use in pregnancy.

The PRAC recommendations will now be sent to the Co-ordinating Group for Mutual Recognition and Decentralised Procedures - Human (CMDh), which will adopt a

VALPROATE PREGNANCY PREVENTION PROGRAMME

ASSESSMENT:

- Assessing patients for potential of becoming pregnant, patient involvement in evaluating individual circumstances and supporting informed consent

PREGNANCY TESTING:

- Pregnancy tests before starting treatment and during treatment as needed

COUNSELLING:

- Providing counselling to patients on the risks of valproate treatment

CONTRACEPTION:

- Explaining the need for effective contraception measures throughout treatment for those at risk

REVIEWS:

- An annual review of treatment for patients

RISK FORM:

- Introduction of a Risk Acknowledgement Form that both patients and prescribers go through at each annual review to confirm that appropriate advice has been given and understood



position. The CMDh is responsible for ensuring harmonised safety standards in medicines through national procedures across the EU.

The active ingredient in valproate medicines, which is also licenced to treat bipolar disorder and migraine (in some countries), may be:

- valproic acid
- magnesium valproate
- sodium valproate
- valproate semisodium
- valpromide

ABOUT THE EMA

The European Medicines Agency (EMA) is a European Union agency for the evaluation of medicinal products. It operates as a decentralised scientific agency of the European Union and its main responsibility is the protection and promotion of public and animal health, through the evaluation and supervision of medicines for human and veterinary use.

More specifically, it coordinates the evaluation and monitoring of centrally authorised products and national referrals, developing technical guidance and providing scientific advice to sponsors.



Don't waste your time saying 'WHY ME?'

Ms Canada 2018, Janice MacGregor, talks frankly about her epilepsy

My name is Janice MacGregor and I am International Ms. Canada 2018. I live in a small town just outside of Saskatoon, Saskatchewan and I have epilepsy. I had my first generalized tonic-clonic seizure when I was 18 years old. I was in my first year of university and it happened in the cafeteria. I just remember feeling dizzy. The next thing I remember was waking up on the floor with two paramedics around me. I don't remember my second, third, fourth, etc. seizures because after a while they all blur together.

I still have a general apprehension about how the "E-word" could influence what happens in my acting, modelling and pageant career

I had my last major seizure a few months ago and I have absence seizures daily. My neurologist and epileptologist have tried several medications and combinations of medications and we're still working to find something that will work. I'm optimistic! I feel it is important for people with epilepsy to live as full a life as is possible. I understand that there are some difficulties that come with epilepsy. I lost my driver's

license, for example, when I was diagnosed. The prescription medications leave me exhausted. And there are extra considerations regarding family planning that women using anti-epileptic drugs (AEDs) have to keep in mind that other women don't have to worry about. I'm not complaining- I realize how blessed I am to have access to AEDs in the first place. We have to play the hand we're dealt in life. I didn't let my situation prevent me from graduating from university with High Honours. I was on the Dean's List and I had an academic scholarship. I earned life-time membership in the Golden Key International Honors Society.

When I was in university I considered becoming a pilot but, after I lost my driver's license, I realized that was not going to happen. I eventually found my way into a career that I love! I love the modelling and talent industry and am blessed to be a part of it. I come alive when I am acting on stage or in front of a camera! Being able to entertain people and being able to inspire discourse is rewarding.

I'm a pageant girl. I was Miss Saskatchewan in 2007 and a national finalist in Miss World Canada 2008. Eleven years later I still have Pageant Fever! I'm competing in the International Ms. 2019 Pageant in Manhattan this August. I am trying to use my position as International Ms. Canada 2018 to raise epilepsy awareness and to draw attention

to other causes that are dear to me, such as the school in Tanzania where I am a volunteer teacher.

Sometimes people don't recognize us as the intelligent and capable individuals that we are and just slap the label "Epileptic" on us.

But we are so much more than a diagnosis!

It's so important to NOT let a diagnosis limit our goals. People with epilepsy and parents of children with epilepsy shouldn't focus on limitations; rather, we should focus on potential and on finding jobs and hobbies that we enjoy and find fulfilling. I think that when people with epilepsy live full lives and strive for their goals it helps tear down the stigma and ignorance surrounding epilepsy.

I've lost modelling and acting jobs when the client found out I have epilepsy. A few years ago, I won a national level pageant title and the night after I was crowned a pageant official told me the pageant would not send me to an international pageant as I would "just go falling down everywhere" because of my epilepsy.

This summer I will represent Canada in the International Ms. Pageant where I am welcome - epilepsy and all. This pageant sees me as a complete person and recognizes that I am an individual with strengths and a personality and not just a diagnosis. I've had the pageant and fellow delegates 'LIKE' my social media posts about epilepsy, message me their support, or thank me for talking about this subject because they have a relative with epilepsy.

I'm not going to lie about having epilepsy. I have nothing for which to be ashamed. Epilepsy just happened.

There are some fantastic people in the world and I have the opportunity of meeting some of them through pageants! Sometimes people don't recognize us as the intelligent and capable individuals that we are and just slap the label "Epileptic" on us. But we are so much more than a diagnosis! I've experienced the discrimination that comes with having this chronic illness and I am fighting against it. But we need to do

this together. We need to strive for our personal best in everything we do from school, work, sports, music, arts, and so forth to show our best selves.

I still have a general apprehension about how the "E-word" could influence what happens in my acting, modelling and pageant career:

- Will clients assume I can't keep up with a demanding gig?
- Will a pageant judge assume I would have to take more sick days than any other delegate would?
- Will a judge assume that I can't manage a national or international pageant title and will they low score me?
- Will a director assume that my epilepsy will somehow cause production delays if they cast me?
- Will people assume I can't pull my own weight during filming or a photo shoot?

But I'm not going to lie about having epilepsy. I have nothing for which to be ashamed. Epilepsy just happened.

I want to end with the message saying "Never give up!" Yes, you will meet ignorant people. Try to educate them but realize that if they don't want to be educat-

ed about epilepsy you can't force them to learn. Never let anyone make you feel inferior or like you are less of a person because you have epilepsy. And don't waste your time asking "why me?" You have epilepsy, accept it and learn to adapt. Questioning why you have epilepsy won't get you anywhere. I often wonder "Why NOT me?"

I live in a country with socialized health care AND I have an amazing insurance package. I have a determined and persevering spirit that won't let anything get in the way of my goals. I'd rather it be me who has epilepsy than someone who doesn't have access to medication or someone who will simply roll over in the face of adversity.

You can handle this. Find friends and family members who will support you through the tribulations that are a part of having epilepsy. And set realistic goals to which you can aspire. Accept that if you aren't allowed to drive a car you likely won't be racing in a Formula 1 competition or flying a plane. Now find something about which you can be equally passionate.

You WILL find something you love. Your future is waiting for you to find it

The European Federation of Neurological Associations (EFNA) has launched a Survey of Young Europeans with Neurological Conditions: <https://www.surveymonkey.com/r/EFNA-YS>.

The objective of this survey is to gain an understanding of the biggest issues affecting participants in their daily lives and also to learn about their relationships with and opinion of patient groups.

Information gathered from this survey will be used in the development of EFNA's future workplans, ensuring that they and their member organisations are working in the best interests of those they represent.

Findings from the survey will be published on World Brain Day 2018 (July 22nd) and will be used to raise awareness among the public, health professionals and policy makers.

MEP GROUP INCREASES TO 63

In celebrating International Epilepsy Day in the European Parliament, members of the IBE/ILAE Epilepsy Alliance Europe joint task force held private meetings with almost 40 MEPs. This was an opportunity to tell them about the problems faced by people affected by epilepsy and to highlight the need for improved services, better public awareness and increased research.

The members of the task force also invited those MEPs who were not already members, to join the European Advocates for Epilepsy group. We are delighted to report that, as a result, membership of the group increased by nine, bringing the total number in the group to 63 MEPs.

The advocates group is led by Brian Hayes MEP, who acts as its President, with Nathalie Griesbeck MEP its Vice President. Created in April 2011, the aim of the group is to improve the quality of life of all people with epilepsy, their families, caregivers and healthcare providers through European Union (EU) policy. Since 2011, the group has hosted an annual day for epilepsy each February, in addition to accommodating regular workshops on epilepsy related topics. Meetings with the Health and Research Commissions have also been facilitated. More recently, In June 2016, 20 members of the group added their signatures to a letter calling on the support of national members for an application for a European Reference Network on Rare and Complex Epilepsies.

The support of the European Advocates for Epilepsy working group is vital in all our efforts in Europe. It has opened doors and provided direction on avenues we can take in our work to make a difference in Europe.

HELP US GROW THE ADVOCATES GROUP

A membership of 63 MEPs is impressive but it is possible to increase the numbers even further. We also need to fill the gaps in those countries where there is no member of the group. Do you live in an EU Member State? Is there an MEP that you or your association could ask to join? By attracting one MEP from each country, we could increase the membership to 90 MEPs.

With European elections due to take place next year, already the sitting MEPs are considering their election plans. As a constituent, with the power to vote for them, this is an excellent opportunity to make contact with them. The time commitment in being a member of the advocates group is not onerous - with perhaps two meetings a year - and each member is provided with a certificate of membership that they can use on their website and in their social media to show their support for the epilepsy cause. For help in making contact with an MEP, please contact Ann Little at the IBE office ibexecd@ibeamer.com.



European Advocates for epilepsy



Tanja Fajon
Slovenia



Eleonora Forenza
Italy



Karin Kadenbach
Austria



Ulrike Müller
Germany



James Nicholson
UK



Annie Schreijer-Pierik,
Netherlands



Igor Šoltes
Slovenia



Nils Torvalds
Finland



Ivo Vajgl
Slovenia

CURRENT MEMBERS

AUSTRIA: Heinz Becker, Barbara Kappel, Karin Kadenbach, Paul Rübiger
CYPRUS: Lefteris Christoforou, Neoklis Sylikiotis, Costas Mavrides, Demetris Papadakis
CZECH REPUBLIC: Pavel Poc, Olga Sehnalová, Tomáš Zdechovský
DENMARK: Bendt Bendtsen, Christel Schaldemose
FINLAND: Liisa Jaakonsaari, Anneli Jäätteenmäki, Miapetra Kumpula-Natri, Merja Kyllönen, Sirpa Pietikäinen, Nils Torvalds
FRANCE: Nathalie Griesbeck, Dominique Riquet
GERMANY: Jens Gieseke, Ulrike Müller
GREECE: Kostas Chrysogonos, Lampros Fountoulis, Dimitris Papadimoulis, Sofia Sakorafa, Maria Spyraiki, Eleftherios Synadinos, Theodoros Zagorakis
HUNGARY: András Gyürk
IRELAND: Matt Carthy, Nessa Childers, Deirdre Clune, Marian Harkin, Brian Hayes,

Seán Kelly, Mairead McGuinness
ITALY: David Borelli, Eleonora Forenza, Giovanni La Via, Patrizia Toia,
MALTA: David Casa, Miriam Dalli, Roberta Metsola
NETHERLANDS: Annie Schreijer-Pierik
PORTUGAL: José Inácio Faria
ROMANIA: Christian-Silviu Buşoi, Marian-Jean Marinescu, Emil-ian Pavel, Claudiu-Ciprian Tănăsescu
SLOVAKIA: Jana Žitňanská
SLOVENIA: Tanja Fajon, Alojz Peterle, Igor Šoltes, Ivo Vajgl
SWEDEN: Jytte Guteland, Anna Hedh
UK: Paul Brannen, Theresa Griffin, Jean Lambert, James Nicholson, Julie Ward.

NO MEMBERS: BELGIUM, BULGARIA, CROATIA, ESTONIA, LATVIA, LITHUANIA, LUXEMBOURG, POLAND, SPAIN.

You will find a full list of MEPs, by country on the EU website: <http://www.europarl.europa.eu>.

GOLDEN LIGHT AWARDS BALI 2018

AWARDING YOUNG PEOPLE WITH EPILEPSY
WHO HAVE MADE A DIFFERENCE AT A
NATIONAL LEVEL

Calling all IBE chapters in the South East Asia and Western Pacific regions 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.

BACKGROUND

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 to 'bring epilepsy out of the shadows and into the light'.

CANDIDATES

For 2018, it is proposed to focus the awards on young people. Candidates must be under the age of 40 years on 1st January 2018.

Each candidate is required to submit a written article, between 500 and 800 words in length, telling their story about epilepsy. The article must be submitted in English and candidates may seek assistance with translation.

The candidates submitting the best three stories will be invited to present their story during the Epilepsy & Society Symposium, taking place on Sunday 1st July 2018.

Candidates selected for a Golden Light Award will be presented

with a trophy at the Congress Opening Ceremony on 28th June. Nominations must be submitted by an IBE chapter. Nominations received from individuals will not be accepted.

SELECTION

Each chapter member of the South East Asia and Western Pacific Regions is entitled to nominate a recipient for the award, based on the following criteria:

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

PRIZE ENTITLEMENTS

Each candidate will receive the following:

- Golden Light Trophy and Scroll
- Support up to US\$300 for travel to Bali and 2 nights' accommodation at the congress
- Free registration to the Epilepsy & Society Symposium on Sunday 1st July

DEADLINE FOR THE SUBMISSION OF NOMINATIONS EXTENDED TO SATURDAY 26th MAY

Nominations should be submitted using the nomination form to Ann Little, Executive Director at ibeexecdir@gmail.com. Please also use this address if you require a copy of the nomination papers.

REPORT FROM IRAN

Making a difference for people with epilepsy in Iranshahr



cultural beliefs, and social stigma contribute to the large treatment gap for epilepsy in that area. The

um Valproate – Carbamazepine - Phenytoin) for the Iranshahr Branch to be distributed to patients.

In addition, IEA bought an XE Serious EEG device and provided an agenda for an epilepsy seminar in Iranshahr.

It is considered that Sunni clerics have more power over people in the region and so they have been identified as a second group for epilepsy awareness.

The first epilepsy seminar was held on 25 April 2018 in Iranshahr Health Home with 150 people (100 people with epilepsy and their families, and 50 teachers and school principals) in attendance.

At first Dr Khodamoradi, MD talked about epilepsy types and treatment and then Nasrin Farrokhi, BS talked about stigma and social aspects in epilepsy.

In the evening, a meeting was arranged with Sunni clerics to discuss negative attitudes toward epilepsy.

During the seminar, the portable EEG device was delivered to Iranshahr Branch and was checked to ensure that it was working correctly. In addition, IEA gave each participant a health package (include shampoo, toothpaste, towel and etc) as a gift. Overall, the project was deemed a great success.



Sistan and Baluchistan is the southeastern province of Iran which is in close to the border of Pakistan and Afghanistan. This Province is one of the more deprived regions of Iran. Most people living there live in poor conditions because of hot climate and its strategic location along the borderline.

Iranshahr is in the centre of Baluchistan with an area of around 30,200km² and covers 15% of the land of the province.

Iranshahr's marginalization leads to increased poverty in the area and the sandstorm winds have an even more negative effect of the quality of life and living standards of its population. Statistics show that there are 51,023 families and a total population of 219,796 – of which 54% are living in urban areas and 45% in rural areas.

It is estimated that the prevalence rate of epilepsy is higher than in other provinces because of low income, marriages in relatives' circles (consanguinity), teenage pregnancies, as well as car accidents.

Furthermore, limited diagnostic equipment, inadequate anti-epileptic drug supplies,

number of people recorded to have epilepsy in Iranshahr, as reported by the Health Department, is 1,008.

The Iranian Health Ministry (IHM) set up a pilot project with the cooperation of Iranshahr Medical Sciences University to empower this deprived area in September 2017. IHM asked national NGOs to participate in the project and organised support and educational activities in the region. In line with this project, the Iranian Epilepsy Association (IEA) arranged an expedition to Iranshahr in March 2018 to establish an IEA Branch in that city. Because the land is widespread and, in some places, inaccessible, diagnosis is difficult. For that reason, IEA suggested providing a portable EEG device for its Iranshahr Branch.

Then IEA had a meeting with the Head of the Ministry of Education in Iranshahr. It was decided to identify students who had epilepsy and to hold an educational meeting for students, their families and teachers.

During its visit to the region, IEA made a donation of 20 boxes of AEDs (Levebel - Sodi-

CONGRATULATIONS!



EPILEPSY SOUTH AFRICA CELEBRATES 50 YEARS!

Last September, Epilepsy South Africa set out on a year long celebration of 50 years service to people with epilepsy in South Africa. Now in operation for half a century, there is indeed reason to celebrate. Epilepsy South Africa is the only national non-profit organisation in the country focusing specifically on the needs of persons with, and affected by, epilepsy while also providing services to persons with other disabilities.

While the organisation has grown from a strong social work back-

ground its vision today shows a change in focus: *Epilepsy South Africa: Igniting the flame of potential*. Its current mission is to promote human rights and an inclusive society for persons with disabilities, primarily persons with epilepsy.

Its work is grounded in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and it has also contributed to the development of the South African White Paper on the Rights of Persons with Disabilities (WPRPD) and the African Disability Protocol. Congratulations to all involved with the organisation!



TIME TO CELEBRATE IN BULGARIA

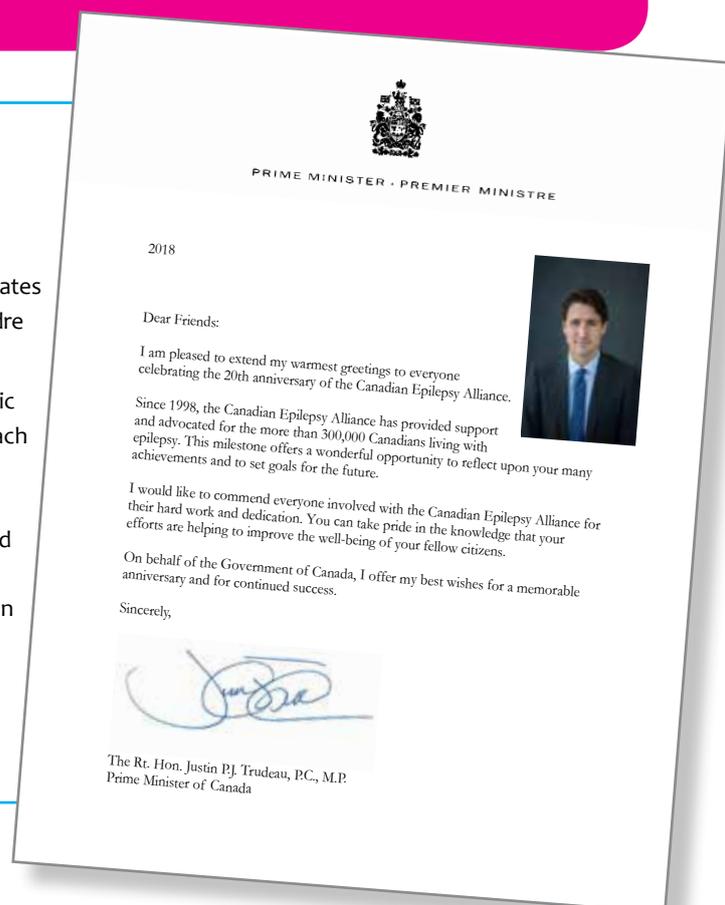
IBE sends its best wishes to Mrs Veska Sabeva and all members of the Association of Parents of Children with Epilepsy in Bulgaria, which celebrates its 20th anniversary this year.

Canadian Epilepsy Alliance celebrates 20th anniversary

As the Canadian Epilepsy Alliance/Alliance canadienne de l'épilepsie celebrates 20 years' service to people living with epilepsy in Canada, its President, Deirdre Floyd, explains how the association has developed:

“There has been a significant shift in how we deliver services to the public and clients living with epilepsy. Now, because of the internet, we can reach more people than ever before. With reference to treatment of epilepsy, there have been significant improvements in diagnosis as well as treatment options for those living with epilepsy. Some forms of epilepsy could not be detected fully twenty years ago but, with the advancements in technology, as well as advances in epilepsy surgery assessment, more can be done to help improve the overall quality of life for clients who have epilepsy.

While this is a new era for us, our passion remains the same in that we strive to help improve the quality of life of Canadians living with Epilepsy.”



Fighting prejudice in Malawi

Report by Terttu Heikinheimo-Connell,
Neurologist, Finnish Epilepsy Association



“The road gets narrower and narrower”



Participants of a meeting in Kachinga, joyful and proud of their achievements.

Photo: Terttu Heikinheimo-Connell

The Finnish Epilepsy Association (FEA), a network of 23 local affiliates, was established in 1969 to promote care and equality for people with epilepsy (epilepsia.fi). Finland is a wealthy Scandinavian country with a population of 5.5 million with a density of 18 people/km².

Malawi, situated in sub-Saharan Africa, has

a population of 19 million with a density of 203 people/km² (worldometers.info). In the human development index Finland lies in 23rd place, while Malawi is 170th place (hdr.undp.org).

Since 2010 FEA has been co-operating with its' sister organization in Malawi, the National Epilepsy Association of Malawi

(NEAM), which functions under the Federation of Disability Organizations in Malawi (FEDOMA). NEAM and FEDOMA are based in a second largest city of Malawi, Blantyre. Since 2013 FEA has supported NEAM financially with moderate funding to promote its work in a country where a person with epilepsy can still be accused of being possessed by an evil spirit!

In March 2018, FEA sent me to Malawi to learn about NEAM's activities and the challenges it faces. When in Malawi everyday-life is time- and effort-taking, internet access is often slow or out of reach. As the work at NEAM is done in a voluntary basis, reporting back has been scarce.

It was better, therefore, to travel and meet the activists and to visit the area. I spent two weeks in this beautiful warm heart of Africa and visited two villages. I met with active local people working against the prejudices they face due to epilepsy; I met guardians, visited the epilepsy clinic in Malawi's largest hospital in Blantyre, and discussed with the board members and



volunteers what they have achieved during the first 8 years.

MEET SAMUEL, FRANCINA AND EVELYN: THE VOLUNTEERS

Samuel Chigamba lives in Thyolo, 47 km from Blantyre, in a tea growing area. He is one of the very active volunteers in his home region and within Blantyre. In Thyolo, he has a group of 35 people who live with epilepsy. A similar group meets in Blantyre and groups are found in Northern Malawi, in Mzuzu, where the chairperson, Francina Gondwe, lives and works. Most NEAM volunteers have epilepsy themselves or they are guardians of a family member with epilepsy. The groups meet, train, talk, and support each other. This makes them feel more valuable, helps them learn about epilepsy, and encourage them to defend themselves against the prevalent prejudices. Since last year there has been violence against people with epilepsy or with other disabilities. They have been attacked, mutilated and some even killed by mockers who accuse the disabled of being blood suckers. These attacks

have reported in the international press, such as BBC World.

Samuel is lobbying. He is Chairperson for Thyolo District Disability Forum, a committee Formed by FEDOMA, where they successfully contribute towards an improved interaction between policy makers, implementers and people with disabilities. The Forum is a participatory space where people with disabilities who are representatives of Disabled People's Organizations discuss their needs and propose solutions, based on their human and citizen's rights, to the district authorities. One of the areas on which they have been working is advocating for the availability of anti-epileptic drugs, where they decide which drugs are needed in the health centres and local hospitals. Samuel wants to ensure that antiepileptic drugs are included in the basic supply of every health centre. Together with volunteer Evelyn Gadama, they help in the weekly epilepsy clinic in Blantyre in distributing the antiepileptic drugs, keeping statistics on clients and informing them on NEAM's activities. Evelyn and Samuel visit the victims of violence and advise them how to seek justice.

NEA -kulimbikisa ma ufulu a anthu amatenda akugwa!

VISITING CHIKWEVO VILLAGE, MACHINGA

The road is getting narrower and narrower. The journey to Machinga takes five hours. When we finally reach the health centre we are welcomed by people singing and dancing. They surround our car and all want to shake our hands. You can feel the joy; the long trip now feels worth it. People have waited under the mango tree the whole morning. Francina, Samuel and I sit down to relax after some dancing and hugging. We give speeches and volunteers sing to us. We are told examples of the achievements of the group. We meet a 10-year-old boy, who is now back in school, because his mother decided to give him the appropriate drug instead of herbal remedies, the shy healthy-looking boy is standing in front of us. A husband and wife stand up and tell their story. They are now married because they have learnt that epilepsy is not a barrier to marriage as they were told before. Two men perform an educational play about a man who wanted to chase away his wife because of her epilepsy. We all laugh at this silly man. The few hours go fast with this inspiring programme. We are about 40 people. I am impressed about how much

Mr. Wachimwa, the local coordinator has achieved. He was trained to be a coordinator by NEAM. Mr. Wachimwa makes people reply to the NEAM call: Promoting the rights of the people with epilepsy – kulimbikisa ma ufulu a anthu amatenda akugwa! NEAM! NEAM! The local herbalist has lost his clients to the health centre, which now has a regular supply of antiepileptic drugs. Impressive!

Sustainable work for the people with epilepsy. The epilepsy clinic at the hospital.

The epilepsy clinic in Blantyre is held once a week on Friday mornings. There I meet Mrs. Millie Kumwenda. She is a registered nurse. Together with her colleague, they meet patients, one by one, finding out whether they have had seizures and deciding if the drug should be increased, reduced or continued. The most common drugs available are phenobarbital, carbamazepine, phenytoine and sometimes sodium valproate. They confirm, education is needed at all the levels: amongst the people with epilepsy and volunteers, amongst the decision makers. Even the health workers and the physicians need more education! So who do these ladies consult if they don't know what to do with the patient with complicated epilepsy? They consult each other!

COOPERATION BETWEEN FEA AND NEAM: HAS IT WORKED?

FEA had to return some of the funds earmarked to NEAM because of lack of reporting and bookkeeping. However, this was due to our lack of experience of this kind of partnership effort and the everyday challenges the volunteers meet when living with epilepsy in a country like Malawi. The Malawians would have needed more training and our presence to support and educate them in the systems and protocols needed in this kind of a project. Still, when I see all the work that has been done for the benefit of people living with epilepsy with our low level of support over the last 8 years, I am touched! Some of the coordinators and activists seem to have a passion for this work. They do it for the cause, reward being the little victories! Our support has been an important backup. They know that there is a country up north that shares a common concern. Since 2010, NEAM has supported and given hope to hundreds of Malawians with epilepsy.

Acknowledgement: Thank you, Samuel Chigamba for reviewing this article.



EpiCARE

European Reference Network

The network for rare and complex epilepsies meets in London

Prof Helen Cross
EpiCARE Coordinator
Photos: Géza Sárvári



European Reference Networks (ERN) are virtual networks involving specialist healthcare providers

across Europe. They aim to tackle complex or rare medical diseases or conditions that require highly specialised treatment and a concentration of knowledge and resources. The ERNs are part of a broader EU strategy to make the national and European health systems more efficient, accessible and resilient.

ERNs for patient benefit

Between 6,000 and 8,000 rare diseases affect an estimated 30 million people in the European Union. An unfortunate feature of rare and complex diseases is the scarcity and fragmentation of specialist knowledge, which is often not available in the patient's region or country. Many people might not receive a satisfactory explanation for their symptoms, have delays to correct diagnosis or have access to the necessary knowledge on treatment options, rehabilitation and care. By consolidating knowledge and expertise scattered across countries, the ERNs give healthcare providers access to a much larger pool of expertise, resulting in a more accurate diagnosis for the patient with advice on the best treatment for their specific condition. Rare epilepsies affect less than 5 people in

10,000 of the general population and are either defined as an epilepsy syndrome or seizures as the result of a specific cause. Advances in brain scanning as well as genetic and metabolic investigations have determined an increasing number of causes behind epileptic seizures, resulting in the description of more than 130 rare diseases.

Capitalizing on the large spectrum of diagnostic and treatment modalities as well as on the individual expertise of centres in the field of rare and complex epilepsies, EpiCARE members are working together to create significant added value for patient care, research, education and training in close collaboration with patient organisations.

EpiCARE, which held its annual meeting at Great Ormond Street in London in March, brings together 28 highly specialized health centres in 13 European countries with expertise in rare and complex epilepsies. EpiCARE centres aim to enhance patient care by providing access to cutting edge clinical knowledge and diagnosis as well as a high standard of care provision by using e-tools and e-consultancy through regular, virtual multi-disciplinary meetings. This way it is the medical knowledge and expertise that travel rather than the patients, who have the comfort of staying in their supportive home environments. The annual meeting was the opportunity for more than 80 representa-

tives from the 28 centres to come together to discuss progress on workpackages and to consider next steps. Also present were representatives from patient organisations, whose input is critical to the success of ERNs. The success of all ERNs, including EpiCARE will be its promotion to all stakeholders.

Patient Pathway for EpiCARE

Through the EpiCARE ERN, people suffering from rare and complex epilepsies will have access to the full spectrum of diagnostic and therapeutic options via the nearest national participating epilepsy centre. If more specialised expertise is required, the members of one participating centre will collaborate with another centre displaying the required specific expertise and, together, they will decide on the best way for the patient to proceed with diagnostic and therapeutic procedures.

To review a patient's diagnosis and treatment, EpiCARE centres will convene a virtual advisory board of medical specialists across different disciplines, using a dedicated IT platform called Clinical Patient Management System (CPMS) as well as virtual meetings via WebEx. At this time, the patient will not be asked to participate in these virtual meetings; his or her medical specialist will do so on their behalf.

 EpiCARE is funded by an EU CHAFEA grant



EpiCARE Centres

1. Great Ormond Street Hospital for Children, London, UK
2. University College London Hospitals, London, UK
3. Queen Elizabeth University Hospital, Glasgow, Scotland
4. Oxford University Hospitals, Oxford, UK
5. University Hospital Gasthuisberg KU Leuven, Belgium
6. Motol University Hospital, Prague, Czech Republic
7. St. Anne's University Hospital, Bro, Czech Republic
8. Pohjois-Savon sairaanhoitopiiri (Kuopio University Hospital), Kuopio, Finland
9. CHRU LILLE, Epilepsy Unit, Lille, France
10. Epilepsy Departments, University Hospitals of Lyon, France
11. Hôpital Necker – Enfants Malades, Paris, France
12. University Hospital Bonn, Department of Epileptology, Bonn, Germany
13. Epilepsy Centre, University Hospital Freiburg, Germany
14. IRCCS Institute of Neurological Sciences of Bologna (INSB)-AUSL di Bologna, Italy
15. Azienda Ospedaliero-Universitaria A. Meyer, UO Neurologia Pediatrica, Florence, Italy
16. Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy
17. Fondazione Istituto Neurologico Nazionale Casimiro Mondino, Pavia, Italy
18. Ospedale Pediatrico Bambino Gesù, Rome, Italy
19. University Medical Center Utrecht, Brain Centre Rudolf Magnus, Utrecht, Netherlands
20. The Children's Memorial Health Institute, Warsaw, Poland
21. Centro Hospitalar e Universitario de Coimbra, Portugal
22. Centro de Referência de Epilepsias Refractorias, Hospital de Santa Maria, Lisbon, Portugal
23. Centro Hospitalar do Porto, Porto, Portugal
24. Alexandru Obregia Clinical Hospital Bucharest, Romania
25. Hospital Sant Joan de Deu Hospital Clinic, Barcelona, Spain
26. Hospital Del Mar-Parc de Salut Mar, Barcelona, Spain
27. Hospital Universitario y Politécnico La Fe, Valencia, Spain
28. Sahlgrenska University Hospital, Gothenburg, Sweden

Affiliated Partner Organisations

1. International Bureau for Epilepsy
2. Paracelsus Medical University, Salzburg, Austria
3. Danish Epilepsy Centre / SCORE Consortium, Dianalund, Denmark
4. Universitätsklinikum Erlangen, Germany
5. Irish Centre For Fetalpediat and Neonatal Translational Research, Cork University Maternity Hospital, Cork, Ireland
6. Dravet Italia Onlus, Verona, Italy
7. Centre Hospitalier Universitaire Vaudois, Lausanne, Switzerland
8. Matthew's Friends Clinics for Ketogenic Dietary Therapies, Lingfield, UK

ANNUAL DUES 2018

Chapter dues for 2016 are now overdue. If your association has not yet paid, it is important to do so as soon as possible. Dues payments are important in funding IBE activities and, for the first time in 11 years, there is a small increase to the dues levels this year.

Another major change is the option to make dues payments in Euro and we would encourage as many chapters as possible, in particular chapters based in Europe, to choose this option in order to reduce bank charges. The new dues levels are:

- **Chapters: US\$175/€150**
- **Associate Chapters: US\$125/€105**
- **Subsidised rate: US\$30/€25.**

In addition, more than 30 chapters based in developing countries will continue to have their dues payments covered by the Solidarity Fund. When settling your dues payment, we would earnestly ask that you consider a donation to the Solidarity Fund to help us to continue to support those chapters who have very limited financial means.

Please contact ibeexecdir@eircom.net with any queries on how to make your association's payment.

The banner features a background image of the European Union flag (a blue field with twelve gold stars) waving in front of a modern glass building. The word "epiXchange" is written in a large, white, sans-serif font across the top. Below the image, the word "Conference" is written in white on a dark blue rectangular background. Underneath that, the text "Seven Projects | One Day | One Place" and "23 May 2018, Brussels" is written in white on a pink rectangular background.

epiXchange

Conference

Seven Projects | One Day | One Place
23 May 2018, Brussels

REPORT IN NEXT ISSUE OF IE NEWS

One-day conference in Brussels that showcased the major findings from seven large European epilepsy research projects

DESIRE EpiCARE EpimiRNA EpiPGX EPISTOP EPITARGET Epixchange