

INTERNATIONAL EPILEPSY NEWS

ISSUE 2 - 2019

GLOBAL EPILEPSY REPORT
EMA approves cannabidiol
THE POWER OF ADVOCACY



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FROM THE EDITOR

Since the last issue of International Epilepsy News, it's been a busy time for IBE.

The biggest event was the 33rd International Epilepsy Congress in Bangkok. For IBE, a highlight of the congress was the Golden Light Awards, which was a major success. One of the eight wonderful young people who received an award, Scarlett Paige, shares her diary post-Bangkok in this issue.

Also in Bangkok, the Global Epilepsy Report was launched during a lively symposium where enthusiasm for and appreciation of the report was clear to see. The full report and a summary are available to download on the IBE website ibe-epilepsy.org.

In Europe, a major issue has been approval by the European Medicines Agency of cannabis projects as an adjunct treatment in two rare epilepsy syndromes and the ePAG group invites you to get involved.

A word of warning on the problems that the use of essential oils can cause is brought to us by Dr Thomas Mathew from India, where such products are very widely used.

Find out about recent initiatives of Epilepsy South Africa and also enjoy reading news from Bolivia, Spain, Australia and Ireland.

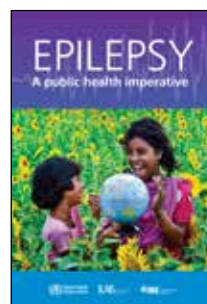
Happy reading!

Ann Little
Editor



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to be taken as advice; they are not
intended to replace medical care.

PRESIDENT'S MESSAGE

DEAR FRIENDS

I was really pleased to meet so many chapter representatives, IBE supporters and people with epilepsy and their families in Bangkok in late June when we gathered to celebrate the 33rd International Epilepsy Congress. We took the radical decision to make significant changes to the previous structure of General Assemblies in order to provide a platform for IBE to report back on the Strategic Planning Meeting held in London in January; our plans for the future based on those discussions; and, most importantly, to allow stakeholders to tell us how they would like to see IBE develop in the future. I believe that it was agreed by all that this was a very successful meeting and the enthusiasm of both our members and supporters bodes well for the future.

Also, during the assembly, we celebrated the official start of the new term of our Regional Vice Presidents. I congratulate all seven on their election and wish them well for their terms of office. In addition, we welcomed two non-elected invitees to the executive committee – Francesca Sofia from Italy and Graeme Shears from Australia.

Of all our activities in Bangkok, the highlight surely was the special International Golden Lights forum and the presentation of the individual awards to the eight International Golden Light winners during the congress Opening Ceremony. The personal stories narrated by these eight young people were truly inspirational. These young people have now returned to their countries invigorated by their time in Bangkok and are already involved in a range of initiatives to raise the profile of epilepsy in their part of the world. We plan to keep them involved in the work of IBE going forward – they are our future! My personal mission is to see 10,000 Golden Lights for epilepsy shining around the world!!

After two years of deliberation, preparation and dedication, by a large team of people, the Global epilepsy report, “Epilepsy: a public health imperative”, had an official launch during a special symposium in Bangkok. The report, and an accompanying summary document, are available to download on our website ibe-epilepsy.org. An important element in its content was the survey of IBE chapters, the results of which were incorporated in the report. This document will be a major tool for chapters and other stakeholders in supporting future advocacy work.

Just before the congress in Bangkok, I was delighted to accept an invitation from Arlette Honein, who leads the inspirational AVANCE organisation in Lebanon. This was my second visit to Beirut to speak at their annual meeting and to see again at first hand the



tremendous work she and her colleagues undertake to provide education and training to young people with epilepsy in her city.

As I write, I have just returned home from the 4th African Regional Epilepsy Congress in Entebbe, Uganda, where I attended a progress meeting of our advocacy project in 6 African countries, supported by the BAND Foundation from the USA. I also was privileged to take part in a special symposium for people with epilepsy. During the session, we videoed interviews with a number of stakeholders and these will be available to view on our website soon.

Finally, we can announce the exciting news of an unusual new initiative – the recent registration of a Scottish ‘Epilepsy Awareness’ tartan. You’ll find out more about the plans for this in the next issue of IBE International News!

With best wishes

Martin Brodie
President, IBE

THE POWER OF ADVOCACY

Scarlett Paige shares her experiences as a Golden Light award winner



On 9th of April 2019, I received an email that would allow me to advocate for epilepsy on an international scale. This would help epilepsy get the respect it deserves and, hopefully, people living with it accepted and not judged.

The email was from Ann Little, Executive Director of the International Bureau of Epilepsy (IBE), congratulating me on my success of overcoming my own personal journey with epilepsy, as well as the many voluntary

have turned their epilepsy into the power of helping others. The awards would be presented in Bangkok at the 33rd International Epilepsy Congress and, along with receiving our awards, we would each give a presentation telling our story.

From the moment the 8 of us met in Bangkok there was an instant connection that we had known each other all our lives we called ourselves the Golden Brothers and Sisters.

hours I have put into helping others right across Australia going along the same, at times, very confronting epilepsy journey.

The email stated that, for the first time, IBE would be acknowledging 8 recipients from each of the their world regions. These acknowledgements would be named the Golden Light Awards to bring a shining light to those who

“There was an instant connection - that we had known each other all our lives”

Little did we know that saying goodbye at the end of the congress would be so hard; we shed many tears, we reflected on the time we had spent together, we spoke about how much we hoped to achieve in the time before we would meet again - hopefully in Paris at the next International Epilepsy Congress in 2021

Since I have returned home to Victoria, Australia I've been involved in many advocacy projects as a result of my IBE award, the first of these was a presentation at the Epilepsy Foundation where I spoke to the staff about my personal experiences in Bangkok.



Graeme Shears, who is the CEO, showed a short video of a presentation I gave at the IBE's General Assembly.

A week later, Epilepsy Foundation asked me to write an article that would feature in their newsletter. Epilepsy Tasmania also featured my IBE nomination presentation in their latest Brainwaves newsletter. I was then approached by the Community Engagement and Fundraising Managers, Maggie and Michael, at the Epilepsy Foundation to feature in an epilepsy focus promotional video part of which would be entered into an advocacy public transport involvement program.

I was approached by the Chronic Illness Alliance of Victoria to present at a women's launch workshop called Working from our Strength. The program is designed for women of all abilities, talents and skills to find or return to employment.

I was asked to take part in a conference call with Seer, which is a science, technology and engineering team that specialise

in products and services that help with diagnosis and management of neurological disorders; this involvement was for an upcoming epilepsy forecasting awareness campaign. Seer work closely with Professor Mark Cook, a world-renowned epileptologists and neurologist and director of neurology at St Vincent's Hospital Melbourne.

The ABC Radio National, Jacinta Parsons, heard about my story and invited me to take part in a series called Life Matters on unseen illness and chronic illness. The programme will air later in September.

The Curriculum Developer and Content Writer at the Epilepsy Foundation was next to get in touch and has asked me to help in the development of the new Epilepsy Smart Workplace Program telling me that my ideas and experiences are important to develop a relevant and effective workplace program.

The final thing I have been involved in during the last 2 months was an Australian Government Department of Social Services

research evening that included 5 others with lifelong chronic illnesses. We reviewed ads that the Government will be using during the Royal Disability Commission.

So, all in all, I have been nonstop in advocating not only for those touched with epilepsy but also the rights cross the disability spectrum; none of this would have been possible without the support and acknowledgement from the IBE and the Epilepsy Foundation of Victoria.

I'm honoured to be the first Golden Light from the Western Pacific Region. Here's to many more Golden Lights.

Photos:

Main photo: awards ceremony in Bangkok, from left, Scarlett Paigne, Australia; Mohammad Agus Rahmatulloh, Indonesia; Elizabeth Dueweke, USA; Rebecca McGhee, Scotland; Martin Brodie, IBE President; Emma Lovise Larsen, Norway; Amirsoheyl Pirayeshfar, Iran; and Nina Mago, Uganda.

Opposite page: Scarlett receiving her award
Above: Preparing for interview.



Introducing EPAG for EpiCARE

Allison Watson explains the background

So, you've heard about EpiCARE the European Reference Network (ERN) for rare and complex epilepsies, but DID YOU KNOW that within EpiCARE your patient and family voices are represented by a dedicated group of 10 volunteers with a background in different rare epilepsies from across several European countries. We are your European Patient Advocacy Group, or EPAG for short.

MEET THE TEAM

"Who are these guys?" You might well ask...? Isabella Brambilla from the Dravet Syndrome European Federation leads the group, supported by Allison Watson from Ring20 Research and Support UK CIO. The team comprises both representatives that

head up patient support organisations large and small and patients themselves.

Head over to the EpiCARE website to find out a little more about the team: <https://epi-care.eu/epag/>

WHAT WE DO

We work in partnership with the clinicians and researchers within EpiCARE and are an integral part of shaping the direction of EpiCARE. We participate in the various Diagnostics, Therapeutics and Resources Work Packages (WP), bringing the patient perspective to the table and even deriving our own patient-oriented objectives.

The key areas we are actively engaged in at the moment are creating a Patient Registry

for all rare epilepsies (including helping to submit a call for funding from the EU), updating Clinical Practice Guidelines in 3 diseases, kicking off Orphanet updates through the Laboratory Diagnostics WP, following in the Dietary Therapies WP and of course Dissemination – informing all of you about the great work of EpiCARE!

MAKING OUR MARK!

We've even added our own workstream, collaborating with the healthcare professionals to create a standard set of leaflets on each rare epilepsy targeted at both healthcare professionals and patient families, which will we hope to be accessible from the EpiCARE website once completed



– all part of improving education and awareness.

Every month we participate in an online call together as an EPAG to share updates and drive forward our strategic objectives and once a year we get to meet up face to face at the EpiCARE AGM, where we present our mission and vision and also get to meet with all of the leads from the 28+ EpiCARE centres across Europe. Isabella and Allison have a place on the EpiCARE Steering Group participating in the monthly meetings too – so as an EPAG we do have a voice right at the very top!

GROWING OUR COMMUNITY

Two and a half years since the ERN's were created, it is now time to expand our EPAG Patient Community so we can truly represent the wider patient voice of all rare and complex epilepsies across Europe and this is where you come in...

Would you like to be regularly informed about the work of EpiCARE? Do you want to be consulted on unmet patient needs and/or be willing to be a patient representative for your rare disease? Would you participate in surveys to tell us more about what you want and need?

If the answer is YES, then sign up to join our EPAG Patient Community TODAY!

You can join through EURORDIS here: online registration portal it's quick and simple. The key pre-requisites are that you must be able to speak fluent English (spoken and written) and that your rare disease is listed within the 130 rare and complex epilepsies currently supported within EpiCARE.

KEEPING YOU INFORMED

Going forwards we hope to have a regular slot in this newsletter to keep you updated on our activities, how they might benefit you in the future and of course, how you can contribute.

Currently we are seeking a Patient representative for Progressive Myoclonic Epilepsies (PME) so if you think you can help do get in touch.

You can contact us on anything EpiCARE EPAG related by emailing us at: epag.epicare@gmail.com

LIKE our Facebook page to follow us on social media:

<https://www.facebook.com/epag.epicare>

Be part of something amazing TODAY, for a brighter future for all of us TOMORROW!

REFERENCES

EpiCARE the European Reference Network (ERN): <https://epi-care.eu/epag/>

European Patient Advocacy Group: <https://www.eurordis.org/content/epags>

Isabella Brambilla (LinkedIn):

https://www.linkedin.com/in/isabella-brambilla-a6428647/?locale=de_DE

Dravet Syndrome European Federation: <https://dravet.eu/>

Allison Watson (LinkedIn): <https://www.linkedin.com/in/allison-watson-661a6891/>

Ring2o Research and Support UK CIO: <https://ring2oresearchsupport.co.uk/>

Diagnostics: <https://epi-care.eu/diagnostics/>

Therapeutics: <https://epi-care.eu/therapeutics/>

Patient Registry: <https://epi-care.eu/databases/>

Clinical Practice Guidelines: <https://epi-care.eu/guidelines/>

Laboratory Diagnostics: <https://epi-care.eu/diagnostics/laboratory-investigations/>

Dietary Therapies: <https://epi-care.eu/therapeutics/dietary-therapies/>

WHAT ARE ERNs?

European Reference Networks (ERN) are virtual networks of 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.

EpiCARE brings together 28 specialized

health centres in 13 European countries with expertise in rare and complex epilepsies. It offers a coordinated approach for epilepsy diagnostics and treatment by utilizing e-tools and cross-country e-consultancy, thus providing patients with the best expertise available.

If you are a healthcare professional and would like to refer a patient to EpiCARE, or are a patient or a family member of a patient, you can get in touch using the contact page on the EpiCARE website epi-care.eu.

CURRENT EpiCARE CENTRES

1. Great Ormond Street Hospital for Children, NHS Trust, London, UK
2. University College London Hospitals NHS Foundation Trust, London, UK
3. Queen Elizabeth University Hospitals Campus, Glasgow, UK
4. Oxford University Hospitals NHS Foundation Trust, UK
5. University Hospital Gasthuisberg KU Leuven, Belgium
6. Motol University Hospital, Prague, Czech Republic
7. St. Anne's University Hospital, Brno, Czech Republic
8. Pohjois-Savon sairaanhoitopiiri, (Kuopio University Hospital) Finland
9. CHRU LILLE Epilepsy Unit, France
10. GHE-HCL (HOSPICES CIVILS DE LYON), France
11. Hôpital Enfant Malade, Necker, Paris, France
12. University Hospital Bonn, Department of Epileptology, Bonn, Germany
13. Epilepsy Centre, University Hospital Freiburg, Germany
14. RCCS 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), Netherlands
20. The Children's Memorial Health Institute, Warsaw, Poland
21. Centro Hospitalar e Universitario de Coimbra, Portugal
22. Centro de Referencia de Epilepsias Refractarias, Hospital de Santa Maria, Lisbon, Portugal
23. Centro Hospitalar do 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

EPILEPSY

A public health imperative



World Health
Organization



International League
Against Epilepsy



International Bureau
for Epilepsy

“I encourage all WHO Member States and partners to build on the findings and recommendations of this report and to share it widely.”

Dr Ren Minghui

*Assistant Director-General for Universal Health Coverage/ Communicable and Noncommunicable Diseases
World Health Organization*

REPORT BY MARY SECCO, CO-CHAIR GLOBAL OUTREACH TASK FORCE AND IBE SECRETARY GENERAL

Epilepsy: a public health imperative is the first global report on epilepsy summarizing the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels. The report was published in June and was produced by WHO in collaboration with the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE).

The report is a call for sustained and coordinated action to ensure that every person with epilepsy has access to the care and treatment they need, and the opportunity to live free from stigma and discrimination in all parts of the world. It is time to highlight epilepsy as a public health imperative, to strongly encourage investment in reducing its burden, and to advocate for actions to address gaps in epilepsy knowledge, care and research.

The evidence in the report highlights that the risk of premature death in people with epilepsy is up to three times higher than for the general population. In low- and middle-income countries, early death among people with epilepsy is significantly higher than in high-income countries. Reasons for this premature mortality in low- and middle-income countries are likely associated with lack of access to health facilities when seizures are long-lasting or occur close together without recovery in between, and preventable causes such as drowning, head injuries and burns.

Roughly half of adults with epilepsy have at least one other health condition. The most common are depression and anxiety: 23% of adults with epilepsy will experience clinical depression during their lifetime and 20% will have anxiety. Mental health conditions such as these can make seizures worse and reduce quality of life. Development and learning difficulties are experienced by 30-



Cover photo: Delegates attending the special symposium to launch the report at the 33rd International Epilepsy Congress in Bangkok, June 2019

Congress delegates from Taiwan, Japan, Singapore, China, Canada and Indonesia celebrate the launch in Bangkok. Mary Secco is pictured second from right.

40% of children with epilepsy.

Stigma is a significant contributor to poor physical, mental and social health, lower educational and employment opportunities in persons with epilepsy. Reducing stigma requires a multipronged strategy that is culturally appropriate, multi-sectorial and collaborative with information campaigns in schools, workplaces, and the broader community. Legislation to prevent discrimination and violations of human rights are important elements of the public health response.

The report also shows that when the political will exists, the diagnosis of and treatment for epilepsy can be successfully integrated into primary health services and that cost effective and sustainable strategies exist to treat and defeat epilepsy. Pilot programmes have led to a considerable increase in access, such that 6.5 million more people have access to treatment for

epilepsy should they need it.

Causes of epilepsy include injury around the time of birth, traumatic brain injury, infections of the brain (such as meningitis or encephalitis) and stroke. It is estimated that 25% of cases can be prevented if effective interventions for prevention of epilepsy are delivered as part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.

The final chapter of the report is the ‘Way Forward’ which is a call to action with details of next steps. This chapter reinforces that everyone has a role to play if we are to treat and defeat epilepsy!

To read a full copy of the report please go to our website: ibe-epilepsy.org

Summaries of the report are available in six languages: Arabic, Chinese, English, French, Russian and Spanish.

Essential Oil Induced Seizures



Dr Thomas Mathew MD sent
IE News this report

Camphor and eucalyptus oil have been implicated as a cause of epilepsy in multiple studies, with both substances used in formulations of common over-the-counter medications such as Vicks, Amrutanjan and Tiger Balm, according to Dr Mathew, a professor and head of the Department of Neurology at St. John's Medical College Hospital, Bangalore, India. Findings of these studies, were published as an article in *Epilepsia Open* in 2017.

"A significant amount of seizure burden and unnecessary anti-epileptic treatment, which in itself carries side-effects, may be prevented by spreading awareness about the epileptogenic potential of these substances", he explains.

Essential oils is a misnomer, the word "essence" herein refers to the concentrate of plant juices and is in fact not essential to humans. Recently, we published a case series of 10 patients predominantly adults who had eucalyptus oil inhalation induced seizures (EOIS). 8 patients had GTCS and 2 had CPS within 2-10 minutes of inhalation of eucalyptus oil (EO).¹ The active ingredient of both EO and camphor oil is 1, 8 – cineole, an epileptogenic monoterpene.² Camphor was used to precipitate seizures in psychiatric patients prior to the development of ECT.³ It is well-known that the stimulus from the olfactory epithelium is conveyed within a fraction of a second to the insular

lobe and hippocampus through the lateral olfactory tract.⁴

While reviewing literature on EO and seizures, we came across an interesting article describing a late seizure following ingestion of Vicks Vaporub.⁵ It was a great realization for us that Vicks VapoRub contained nothing but eucalyptus, camphor and menthol. On searching, we found that many other over-the-counter oils, balms, gels, sprays and vaporizers available worldwide contain eucalyptus and/or camphor which are listed in table 1. Furthermore, in some of these preparations, the percent composition, dosage and method of administration are not indicated.

A brief survey of 190 people at our centre showed that a vast majority used, misused and abused these essential oil containing preparations to treat their headaches, cold, cough, insomnia, flu and musculoskeletal pain. Nine per cent (9%) of the sample was addicted to these preparations and 52% had been using them for over 6 years. In our epilepsy clinic, we were shocked to find that many patients with recurrent seizures used these preparations and subsequently had breakthrough seizures.

We have identified 4 circumstances in which essential oil induced seizure should be suspected – seizure associated with common cold, headache preceding seizure,

nocturnal seizure, and seizure associated with hot water burns. We had cases where seizures happened first time after the use of these essential oils (EOIS- Essential Oil Induced Seizure) and also breakthrough seizures in known epileptics after use of various preparations of essential oils (EOPS-Essential Oil Provoked Seizures), (table 2). The mode of use of the essential oils were topical application over the forehead, nose, throat etc., inhalation of the steam after mixing with water and ingestion. Time of onset of seizures after inhalation was 2 to 10 min, after ingestion was 30 min to 4 hours and after topical application was 1 – 24 hours.

We have started a prospective study on the use of essential oils and seizures both denovo (EOIS) and provoked (EOPS).

From the preliminary data it appears that essential oils related seizures is common and might turn out to be the most unrecognized provoking factor of seizure/epilepsy unrecognized by physicians, neurologists and epileptologists across the globe.

In all patients with first episode of seizure or breakthrough seizures with epilepsy, exposure to essential oils and its preparations should be sought. Since medical professionals are largely unaware of the implications of exposure to these preparations, it is typically overlooked while taking case histories, even in patients with seizures or epilepsy, which may result in falsely labelling the seizure as idiopathic.

Considering the widespread use of essential oil preparations and its potential to cause seizures, the relationship between these preparations, seizures and epilepsy should be further explored. All patients of seizure and epilepsy should invariably be advised to avoid all epileptogenic essential oils and various preparations containing them. The concept of EOIS and EOPS has to spread across medical professionals and public so that many seizures can be prevented and unnecessary anti-epileptic treatments can be avoided.

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Día Nacional de la Epilepsia en España

National Epilepsy Day in Spain



Isabel Madrid Sánchez, President of APNE (Asociación Nacional de Personas con Epilepsia) shared with us some images from activities to celebrate National Epilepsy Day in Spain, which took place on 24 May.

Many public building, including the Spanish Parliament, were illuminated in recognition of the day. This was the third year in which this had been arranged.

Another activity to raise awareness was a football tournament with mixed teams, which took place in Dos Hermanas, in Seville.

HEAR MY STORY

Communications workshop for young adults

Dublin • Ireland • 4 - 6 October 2019

IBE is organising a workshop for young adults with epilepsy entitled 'Hear My Story' with up to 20 young adults from across Europe aged 18 years to 30 years participating in a two-day event in Dublin. Workshop sessions will explore ways in which the young adults can raise awareness of the issues identified by them as impacting on their ability to reach their full potential and then suggest how the young adults can use modern media avenues to solve them.

HOW TO GET INVOLVED

- Each IBE chapter in Europe is invited to nominate a candidate to attend the course.
- Participants should be under 30 years of age on 1st January 2019.

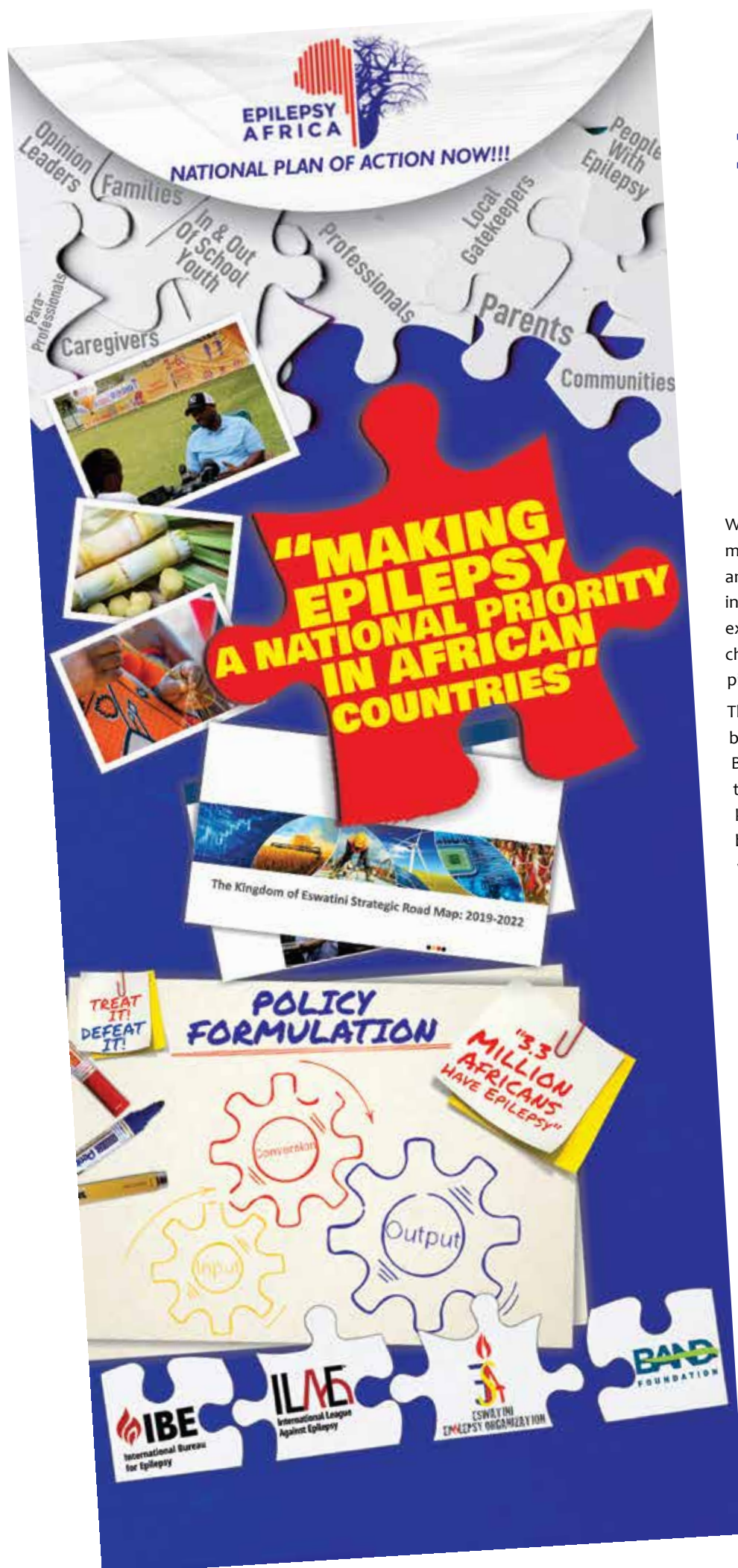
- The summit will be held in English and participants should have a good working knowledge of English.
- The candidate should be capable of travelling independently.
- First preference will be given to one candidate per chapter. Where there are more than 20 applications for places, the first 20 applicants will be chosen, with the remaining applicants forming a waiting list to fill any vacancies that might arise.
- The closing date for registration is 1st September, so time is running out!

*The workshop is made possible by sponsorship from
Shire International GmbH and UCB Pharma.*



Inspired by patients.
Driven by science.





Providing IBE chapters in Africa with tools to develop national action plans

Work on this important initiative began in mid-2018 with a call to chapters to express an interest in the project, such interest to be indicated by the end of August. From these expressions of interest a final short list of six chapters were selected to be involved in a first pilot programme.

The overarching goal of the project, which has been made possible thanks to funding from the BAND Foundation, is to reduce the epilepsy treatment gap and to improve epilepsy knowledge throughout Africa. This goal will be achieved by providing IBE chapters in Africa with the tools to develop and execute country-specific national action plans and thereby implement the WHO Epilepsy Resolution (WHA68.20).

Work on developing national projects began with a workshop, which took place in Nairobi earlier this year. The 4th African Epilepsy Congress taking place in Entebbe, Uganda from 22th to 24th August is the opportunity to review progress to date.

A full report will be included in the next issue of IE News.

Countries in pilot programme:

- eSwatini
- Kenya
- Mauritius
- South Africa
- Zambia
- Zimbabwe

EPILEPSY SOUTH AFRICA

Epilepsy South Africa is one of the longest established epilepsy associations in Africa. At the time of the 4th African Epilepsy Congress, in Entebbe, we take the opportunity to showcase the association that celebrated a half century of services for people with epilepsy in 2017. This article was first published under the IBE banner in *Epilepsy & Behavior* in 2018.

On 29 September 2017 Epilepsy South Africa celebrated our 50th anniversary. This marked the start of a year-long celebration.

Until the 1960's the South African National Council for Mental Health delivered services to persons with epilepsy. Dr AV Bird from Johannesburg presented a "Blue Print on Epilepsy" to the National Council for Mental Health, which led to the establishment of a "Division of Epilepsy" in October 1963. It soon became clear that the "Division for Epilepsy" needed to function as an autonomous national council and in October 1964 this Division became a steering committee.



THE BEGINNING

A national conference on epilepsy was held in Pretoria from 27 to 29 September 1967 with the South African National Epilepsy League (SANEL) founded on 29 September 1967. An Executive Committee was elected with Mr WH Barnard as chairman and Dr H Moross as vice-chairman and on 1 June 1970 Mrs A de Villiers was appointed as the first National Director with an office in Pretoria.

At an Extraordinary General Meeting held on 20 April 2002 in Durban the name and logo of SANEL changed to EPILEPSY SOUTH AFRICA. The National Chairperson was Rowena Stewart and the National Director Kathy Pahl.

WHO WE ARE

Epilepsy South Africa is the only national non-profit organisation in the country focusing specifically on the needs of persons affected by epilepsy, whilst also providing services to persons with other disabilities. While the organisation grew from a strong social work background, our vision today

clearly shows the change in focus: Epilepsy South Africa: Igniting the flame of potential. Our current mission is to promote human rights and an inclusive society for persons with disabilities, primarily persons with epilepsy. As such, our work is grounded in the United Nations Convention on the Rights of

Persons with Disabilities (CRPD) while we also contributed to the development of the South African White Paper on the Rights of Persons with Disabilities (WPRPD) and the African Disability Protocol (currently in its final stages).

A GLIMPSE AT OUR WORK

Epilepsy South Africa is one of the smaller disability organisations in South Africa with a National Office based in Cape Town and with six Branches.

The organisation is governed by a National Board and National Executive Committee. Our current National Chairperson is Dr Phindile Mnguni (a radiologist by profession), our Vice-Chairperson is Mr Tim de Villiers (a traffic engineer who has epilepsy) and our Treasurer is Ms Sibonokuhle Mbeve (an entrepreneur). Our current National Director is Marina Clarke who also serves on the IBE Education Commission.

THE 50FOR50 CAMPAIGN

The Campaign was inspired by international cricketing legend, Jonty Rhodes who has been a vocal ambassador for persons with epilepsy. His achievements have inspired many and we are drawing on this to challenge South African sports-men and -women to donate ZAR50 (approximately US\$4) on achieving their own magical "50's".

In terms of public awareness we are asking individuals to challenge their social network to repeat an action 50 times (aligned to their own ability and creativity) via recorded video to raise awareness around the initiative. Participants are also asked to announce that they are celebrating 50 years of Epilepsy South Africa to ensure a strong link to the campaign. Our international supporters can contribute to the Campaign via our GivenGain page (<https://www.givengain.com/c/epilepsy/>).



Agricultural project creating jobs for persons with epilepsy in Parys, Free State Province, South Africa

We are also leveraging our current corporate links to encourage competitive participation and involvement in extended sponsorship initiatives. Initiatives include fundraising through retail links (e.g. donating R5 for every R50 spent by customers); urging companies to incorporate sponsorship and donation mechanisms into daily operations; and creative execution of the #50for50 initiative and challenge intra-company/inter-company/industry/ departmental initiatives.

Supporters can contribute to our campaign by:

1. Forming a partnership with Epilepsy South Africa to promote our 50th anniversary on activities of their choosing;
2. Encouraging staff and customers to support our initiatives;
3. Making donations;
4. Working with Epilepsy South Africa on volunteer projects;
5. Helping publicize our 50th anniversary through social media interactions;
6. Using the hashtag #50for50 to show support for the Campaign.

We elevated disability awareness through encouraging disability disclosure during National Disability Rights Awareness Month (3 Nov – 3 Dec 2017) culminating in International Day of Persons with Disabilities (3 Dec 2017) and improving people's understanding of epilepsy on International Epilepsy Day (12 Feb 2018) followed by National Epilepsy Week (12 – 18 Feb 2018) aligned to the 2018 theme - Epilepsy is more than seizures.

Other events on our calendar include celebrating Human Rights Day in March, Tekkie Tax Day (a South African national fundraising campaign benefiting five non-profit sectors) in June, and celebrating National Women's Month in August.

CONTACTING US

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Reference:

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If you have an article that you would like to have published in *Epilepsy & Behavior* under the IBE banner, the IBE office would love to hear from you.



Above: residential care centre for persons with epilepsy in Dullstroom, Mpumalanga Province, South Africa.

Below: lighting candles in support of people with epilepsy

Bottom: Epilepsy South Africa branch network





European Medicines Agency approves use of cannabidiol as adjunct treatment

GW Pharmaceuticals marijuana-based treatment Epidyolex has won a positive recommendation for marketing approval from the European Medicines Agency (EMA) in late July for use as an additional treatment for two types of seizures.

EMA's human medicines committee (CHMP) cleared the cannabidiol oral solution for use with clobazam to treat seizures associated with Lennox Gastaut syndrome (LGS) or Dravet syndrome for patients aged two and older.

In its announcement, EMA explained that, in medical terms, Epidyolex reduces the hyperactivity of neurones through different actions: modulation of intracellular calcium via G protein coupled receptor 55 (GPR55) and transient receptor potential vanilloid 1 (TRPV 1) channels, as well as modulation of adenosine mediated signalling through inhibition of adenosine cellular uptake via the equilibrative nucleoside transporter 1 (ENT 1).

The benefits with Epidyolex are its ability to help manage seizures associated with LGS and DS. The most common side effects are somnolence, decreased appetite, diarrhoea, fever, fatigue and vomiting.

While final approval lies with the European Commission, this usually follows CHMP recommendations, with endorsement coming a few months after the EMA decision. In the case of Epidyolex, a decision is expected by the end of September. The European Commission has the authority to approve medicines for use in the (currently) 28 countries of the European Union, as well as in Iceland, Liechtenstein and Norway, who are members of the European Economic Area (EEA). It also follows approval of the drug last year in the US, where it is branded as Epidiolex. The US Drug Enforcement Administration viewed the drug as having low abuse potential.

The drug is made up of cannabidiol (CBD),

one of the many hundred molecules found in the marijuana plant, and contains less than 0.1% of tetrahydrocannabinol (THC), the psychoactive component that gives users a high.

GW Pharmaceuticals, which grows the marijuana plant under glass on its own farms in the UK, has reported that trials had shown the treatment to be successful in treating seizures in patients with tuberous sclerosis, a rare form of childhood epilepsy.

In response to the EMA decision, Professor Martin Brodie, IBE President said - "This is a significant milestone for patients with LGS and Dravet syndrome as there remains a severe unmet medical need for these rare, lifelong forms of epilepsy. The positive opinion brings hope to both patients and their families of a treatment option which has the potential to better control seizures and notably improve quality of life."

PERSONALISED CARE FOR PEOPLE WITH EPILEPSY MOVES ONE STEP CLOSER

Epilepsia paper reports on Irish research efforts

Researchers in Ireland has brought personalised care one step closer for people with epilepsy. The researchers report that they have developed a genomics module within an epilepsy-specific electronic patient record (EPR). Better access to genomic data will allow clinical teams to understand the causes of a person's epilepsy and develop personalised care.

The research was published in August in ILAE's *Epilepsia* journal under the title "Development of a genomics module within an epilepsy-specific electronic health record: Toward genomic medicine in epilepsy care."

In a press release, Prof Norman Delanty, lead author, explained: "We now know that much of previously unexplained epilepsy is due, in part, to damaging variants in a person's genome. The potential to understand the reason for a particular person's epilepsy at a molecular level, and to use this information to develop personalized therapies, will become a significant advancement in the way we practice medicine."

Prof Delanty is an associate professor at Royal College of Surgeons Ireland (RCSI) in Dublin and consultant neurologist at Beaumont Hospital. He is also a FutureNeuro Investigator. FutureNeuro is Science Foundation Ireland's Research Centre for Chronic and Rare Neurological Diseases and is hosted by the RCSI. The research was undertaken by Prof Delanty and his colleagues with researchers from the Irish government's Health Service Executive's Epilepsy Lighthouse Project, which focuses on personalising epilepsy care.

The authors said their work illustrates the role of eHealth technology in embedding genomics into the clinical pathway. Many adults and children with epilepsy of unknown cause now undergo genomic testing, in efforts to establish the underlying cause of their epilepsy.

In recent years, scientists have discovered more than 20 different syndromes that have epilepsy as a main feature. These have been mapped to specific genes. Research-

ers have identified mutations in genes that encode sodium, potassium, and calcium channels that can cause epilepsy. These discoveries have begun to impact clinical care for epilepsy.

The new epilepsy EPR module facilitates regular multidisciplinary meetings between clinicians, geneticists, bioinformaticians, and other team members, where they review data from genomic testing to determine if there is an identifiable genetic cause for a patient's epilepsy.

"The epilepsy EPR system is one of the largest, most detailed collections of active epilepsy eHealth records in the world," said Mary Fitzsimons, FutureNeuro epilepsy eHealth lead and director of the Epilepsy Lighthouse Project at RCSI, in the press release. "We believe the combined power of genomics and electronic patient records has the capability of enhancing, and in some cases transforming, the practice of medicine," she added.



EPILEPSY WEEK IN BOLIVIA

Report by Tomás Mesa, IBE Vice President Latin America and Carlos Acevedo, Director PAHO/WHO Collaborating Center Chilean League against Epilepsy LICHE

The 5th Bolivian Epilepsy Week, held in Cochabamba, held in July, was very successful both for the participation of people (between 30 to 50 people per session), the content and broad focus of the issues discussed, and the participation of people with epilepsy. It is also worth highlighting three important facts:

1. The presence of PAHO authorities, who pledged to support all initiatives in epilepsy by the current ILAE, the future IBE chapter and the Bolivian government.
2. The formation of a group of Bolivian professionals to create the IBE chapter in Bolivia, with the goal of attaining

membership before the next Latin American Epilepsy Congress, which will be held in Medellín, Colombia in May 2020.

3. The participation of people with epilepsy and their families.

The participation of people with epilepsy and their families was particularly important on Saturday, July 20, with the presence of municipal authorities, a youth folk ballet group, and various media representatives - specifically newspaper, radio and television in Cochabamba.

We have seen, as in other cities, teams of volunteers and local leagues that are formed to work together to facilitate the

treatment and quality of life of people with epilepsy. Recently in Cochabamba, the International League Against Epilepsy chapter has created a drug bank facility.

These activities, which are part of the Strategic Plan for Epilepsy, a documented program created by IBE, ILAE and PAHO, will assist in ensuring that people with epilepsy have a better quality of life. It also represents another element of the integration of collaborative work in education of the Alade Commission of ILAE and the PAHO/WHO Collaborating Centers.

We congratulate the entire team that organized this Bolivian Epilepsy Week.



EPILEPSY NURSE LINE LAUNCHED

Epilepsy Action Australia launches new service to support people living with epilepsy and their families

An Australian telephone and email service to support people living with epilepsy and their families has been launched by Epilepsy Action Australia.

On introducing the new service in Australia, Carol Ireland, the association's CEO, explained: "The Epilepsy Nurse Line has been developed specifically to improve health outcomes for people affected by epilepsy. Each call will be answered by a registered nurse with special training in epilepsy management, so callers can trust that the information they receive will be accurate and safe."

Minister for Health, Greg Hunt said: "People living with epilepsy in Australia now have a trusted and responsive resource they can count on for all kinds of information related to their condition. The Epilepsy Nurse Line will greatly reduce the amount of time it would otherwise take for a person with epilepsy to receive trustworthy advice from a qualified allied health professional, and the Morrison Government is proud to have provided funding for such a valuable service."

The Epilepsy Nurse Line, which includes both a telephone and email service, will be especially life-changing for people living in rural and remote regions of Australia, who may have limited access to medical professionals trained in epilepsy management.

"There are around 250,000 people diagnosed with epilepsy in Australia and many of them only see their epilepsy specialist once or twice a year," Ms Ireland said. "The Epilepsy Nurse Line will mean that a person who has a question about their medication can get an almost instant response, or a person concerned about a family member who has had a seizure can get immediate advice as to what to do next," she added.



Australians living with epilepsy now have access to a new helpline!

The national EPILEPSY NURSE LINE is available 9am to 5pm, seven days per week and is proudly provided by Epilepsy Action Australia. This is an Australian-first phone and email service to support people living with epilepsy and their families.

The Epilepsy Nurse Line which is available in all Australian states and territories, has been funded by the Australian Government Department of Health, addressing a condition that the World Health Organisation refers to as 'neglected'.

The Epilepsy Nurse Line has been developed specifically to improve health outcomes for people affected by epilepsy. Each call will be answered by a Registered Nurse with special training in epilepsy management, so callers can trust that the information they receive will be accurate and safe.

The Epilepsy Nurse Line will be especially life changing for people living in rural and remote regions of Australia, who may have limited access to medical professionals trained in epilepsy management.

Calls to the Epilepsy Nurse Line will be answered immediately by a Registered Nurse and emails will be answered within 24 hours. An Australian service like this will provide a vital resource for many people living with epilepsy or impacted by it.

People with epilepsy can speak with a qualified epilepsy nurse on the Epilepsy Nurse Line by calling 1300 Epilepsy (37 45 37) or via email epilepsy@epilepsy.org.au

1300 EPILEPSY (37 45 37) epilepsy@epilepsy.org.au

ANNUAL DUES 2019

FINAL CALL FOR PAYMENT

Dues payments are important in funding IBE activities and in helping us support members in disadvantaged regions. This is also a final reminder to those chapters with outstanding dues to settle any such payments as soon as possible in order to safeguard their membership status.

Did you know that you can pay by PayPal? PayPal can be used with any credit card and is the easiest method for both the payer and the payee. Just let us know and we will issue a Request for Money for this purpose.

The dues levels are:

- **Chapters:** US\$175/€150
- **Associate Chapters:** US\$125/€105
- **Subsidised rate:** US\$30/€25
- **Provisional chapters:** no payment

More than 30 chapters based in developing countries continue to have their dues payments covered by the Solidarity Fund. When making your dues payment, please consider a donation to the Solidarity Fund to help us to continue to support those chapters who have very limited financial means.

Contact annlittle@ibe-epilepsy.org with any queries on making a payment.



International
Epilepsy Day

MONDAY, 10 FEBRUARY 2020

'EPILEPSY - A GLOBAL HEALTH IMPERATIVE'



CELEBRATED IN 120 COUNTRIES WORLDWIDE

www.internationalepilepsyday.org

#EpilepsyDay