



INTERNATIONAL
EPILEPSY NEWS

ISSUE 4 - 2019

Friendship and Inclusion
Celebrating International
Epilepsy Day 2020

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FROM THE EDITOR

The dust has yet to settle on International Epilepsy Day 2020 as I write this short message to you, dear readers. Yet, it is already clear that this has been the best year yet for this important calendar date. IBE and ILAE chapters, epilepsy self-help groups, bloggers, doctors, hospitals and clinics, and all stakeholders all got involved with a vast array of activities. We had the chance to see the Colosseum in Rome turn purple and spell out International Epilepsy Day and witness the roof of a skyscraper in London lit up with the International Epilepsy Day logo! And this is just the tip of the iceberg. In the next issue of IE News, we will bring you a gallery of some of the best photos from the day.

But for the moment, we are concentrating on celebrating the results of the art competition. You can find the winning images on page 4 and we also feature one on the cover.

Also in this issue is a short report on the WHO Executive Board meeting when epilepsy and the need for a Global Plan for Epilepsy was on the agenda. You will be hearing more on this over the coming weeks in advance of the World Health Assembly in May. There's a report from China, tips on how to make your own video, we introduce YEAH (Young Epilepsy Advocates Hub) and introduce our new Vice President North America, Mrs Susan Pietsch-Escueta, following the resignation of Phil Gattone from Epilepsy Foundation and his change of career path.

And there's more....!

Happy reading!

Ann Little
Editor



CONTENTS

4
FRIENDSHIP
& INCUSION
Art Competition
results



8
REPORT
FROM CAAE
International
Epilepsy Forum

10
A DAY IN THE
LIFE
Sharing your
video



12
GENEVA
REPORT
WHO Executive
Board discusses
epilepsy

14
GETTING IN-
VOLVED WITH
ePAG
ERN for epilepsy



16
YEAH IS
LAUNCHED
New online plat-
form for young
adults

18
MEET SUSAN
Introducing
new VP Susan
Pietsch-Escueta



19
MAURITIUS
Congratulations
on prestigious
award

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PRESIDENT'S MESSAGE

DEAR FRIENDS

The holiday period is now well behind us and 2020 is moving forward at breakneck speed. As are activities at IBE!

As 2019 came to a close, we learned with disappointment that our Vice President for North America was stepping down due to a change in career direction. Phil Gattone had been a member of the IBE board for 6 years, during which time he had brought to it his expert knowledge in leading one of the world's largest national epilepsy associations – Epilepsy Foundation in the US. His vast experience will be greatly missed, but I am delighted to welcome his successor, Susan Pietsch-Escueta, who will replace him.

In late January, we held our annual Board meeting, in London, to discuss what we had achieved in the previous year and to plan for the future. Like all associations around the world, there is an on-going concern with sustainability and, with this in mind, one of the important decisions taken at the meeting was the creation of a task force to specifically address this.

Our EpilepsyNext programme is growing in strength. This year we will present Golden Light Awards at three regional congresses – Medellin, Colombia; Toronto, Canada and Fukuoka, Japan. Already the chapters in Latin America have been invited to nominate a candidate from their country to receive the award in Medellin in May and, in the coming months the North American chapters will choose their candidates for the Golden Lights in Toronto, while chapters in the South East Asian and Western Pacific regions will receive a call for nominations for Fukuoka later in the year. Still on the subject of EpilepsyNext, the TEA Room module has had a complete revamp. Now known as YEAH (Young Epilepsy Advocates Hub), we have an online Facebook platform for young adults under the age of 30 to meet others to discuss issues of common interest.

I don't have to mention International Epilepsy Day, as I am sure you have been busy with this great initiative in recent weeks. The culmination of our combined efforts ensured that International Epilepsy Day 2020 was the best yet! This is a fantastic opportunity for us to raise awareness, as well as funds, in a vast array of activities across the globe. Well done to everyone involved!

Epilepsy has been on the agenda in Geneva too – in a very important way. After many months of effort by chapters to encourage their health ministries to support the call for a Global Plan for Epilepsy and inclusion of this agenda item at the World Health Assembly in May, I am pleased to report that a large number of countries spoke in its favour when the issue was discussed at the WHO Executive Board meeting in Geneva on 7th February. Action



Amos, IBE Vice President Africa, represented us admirably at this meeting, speaking with passion when delivering the IBE statement. You will be hearing more about this in the coming weeks; for now I would like to thank those chapters who got involved in this effort. Without your support, we may not have had the same impact. So, thank you all!

With best wishes

Martin Brodie
President, IBE



Friendship and Inclusion

Art competition to celebrate International Epilepsy Day

ANNOUNCING THE WINNERS!

We are delighted to announce the winners of our art competition, organised to celebrate International Epilepsy Day. More than 200 entries were received from 33 countries around the world, showing just how popular drawing and painting are as an activity for all age groups.

Open to everyone, the competition had three categories – under 8 years, 8 to 15 years, and 16 years and older. In each category, the winner will receive a prize of US\$250, with four runners-up prizes of US\$100.

The judges praised the talent of the artists and found selecting the winners extremely difficult. All entries feature in a special gallery on the International Epilepsy Day website internationalepilepsyday.org, so you can judge for yourself!

Thank you to everyone who took part and congratulations to the winners!



1

CATEGORY: UNDER 8 YEARS

1. 'Friendship Rainbows'
Samuel Correia (7), Portugal
2. 'Friendship and Inclusion'
Hirunodi Sawindya Thennakoon (7), Sri Lanka
3. 'Art and epilepsy'
Sunjoy Chanel So (6), Philippines
4. 'Friendship and Inclusion'
Wong Tsz Tat Davis (3), Hong Kong
5. 'We are friends forever, no matter what'
P B Lavindu Kithnuka (7), Sri Lanka



2



3



4

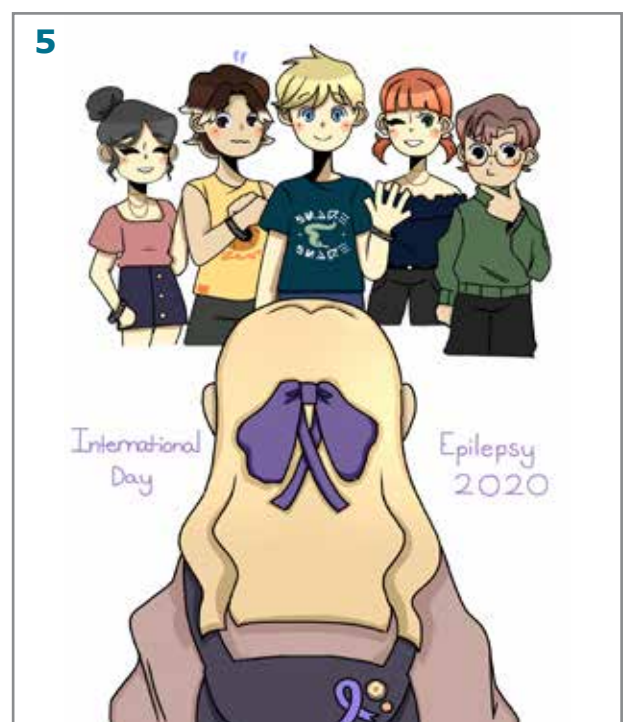


5



CATEGORY: 8 to 15 YEARS

1. 'Love what we have'
Chi Tin Cheng (11), Hong Kong
2. 'International Friends'
Kothari Dikshita (14), India
3. 'Friendship and inclusion'
Indunadee Dewdunya Thennakoon (9),
Sri Lanka
4. 'Friends in need... extending hands of
empathy'
D M T V Dissanayake (11), Sri Lanka
5. Untitled
Kiara Higginson (13), Australia



CATEGORY: 16 YEARS AND OVER

1. 'Heart of service'
Aja Mills, United States
2. 'A place of peace'
Rebecka Lamb, United States
3. 'Big Love'
Justin Mogler, Australia
4. 'True friendship, love and belongingness come when the need for the same is vital'
A A R Nethmi Adhikari, Sri Lanka
5. 'We Belong to Each Other, Both Heart and Mind'
Ramilita Galeos Sacerdoti, Philippines



CAAE INTERNATIONAL EPILEPSY FORUM

Tomas Mesa, IBE Vice President Latin America, reports on the 8th CAAE forum held in Qingdao, China



In October 2019, I was invited by the China Association against Epilepsy (CAAE) to attend the 8th CAAE International Epilepsy Forum in Qingdao, a beautiful city in the north of China.

At the Forum opening ceremony, the biggest applause was given to Lin Jianxu, a 12-year-old-boy who struggles with epilepsy. With the support of his family and working staff, Lin took to the main stage, and played a piece of Chinese Zither music with a high level of confidence and elegance, that won thunderous applause. Although blind from birth and then diagnosed with epilepsy, Lin

still vigorously pursued his musical dream, fighting against his epilepsy with the help of his family and doctors, bringing calm and healing to his life with flowing notes.

As a disease that was first recognised in ancient barbaric times, epilepsy is often still be misunderstood. According to China's latest epidemiological data, the overall prevalence rate of epilepsy in China is 7.0%; the annual incidence rate is 28.8 per 100,000, and the prevalence rate of active epilepsy is 4.6%. Based on these data, it is estimated that there are about 9 million people with epilepsy living in China, of whom between

5 and 6 million are patients with active epilepsy. In addition, there is an annual increase of about 400,000 new patients with epilepsy. Epilepsy in China has become the second most common neurological disease, next only to head-

ache. According to the Global Epilepsy Report released by WHO in 2019, epilepsy was cited multiple times as a disease that results in stigmatization; people with epilepsy are easy to be discriminated against, even having their rights infringed.

The "Patient Care Symposium" took place in parallel to the scientific conference, This symposium is now in its 5th year, having been established by the International Epilepsy Forum in 2011. Both meetings take place biennially.

Professor Hong Zhen, President of CAAE, mentioned "quality of life" and "social responsibility" several times within his six-minute speech at the beginning of the symposium. He said: "Discrimination influences the patient's normal social life, and therapy for epilepsy should not be limited to controlling the medical symptoms; instead, we should strive to strike a balance between onset control and an improvement of quality of life". As an expert epileptologist, epilepsy is not terrifying to Professor Hong's eyes; what's terrifying is something other than the disease, he explained, "Epilepsy affects not only the medical arena, but society as a whole; deep-rooted social prejudices and public discrimination can lead to misfortune and setbacks in the family. There are fewer



Lin Jianxu, who has epilepsy and is also blind from birth, plays the Chinese Zither at the Opening Ceremony

opportunities for education and employment for the person with epilepsy and this seriously impacts on the physical and mental development of patients with epilepsy, and can result in a burden to the patients' families, and society as a whole. “

An epilepsy nurse, Ms. Li Xiaoning, shared a story of what had happened in XiJing Hospital in Xi'an city, about how she had helped an 18-year-old girl and her family to deal with the disease. As a nurse with psychiatry training, Ms. Li understood the mood and emotional instability of people with epilepsy and their families, which was behind the EEG curves: stigma and discrimination. “When you understand with how many things they were burdened, you will understand them well”, Ms. Li said, “people with epilepsy have quite serious psychological and psychiatry problems, which is even more severe than the effects of the disease itself, therefore psychological support and intervention is very important”.

Living with epilepsy, the life of patients and their carers can be very different. Chensu, a lady with epilepsy from Changchun, joined the patients caring group in 2016, and has been encouraged and supported by doctors and her family. Now, she is enjoying her life as an English teacher and an oil painting lover as well. She said: “epilepsy doesn't affect my normal life; instead, it teaches me to be grateful—being grateful to my family for their acceptance and care, which let me understand the meaning of the word ‘cherish’; therefore, I want to thank the disease, for it's such a life-changer.”

Like Chensu, the story of Bin was also awash with gratitude. A tragic and heroic life trajectory begun again from epilepsy: his seizure came after an attack of cerebral haemorrhage. He and his mother suffered an extremely difficult time treating his health problems. When his condition improved, Bin also joined the caring group. He did lots of work in translating articles published in the “International Epilepsy News” from English to Chinese, to help Chinese people with epilepsy to understand the epilepsy care community and to be able to read stories of people with epilepsy from foreign countries. “Just treat the disease as part of your body and try to accept it”, Bin said, “you know the worst outcome would be no more than seizure, after which you can always come back again.”

After hearing the personal stories of these outstanding people with epilepsy, Dr. Hidemoto Kubota from Japan and I were warmly welcomed by the audience since we were sharing the experiences from our countries.

Dr. Kubota is from the National Hospital, Shizuoka Institute of Epilepsy and Neurological Disorders, Uru-shiyama, Aoi-ku Shizuoka, Shizuoka, Japan. His topic was “Social support for people with epilepsy: driving issues in Japan”. Social ignorance and discrimination make it difficult for people with epilepsy to integrate into society. People with epilepsy also face many kinds of problems in the inter-cultural period. Dr. Kubota briefly reviewed the current Japanese social support systems for people with epilepsy, especially the driving legislation issue. For example, since 2002 in Japan, people with epilepsy are allowed to hold a driving license if they are seizure free for more than 2 years, or can prove that their seizures occur only during sleep for more than 2 years, and can also prove that these seizures neither impair consciousness (simple partial seizure) nor affect their ability to drive for more than 1 year. He concluded that, “social support for people with epilepsy is important, and doctors should be aware regarding the social resources, social welfare systems, and laws for people with epilepsy”.

I introduced the Chilean League against Epilepsy (LICHE), a non-profit organization, founded May 6th, 1953. The mission is to improve the quality of life of people with epilepsy, their families and caregivers, through medical and psychosocial treatment, as well as through education, training and rehabilitation. The structure of LICHE, is a board of directors composed 50% by physicians (including the President) and 50% by non-physicians volunteers. LICHE has 270 salaried employees 300 unpaid volunteers with 16 local groups across Chile. For more than 30 years, the Chilean League has been developing a successful model of economic administration. This allows self-financing and a major benefit in providing education



Drs Ding-Ding, Tomás Mesa, Hong Zhen (Congress President), Li Shichuo, Hui Gao and colleagues

and treatment to thousands of people with epilepsy in Chile and has been achieved through the “Drug Bank” initiative. It is a system developed to help people with epilepsy, therefore is based on solidarity. Neurologist or psychiatrists from the private health system prescribe drugs to their patients who buy it at a cheaper price at the drug bank. LICHE has the availability of all prescription drugs (AEDs and others), at a lower price in comparison to private pharmacies. Patients who have low economic resources to sustain their treatment receive reduced priced or totally free drugs and services. Dr Mesa mentioned the LICHE educational video “The Story of Juanito” which is used to educate primary- and secondary-school students about epilepsy through audio visual techniques according to their language, interests, attention span and understanding.

At the end of the symposium, Prof Ding Ding said: “nowadays, comprehensive management modes mainly focus on epilepsy, with anti-seizure therapy as a foundation, as well as the integration of resources including clinicians, caregivers, and social workers, by which can we help improve skills, health conditions and quality of life for patients with epilepsy.”

“To cure sometimes, to relieve often, to comfort always”, the epitaph of Doctor Trudeau is the reality of doctor-patient relationship in the cause of fighting against epilepsy in China. Doctors engaging in epilepsy therapy have been striving to do more for patients with epilepsy beyond the disease itself, including helping them realize the value of their life. It's doctors top values that have always been shining in the field of epilepsy in China.

A Day in the Life...



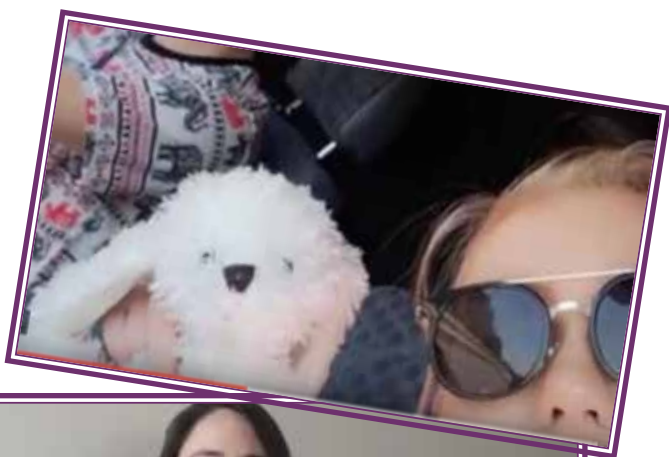
Share your video and help raise awareness

For International Epilepsy Day 2020, we invited people to create and share short personal advocacy videos. This came about as an initiative of the young adults who had attended the EpilepsyNext Young Adults Workshop ‘Hear My Story’, that took place in Dublin last October. The idea was to create short videos about the daily life of people living with epilepsy or caring for someone who has epilepsy.

While International Epilepsy Day is now over for another year, there is still the opportunity for you to make a share a short video telling us how epilepsy affects your everyday life and how you deal with the challenge. Because every day is a good day to raise awareness about epilepsy!

The most important part about making a video message is to share your personal story. We want to increase the public’s understanding of how epilepsy affects people as they go about the day - the challenges they face and their strategies for overcoming these. No one can explain epilepsy better than the person who has the condition. Everyone’s day is different and everyone’s story is unique, so please tell us your story in whatever way is most comfortable for you.

Need inspiration? You can enjoy some of the videos already created at <https://internationalepilepsyday.org/epilepsy-stories/>. And, if you need encouragement to get involved or are not sure how to get started, you’ll find some tips on the next page!



Making your first personal video? Here's how:

Plan your message

It's best to plan your video's message and make notes of what you would like to say. Choose a theme and identify the key message you wish to share. Don't want to share your day? Your video could focus on one of many other themes. Some examples include:

- something you would like people to better understand about epilepsy
- the story of your diagnosis
- how epilepsy has affected your work or education.

The only thing we would ask is that you don't make medical recommendations when sharing your story.

Practice your message before recording to help you keep on point!

Keep it brief

People have quite short attention spans, so they are less likely to watch longer videos. Video for Instagram should be a maximum of 1 minute long. This could be limiting, so if you have a number of points to communicate you might consider creating a series of short videos. For a longer video we would recommend a maximum length of four minutes. This can be shared on YouTube and Facebook.

A Quiet Space

Find a calm and quiet space to record your video message, not only will this make things more comfortable for you, but it will also mean that the audio is nice and clear. Make yourself comfortable too! And try not to speak too quickly.

Framing the Shot

You can use whatever you like to record your message, whether it's an iPhone, Webcam, etc. It's always best when using a camera phone to place it horizontally as it will look best on Youtube this way.

If you find it awkward to hold the camera while recording your

message, ask a friend to help or prop it up on a desk or shelf. Webcams can be a good alternative.

Remember that you do not have to feature in the video if you prefer not to; instead you can have a background image(s) such as a scenic shot of the countryside or city that you live in with your voice recorded while the video captures the scenery.

Language

Videos can be created in any language. If creating a video in your own language please also consider creating a version in English, if possible. For videos created in languages other than English, please send us a transcript of the text that can be converted into subtitles by our team.

Sharing your video

Your video can be shared through your personal social media accounts. Videos can be shared directly to Instagram, Twitter and Facebook. You can also upload your video to YouTube. Please make sure you tag your video with the '#epilepsyday' hashtag. You may also like to include other keywords such as #epilepsy, #epilepsyadvocate, and any other words you find appropriate.

If possible, tag the appropriate International Epilepsy Day social media account (@intepilepsyday – Twitter/Insta, @epilepsyday – Facebook), so we can find and share your messages!

If you are not a social media user, but would like to be involved, you can email your videos to elizabeth@ibe-epilepsy.org. We will not share your name or personal details, unless you give us prior permission to do so.

Photos:

Clockwise from left: Nina Mago (Uganda), Emma Larsen (Norway) and Scarlett Paige (Australia), three Golden Lights who have already shared their personal videos. Now it's your turn!



Report from the WHO Executive Board Meeting Geneva

From the notes of Action Amos, IBE Vice President Africa

Photo left: Action Amos, Sam Wiebe, ILAE President, and Alla Guekht, ILAE Vice President, at WHO Headquarters in Geneva

INTRODUCTION

After several months of effort by IBE and its chapters as well as ILAE and its chapters, on 7 February 2020 the need for a Global Plan on Epilepsy was discussed by the WHO Executive Board at its annual meeting in Geneva.

Arriving in Geneva two days prior to the date set for the formal discussion at the WHO Executive Board, provided the opportunity to meet with country representatives to discuss with them the urgent need to make epilepsy a healthcare priority and to seek their support. Having national representatives speak in favour of the motion (and, better still, to have them declare the wish of their country to act as a co-sponsor to the motion) is vital to the success of any proposed activity.

As IBE Vice President for the African region, and as a person living with epilepsy, Action Amos was well-placed to seek out meetings with country representatives from his region and to present his case. In this he was highly successful, meeting with representatives from eight African countries, all of whom promised their support when the agenda item came up for discussion. He met with:

1. **Dr Simon Mfanzile Zwane**, Principal Secretary, Eswatini
2. **Ms Bawelili Philomena Simelane**, First Secretary, Permanent Mission of Eswatini
3. **Dr Kennedy Malama**, Permanent Secretary, Zambia

4. **Dr J Wekesa Masasabi**, Director General for Health, Kenya
5. **Dr Didier Agossadou**, Permanent Secretary, Benin
6. **Dr Theophile Olivevier Bosse**, Second Counsellor, Cameroon Mission and Coordinator of the AFRO Region in Geneva
7. **Mr Loudon Overson Matiyya**, Deputy Ambassador of Malawi
8. **Mr Martin Essono Ndoutoumou**, Directeur Général de la Planification des Infrastructures Sanitaires et des Equipements, Gabon

ACTION AMOS EXPLAINS

In addition to these face to face meetings, the WHO AFRO Region held a meeting on 5 February where it discussed the Epilepsy Agenda Item EB146/11 and unanimously agreed to support the development of a Global Action Plan. The Cameroon and Eswatini Missions (Geneva), as Coordinator and Secretary respectively of the African countries, volunteered to support an engagements on epilepsy in Geneva if we need their support in the future.

As noted above my main strength was engagement with the African Region more than other regions. These engagements assisted in creating a network of key influential supporters in the African region that will support our cause in the future.

PLENARY DISCUSSION

The agenda item 'epilepsy' was discussed by the Executive Board on 7 February with

a tremendous level of support by country members and non-members alike. Some of those who spoke, confirmed that their support was being presented on behalf of a number of countries (either whole WHO regions and a number of countries within a region - see box on facing page).

The decision taken was to request the WHO and Member States to develop a document (WHO Technical Policy Brief) on epilepsy and its comorbidities and to develop and present a new Resolution "Epilepsy and Other Neurological Disorders" at the World Health Assembly in May.

WAY FORWARD

At the 'post-mortem' meeting involving the IBE and ILAE representatives, Prof William Carroll, President WFN and Dr Taurun Dua (WHO) it was highlighted that the WHO Director General Report that was discussed can now be used as reference in our advocacy work.

For now, there are some tasks to be addressed:

1. WHO to develop a Technical Guidance Policy based on the Director General report of 6 February. IBE and ILAE were requested to support the development of this guide.
2. Develop and present to the WHA in May, a new Resolution on "Epilepsy and other Neurological disorders".
3. If Member States agree to the request for an Action Plan then this will be developed after the WHA in May, aiming for its approval in January 2021.

IBE STATEMENT TO THE WHO EXECUTIVE BOARD 6 February 2020

Delivered by Action Amos, IBE Vice President Africa

My name is Action Amos and I live in Malawi. I am also a person living with epilepsy. I am here today speaking on behalf of the International Bureau for Epilepsy.

The International Bureau for Epilepsy represents 140 patient education and advocacy organizations worldwide. We work to ensure that the human and civil rights of people with epilepsy are enhanced and protected.

In every part of the world, people with epilepsy and their families suffer from human rights violations, stigma, social isolation, seizure related injuries and systemic discrimination. Persons with epilepsy have access barriers in schooling, employment and health care.

We are here to work with member states to develop plans and policies to create a world where understanding and care replace ignorance and fear of epilepsy.

Epilepsy affects people of all ages and all ethnicities. Close to 80% of the 50 million people living with epilepsy live in low- and middle-income countries. It is unacceptable that 75% of people with epilepsy living in low- and middle-income countries do not have access to treatment. Without access, these people will continue to live in poverty and be at risk of premature mortality.

WHO demonstration projects have indicated that it is possible to diagnose and treat most people with epilepsy at the primary health-care level without the use of sophisticated equipment. To do this we need to have a commitment from governments that epilepsy is a public health priority. The 2019 Global Report “Epilepsy a public health imperative” outlines concrete plans for the way forward. It calls for a commitment from member’s states and the Director-General to develop a set of essential immediate recommendations to strengthen country actions against epilepsy and its comorbidities. This commitment will reduce premature deaths, promote mental health and well-being, reduce stigma, achieve universal health coverage and ensure access to quality services and affordable medicines.

The time to act is now.



Countries acting as co-sponsors

1. Russian Federation
2. Republic of China
3. Guyana
4. Tajikistan
5. Eswatini
6. Zambia
7. Chile
8. Germany (also representing the 26 other EU member states)
9. Kazakhstan
10. Honduras

Countries speaking in support

1. Finland (also representing 7 other Nordic countries)
2. Gabon (also representing the 46 other AFRO countries)
3. Italy
4. Japan
5. Tunisia (also representing 21 other EMRO countries/territories)
6. Australia
7. Georgia
8. Indonesia
9. Sudan
10. Thailand
11. Iran
12. Turkey
13. India



EPILEPSY DAY

EPILEPSY THE MOST COMMON SERIOUS NEUROLOGICAL CONDITION IN UK AFFECTING MORE THAN 600,000 PEOPLE ACCORDING TO EPILEPSY SOCIETY

07:16 YARD OF TRAINER SIMON CRISFORD

BREXIT CRISIS: PRIME MINISTER THERESA MAY HAS ACCEPTED THE OFFER OF

GETTING INVOLVED WITH ePAG!

Torie Robinson, Motivational Public Speaker and CEO of Epilepsy Sparks

As a person with “regular” temporal lobe epilepsy’ and as someone who was just trying to get on with one’s life, I hadn’t ever heard of rare and complex epilepsies.

Who has heard of Tuberous Sclerosis^{2?} Or CDKL5^{3?} Or Ring2^{4?} If you have – I take my hat off to you! Prior to my involvement with EpiCARE⁵, I hadn’t heard of any of these types of rare and complex epilepsies – the research into which has now identified approximately 130 rare diseases (and counting!)⁶. I wish that I’d read about/heard of rare and complex epilepsies sooner (thank you so much to Allison Watson⁷ for introducing me to this world!).

The set-up

The EpiCARE European Reference Network (ERN) is an European Union (EU) funded body which was set up to collate the scarce, reliable, cutting-edge clinical knowledge⁸ about rare and complex epilepsies from all around Europe in order to make it accessible to healthcare providers. After all, a person should receive as accurate a diagnosis and treatment advice as possible, no matter their EU location.

In addition to the above, there is the EpiCARE European Patient Advocacy Group

(ePAG) that involves patient representatives and related charities (if you know one: get them to contact us⁹!); getting us together to have the patient voice heard and taken into account regarding treatment and care. Of course, we are essential because rare and complex epilepsies are more than just a diagnosis and treatment – patients and carers live with their rare and complex epilepsy 24/7.

How I relate

Since becoming a member of the European Patient Advocacy Group for EpiCARE, I’ve learned how much in common I, and millions of others with a general epilepsy, have with those with rare and complex epilepsies. Don’t get me wrong – I am very conscious that we have differences, but we all take antiepileptic drugs¹⁰ (AEDs); lots of us have refractory epilepsy¹¹; many of us have mental health issues and sleep disorders¹² (and often need to take drugs for those too); lots of us have cognitive impairments¹³ or/and a learning disability¹⁴; and our loved ones worry.

When you have a rare disease, the loneliness felt by both those with the diagnosis and loved ones can be overwhelming.

That’s why, in November 2019 I delivered a keynote speech¹⁵ on depression for the Tuberous Sclerosis Association¹⁶ in Nottingham, UK. I spoke to many families, carers and people with Tuberous Sclerosis (TS) and together we said: “We have so much in common!”. I’m so, so lucky to not have brain tumours (or indeed any other type of tumour), but, around 80% of people with TS have epilepsy¹⁷ – and so do I. Some people with TS have neurosurgery – as I have had. Lots of people with TS experience depression¹⁸ – as do I. Lots of people with TS have negative side effects of AEDs¹⁹ – as do I.

Lots of us also had a laugh about things other than TS, epilepsy or mental health – and this I think is so, so important! People smiled and friendships were built.

You aren’t alone

What I’ve gathered from several other ePAG members is that they really appreciate knowing that they are not alone. That they are not the only ones struggling to cope with seeing the one they love experience such an awful illness(es) that can’t yet be cured. That they are exhausted from lack of sleep, stress, and their own consequential illnesses. That they must re-

volve their lives around their loved one who has the rare and complex epilepsy (plus everything else). That they do love them 'to the moon and back', but life is so unfair for both parties. And it is.

We ePAG members bring together personal experiences, and those of other families affected by rare epilepsies, to the attention of EpiCARE and thereby influence change. We take the time to learn about each members' rare and complex diseases and the challenges that they bring (including physical, physiological, neurological, psychiatric, social, and economic), then advocate for all! We give families a voice – and will do so even better with your support: let's work together!

Email us for more information!

What I've gained so far

- I've met some wonderful people in both the ePAG and the ERN from around the EU; all of whom take serious time out every week to contribute (in addition to their regular workload). Each time I think of them and their families, I am inspired;
- I've started doing talks with rare epilepsy organisations and met some wonderfully inspiring people in the process with whom I'm still in touch!
- I've added a "rare epilepsies"²⁰ section to the Epilepsy Sparks website²¹ to encourage awareness – and the list is growing! Epilepsy Sparks has now even become a Friend of Rare Disease Day²²!
- I've identified a personal interest in genetics, epigenetics²³, and mutations – e.g. how one or both biological parents don't have to have a certain gene mutation to pass on to their child but how the gene can mutate in the foetus. It's so interesting!

Ready, Set....

If you are, or if you know anyone who is affected by a rare and complex epilepsy, then please join us on our journey of caring, learning and empowering! We know that rare and complex epilepsies can be much harder to diagnose than general epilepsies, that AEDs are much less likely to be effective, that comorbidities²⁴ occur at a higher rate, and more. We want you to know that you needn't feel as alone in what you are going through.

Go!

- We have new webinars coming up! These will involve medical professionals such as Prof Helen Cross and Prof Alexis Arzimanoglou²⁵, and us Patient Engagement members (those of us with a family member affected by a rare and complex epilepsy). Watch out for our sign up details in 2020!
- We are planning a greater social media presence to make information more accessible for everyone. Follow us on Twitter²⁶, Facebook²⁷, or LinkedIn²⁸!
- We have a newsletter all about rare and complex epilepsies - email us to be added to the distribution list.
- Do you know any rare epilepsy organisations in Europe who aren't yet part of EpiCARE? Get them to join our patient community by applying through EURORDIS.
- Please join us in our quest to support those affected by a rare and complex epilepsy, and if you have any ideas for our blogs, webinars, etc., then please get in touch using the contact details above. We'd be delighted to hear from you!

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YEAH
Young Epilepsy Advocates Hub
COMMUNITY



Young Epilepsy Advocates Hub

Are you a person with epilepsy aged under 30 years?
Interested in getting in touch with others like you?
Then YEAH could be the answer!

Launched by IBE, YEAH is an online space to meet
and chat with others.

Join us on Facebook

<https://www.facebook.com/YEAHepilepsy/>

and there is also a closed group page for member discussions

<https://www.facebook.com/groups/YEAHepilepsy>

YEAH is already live - so, what's keeping you?!

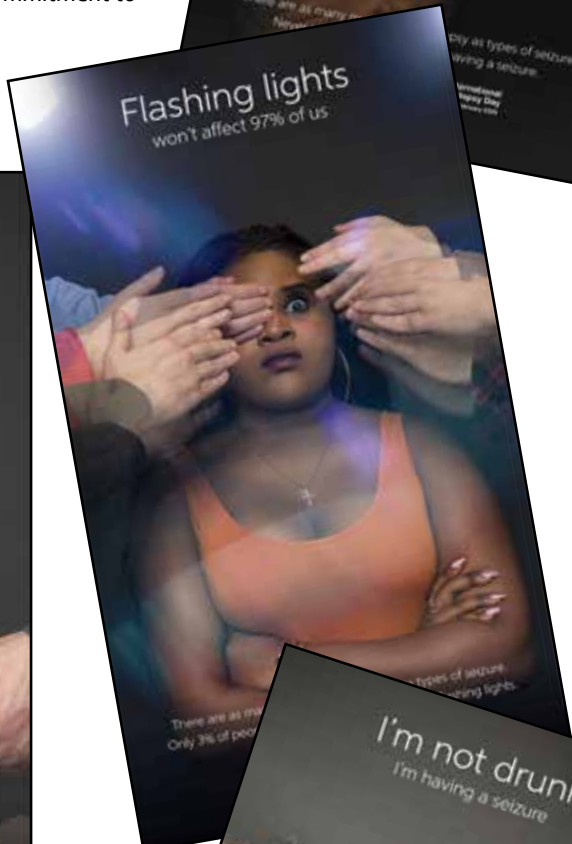


EYE-CATCHING CAMPAIGN for International Epilepsy Day

Epilepsy Ireland has launched a new poster campaign to mark International Epilepsy Day 2020. Featuring four young adults who have epilepsy, the posters take a wry look at four common misconceptions, or poorly understood facts, about epilepsy:

Two of those who appear on the posters, Lorraine Lally (below) Debra Marino (centre right) participated in the Young Adults Workshop, organised by the IBE European Regional Executive Committee in Dublin last October, where their commitment to raising awareness through positive action was clear to see.

The posters were published in prime positions in the principal Irish national daily newspapers, guaranteeing a very large audience. Congratulations to all involved!





Introducing Susan Pietsch-Escueta IBE Vice President North America

Following the resignation of Phil Gattone from Epilepsy Foundation, and his stepping down from the IBE Board, we are pleased to introduce you to Mrs Susan Pietsch-Escueta MPH, who took over the his role at IBE in January.

If you had asked me 40 years ago – “what are your professional goals?” I would probably have responded “something to do with international health”. And that’s fairly close to what happened. After all, the epilepsies are an international public health problem, affecting people of all races and ethnic groups worldwide. Los Angeles is almost a microcosm of the world so, in a sense, I have spent my career in “international health” even though I have focused on epilepsy and remained in Los Angeles.

My undergraduate degree is in Community Health Education and

International Relations, and I got my graduate degree in Public Health from UCLA where I focused on International, Population and Family Health. For over 30 years, I’ve enjoyed a rewarding career advocating with and for individuals and families affected by the epilepsies. I worked at three epilepsy centers in LA and, since 1996, I’ve worked for the Epilepsy Foundation in LA and now for the Epilepsy Foundation national office.

I have four areas of rich influence: my parents, my husband, our co-workers and colleagues, and the many individuals affected by

epilepsy and their families whom I have met over the years. My parents were missionaries in Pakistan for 36 years. They raised four of us children there, and set a great example of dedication to a mission. My husband, Antonio Delgado-Escueta, is a professor of neurology at UCLA, and he continues to devote his life to solving the epilepsies. Besides evaluating and treating patients in the clinic, he does research to understand the genetic basis of some epilepsies with the goal of finding cures. I'm inspired by his singular focus. And along the way, I have been blessed to make friends with his friends and collaborators working in epilepsy care and research in many countries around the world. We both work with amazing people who share our passion for this cause.

I've also met so many individuals and families affected by epilepsy who motivate me daily. Their resilience inspires me. I've been with parents who keep pursuing treatment options relentlessly. I've met teens who find their voice and confidence at Teens Speak Up. I've seen and heard life-changing stories of kids making friends at camp. I've known amazing volunteers who step-up to create change.

One of my current priorities is working with a small team to take our END EPILEPSY® campaign across the USA with the Epilepsy Foundation. We're focusing attention on the brain – "Let's Use Our Brains to END EPILEPSY" because the brain is our common ground with everyone. The brain is the source of epilepsy and the source of the solutions to END EPILEPSY. We highlight the brain and stories of epilepsy in order to combat the ignorance and amplify awareness about epilepsy.

We all agree that for too long people with epilepsy have endured in hiding and silence, and suffer from the lack of awareness, attention and research. Let's keep fighting together for something greater for people with epilepsy – worldwide. As one example, it's great to see how more and more people are engaging in International Epilepsy Day.

This is an informal photo of me with my Brain Art. I invite my colleagues in the IBE to create your own Brain Art at EndEpilepsy.org/BrainArt. Our next phase is to create a few key words in other languages and I am sorry we aren't ready with that yet.

Key Messages

In Los Angeles, we did an informal survey on social media and asked people affected by epilepsy: "What is the most important thing that you want everyone to know about epilepsy?" We then collated the responses and these five ranked at the top.

1. The epilepsies are more common than most people realize. The epilepsies affect men and women of all ages, races, creeds and socio-economic backgrounds. Anyone can have a seizure and develop epilepsy. Know the facts and learn Seizure First Aid.
2. Even though epilepsy is often invisible, there is an emotional, social, mental and/or financial toll that affects each family differently. Learn the deeper story about living with epilepsy.
3. A person is more than their epilepsy. Some people with epilepsy have full lives and thrive. Others face challenges in all aspects of life. Don't stereotype epilepsy or the person with epilepsy.
4. Epilepsy is not a joke or a punch line or an excuse to bully. Seizures aren't funny. Take epilepsy seriously.
5. Research for cures in epilepsy is seriously underfunded. Take action to END EPILEPSY.

I wonder how similar or different the responses would be in different countries.

CONGRATULATIONS!

Edycs Epilepsy Group Mauritius was attributed the Africa Leadership Award in Healthcare & Social Care Support at the World CSR (Corporate Social Responsibility) Day & World Sustainability Congress held in December 2019 in Mauritius.

The event, which was organised by CMO Global, brought together a hundred delegates from all over Africa comprising business entities, civil societies and the media. The Chief Guest of the award ceremony was the former President of the Republic of Mauritius, Her Excellency, Mrs Ameena Gurib Fakim.

Edycs Epilepsy Group, which was established in 1997, will celebrate its 23rd year of activities in the Republic of Mauritius as the only organisation working to support and rehabilitate persons with epilepsy in the country. Edycs Epilepsy Group is managed by a multidisciplinary team of both medical and non-medical professionals and operates two Epilepsy Support Centers for persons with epilepsy and their families, as well as two SENS (Special Educational Needs) schools

for children and adolescents with epilepsy in Mauritius and Rodrigues. Edycs Epilepsy Group is a registered chapter and has been a chapter of the International Bureau for Epilepsy for many years.



Thank You

for helping us make
International Epilepsy Day 2020
the best one ever.
Here's to 2021!

