

# INTERNATIONAL



# EPILEPSY NEWS

**ISSUE 4 - 2021** 

# FROM THE EDITOR

After 25 years working at IBE and 15 years as Editor of IE News, this is a sad moment for me as I pen this, my final message to you as IBE Executive Director and IE News Editor. All good things must come to an end and on 31st December I will retire.

This last editor's message is, therefore, the opportunity for me to say Thank You to all the wonderful people I have met through my time working for IBE. Although, as the saying goes, if you enjoy what you are doing, you will never work a day in your life!

Working for IBE has provided an open window through which to witness the struggles, efforts and undaunted bravery and commitment shown by people right across the world as they work to improve the lives of people with epilepsy - whether as a parent, sibling, healthcare provider, or chapter employee. In travelling to regional and international congresses and on the invitation of chapters, I have also been privileged to meet countless people with epilepsy who never allow their diagosis to hinder them from striving to achieve their dreams; they are truly inspiring and I will never forget them.

Finally, I would like to send my successor, Donna Walsh, my very best wishes. I know that she will be a terrific asset to IBE as it moves to introduce new plans and initiatives to meet future challenges over the coming months and years.

As always, happy reading!

Ann Little Editor



# **CONTENTS**

3 PRESIDENT'S **LETTER** Looking forward



6 **INTER** NATIONAL **EPILEPSY DAY** Are you getting involved?

11 FIRST IBE **EGM** Planning the way forward



14 **IBE DAY AT** THE IEC Looking back on a successful programme

12 **PROJECT** REPORT FROM **AFRICA** Advocacy

project phase II



Ratified at AGM



15 50 MILLION **STEPS** Time to get your

walking shoes on



20 **EPILEPSY & PREGNANCY** Website launched

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# PRESIDENT'S **MESSAGE**

# **DEAR FRIENDS**

Those of you who have heard me speak before will know that I like to start with a question. Why? You see - already I am asking a question! It is only in asking questions, and being curious, that we can find the information we seek. Perhaps I am following the advice of Albert Einstein who once said 'The important thing is not to stop questioning'.

When I was elected President, I was pleased to take on the work that my predecessor, Martin Brodie, had already set in train redefining the structure and role of IBE to meet the demands of our ever-changing world. And, as IBE celebrates its 60th birthday in 2021, this is the ideal time, not only to reflect on the past but also, to ask important questions about the future so that we are sure that we remain on course and don't get lost along the way.

Our recent Extraordinary General Meeting (EGM) provided us the opportunity to ask our chapters for their views and ideas on where IBE should be going. Taking these opinions on board is vital if we are to serve our members in the best way possible. We must never forget that IBE is its members and it is only by working together, towards a common shared goal, that we can hope to make a real and tangible difference.

Bearing all this in mind, we are agreed that our objectives for the future are:

- To position epilepsy as a global public health priority
- To empower and amplify the voice of people living with epilepsy
- To serve and support our chapters and committees in all regions

In doing so we can achieve a transformational social change for people living with epilepsy worldwide by focussing on four key strategic areas: advocacy and awareness; knowledge creation and exchange; capacity building; and partnership development.

The IBE board and I were extremely pleased to find that the large number of chapter representatives that attended the EGM were agreed on this strategy and over the coming months, at all times referring back to the chapters and seeking their views through further webinars allowing open candid discussion, we will begin to flesh out these key areas through a planned IBE Knowledge Hub.

An important step on our journey will be a review of our governance policy. There have been a number of amendments over the 60 years of IBE's existence but this may be the time for a major redrafting to ensure it remains fit for purpose. We need to improve our organisational effectiveness, efficiency and sustainability



through increased staffing; optimise membership and our volunteer/youth networks; while at all times monitoring and evaluating outcomes.

So, there are exciting, and very busy, times ahead for all of us as we begin the journey to a better world for people with epilepsy and those who care for them in 2022. Will you join us? Yes - it's another question!

Wishing you all a very Happy New Year.

Francesca Sofia President



# Do you love someone with epilepsy?

## **ABOUT THE DAY**

International Epilepsy Day is a special event which promotes awareness of epilepsy in more than 130 countries each year. Every year on the second Monday of February people join together to acknowledge and highlight the problems faced by people with epilepsy, their families and carers. We want to make International Epilepsy Day 2022 an even bigger success than ever and we need your help to do that.

International Epilepsy Day is a day for everyone, no matter where you are, no matter how small your group or how large your area, no matter whether you focus on the medical or the social aspects of the disease. We want you to help us celebrate International Epilepsy Day 2020. Let's voice the volume and speak with one global

For the very first time, since the event was launched in 2015, International Epilepsy Day will fall on Valentine's Day - February 14, in 2022. Valentine's Day is a day when it is traditional to show love for one another so let's take this opportunity to show our love for the epilepsy community around the world.

## **RESOURCES**

To help you and your association and friends to celebrate our theme for 2022 - I love someone with epilepsy - we have created a selection of resources that you can use, including posters and graphics for social media. Template files are available that you can edit all these resources and translate them into your own language. You will find a link to the editable files on this page of our website: https://internationalepilepsyday.org/resources/. There are 10 posters to choose from - or you can use them all! You'll find nine of them on the facing page, so you can see just how attractive they look.So, let's show some love!

### **SOCIAL MEDIA**

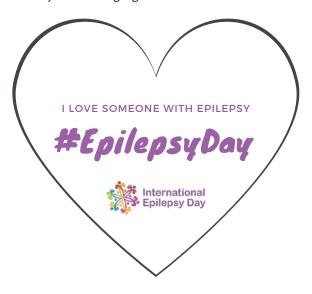
Social media will play a huge role worldwide in getting the epilepsy awareness message out to the public on International Epilepsy Day.

On Monday, February 14, 2022 there will be a worldwide effort to get #epilepsyday to trend on Twitter and other social media sites. We're looking for all social media users to post a photo on the day using a sheet of paper or card to display the hashtag and your location. You can download two versions of our message card on the website resources page: https://internationalepilepsyday.org/ resources/.

You might also like to create and share an advocacy video. We have created a guide to help you create your video message, and where you can find some examples of what you might do, which you will find here: https://internationalepilepsyday.org/online-awareness/ video-advocacy-for-epilepsy-awareness.

Change your cover photo and profile picture to the International Epilepsy Day logo, which is available here: https://internationalepilepsyday.org/wp-content/uploads/2016/01/TwitterProfile.png.

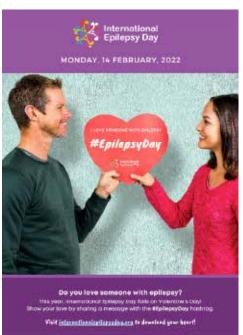
Whatever you do on International Epilepsy Day, be part of the worldwide social media effort!

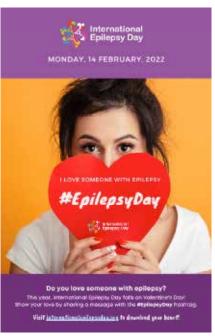


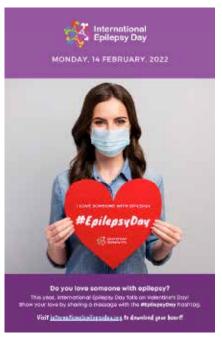






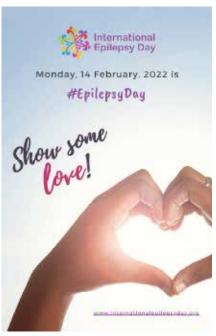














# 50 million

# STEPS FOR EPILEPSY

50 million people worldwide are affected by epilepsy. To raise awareness of this and to raise vital funds for epilepsy organisations across the world, we are asking you to help us walk 50,000,000 steps ahead of International Epilepsy Day.

Complete your steps between Monday, January 10 and Monday February 14, 2022.

# Step up epilepsy awareness on International Epilepsy Day!



50MillionSteps.org





# Are you up for the challenge?

In 2021, our 50 Million Steps for Epilepsy campaign exceeded our wildest expectations, with more than 16 million steps taken for epilepsy. Around the world, despite Covid restrictions, you stepped up to the mark and helped us to make our inaugural 50 Million Steps for Epilepsy campaign the amazing success that it was.

## A big Thank You to everyone!

Now we are asking you to put on your walking shoes and to get ready to help us repeat the success we all shared this year, as prepare for the 2022 running of the campaign as part of International Epilepsy Day celebrations.

Join or organise a walk and help us walk 50 million steps – a step for every person affected by epilepsy in the world. Or better still, let's try to beat the results of 2021 by covering an every greater distance!

Starting on Monday, January 10th 2022 and ending on International Epilepsy Day 2022 – Monday February 14th - we'll be walking, running, climbing, skating or dancing our way to raise awareness, to improve visibility and to increase understanding of epilepsy. Your effort could also be an opportunity to raise vital funds for your local or national epilepsy support association!

# How to count your steps

People with a Fitbit or step tacker can easily track their daily steps. Anyone who has a smart-phone can also use this to track steps taken. If you do not have a tracker or smartphone, participants can estimate their steps. On average, there are 1,350 steps in every 1 kilometre. If you walk a distance of just over 3.8 kilometres, the average person will have achieved 5,000 steps.

# **Enter our competition**

We're running a fun competition for those taking part in the #50MillionSteps Challenge and there are 4 prizes of \$250 each to be won!

## Silliest steps

It might be a one-legged hop or walking on stilts. It might be a walk in a silly costume. But we want to see it!

# **Cutest pet steps**

Who doesn't love a cute pet video? Wheter your have a cat, a dog, a parrot or a pony, if your pet is taking steps to raise epilepsy awareness then we'd love to see it!

## **Best baby steps**

Everyone can take part in the 50 Million Steps challenge, whether big or small. Your little one might not be too steady on their feet but every step counts! We would love to see your videos.

## **Best dance steps**

You don't have to be a prima ballerina to impress us with your dance steps! Share your moves and you could win \$250!

To enter, you just need to share your video on social media using the **#50MillionSteps** hashtag between Monday, 10 January, 8am CET and Monday, 14 February, 8pm CET 2022.

## **Download resources**

Why not download and share some of our great resources to let people know about the #50MillionSteps campaign and how they can get involved? We have posters, graphics and logos available for your use: https://5omillionsteps.org/resources/

If you would like to have any of the resources made available in another language, and can help us with translation, please contact us.

To help both individual epilepsy advocates and the IBE Chapters around the world to get involved in the 50 Million Steps for Epilepsy campaign, we have created toolkits that contain information about the campaign, suggested ways to get involved, sample messages to share on social media as well as links to all the resources.

Let's make it a great campaign!





# A PROGRAMME WITH SOMETHING FOR EVERYONE

There is no doubt that the world has faced a very difficult time as the fight against the Covid pandemic continues and new variants emerge to taunt us each time we believe we are gaining the upper hand.

Around the world, social distancing measures and restrictions on face to face events, have impacted greatly on the congress industry. Yet, these very restrictions have seen an enormous rise in the use of technology to host virtual events and facilitated the attendance of participants who would otherwise not been able to attend due to the cost of flights and accommodation, or work or family commitments.

IBE has been making much use of online webinars and meetings and, on 1st September, held a full day programme as the first virtual IBE congress symposia as part of the programme of the 34th International Epilepsy Congress. The event was free of charge and attracted almost 400 registrations.

The IBE Day programme comprised three 2-hour sessions, each one addressing disparate but important issues relevant to people with epilepsy and those who care for them. Key to the presentations was the opportunity for interactive dialogue with the speakers during the Q&A segments of each session. IBE is an organisation of its members and in determining future direction, the views and suggestions of its chapters is vital.

IBE would like to thank the session chairs and the 22 speakers who made this a truly memorable event.

Unfortunately, there is a downside to virtual meetings where participants are based around the world and living in different time zones. Between our chapter in New Zealand and one of our chapters in the US, there is a time difference of 21 hours! This makes it very difficult to find a time that it suitable for all. The good news is that, if you missed the IBE Day or would like to watch some of the sessions again, you can find them online on the IBE website.

https://www.ibe-epilepsy.org/ibe-day-at-the-34th-international-epilepsy-congress/

# SPEAKERS AND TOPICS

# Making Epilepsy a National **Health Priority**

Chairs: Action Amos and Mary Secco

# **Topics and speakers:**

- 10-year Intersectoral Global Action Plan (IGAP): Tarun Dua, WHO Brain Health Unit
- Leveraging IGAP to improve care: Alla Guekht, Chair ILAE Global Advocacy Council
- Improving care for children with neurological disorders in resource poor settings: Jo Wilmshurst, President International Childhood Neurology Association
- Improving access to essential medicines: Gaby Ooms, Health Action International
- Working with donors: Gardiner Lapham, BAND Foundation
- **Epilepsy Advocates Toolkit:** Karen Robinson, Epilepsy South Africa
- Global health in epilepsy database: Karen Parko, ILAE North America

# **Empowering Youth to Raise their Voices:**

Chairs: Lorraine Lally and Scarlett Paige

## **Topics and speakers:**

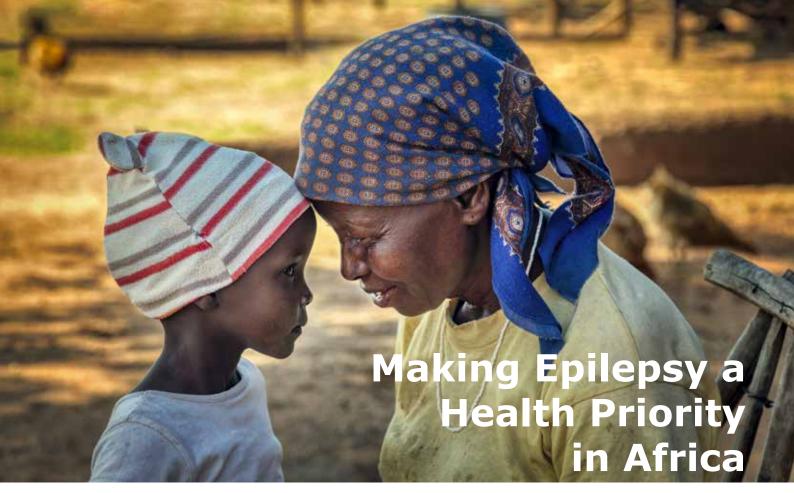
- Epilepsy & Pregnancy: launching IBE's new toolkit:
  - Lorraine Lally, Co-chair Global Youth Team
  - Gus Baker, Chair Epilepsy & Pregnancy Campaign and Secretary General
- Meet the International Golden Light Award Winners 2021: Presentation of 19 awardees
- Hear my Story: International Golden Lights from IBE's seven regions share their stories:
  - Bright Bwalya (Zambia),
  - Mohsen Fariborzi (Iran),
  - Lynna Held (Germany),
  - Luiza Gatto (Brazil)
  - Valentina Kahn (Chile),
  - Cassidy Megan (Canada),
  - Vinay Jani (India)
  - Meng-Leo Chou (Taiwan China)
- Introduction to the IBE Global Youth Team: Lorraine Lally and Scarlett Paige, Co-chairs Global Youth Team

# **Psychologic treatment and** self-management of epilepsy

Chair: Gus Baker

# **Topics and speakers:**

- The comorbidities of epilepsy: a review: Gus Baker (Chair, IBE Research Team and Secretary-General)
- The psychological management of epilepsy: Turkish experience: Nuran Aydemir (Turkey), Co-chair **IBE Research Team**
- Self-management programmes in children: Scottish experience: Liam Dorris (Scotland)
- Psychological treatment of epilepsy: Mauritian experience: Devisha Dassyne (Mauritius)
- Self-management programmes: US Experience: Rosemary Kobau (USA)



# Project Phase II Summary Report

provided by Action Amos, IBE Vice President Africa and Project Co-ordinator

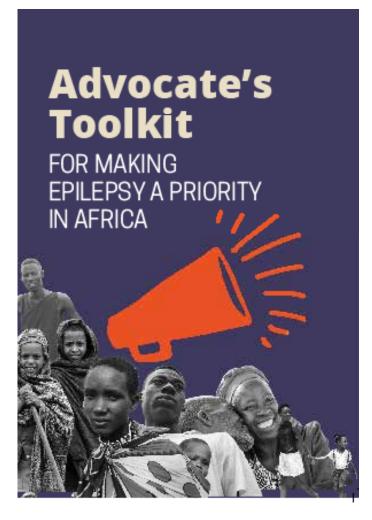
# Background

Since 2019, the BAND Foundation has generously supported the International Bureau for Epilepsy's Africa region with a goal of ensuring that epilepsy becomes a health priority in Africa. In Phase II of this initiative, we focused on the following objectives:

- Improving the visibility of epilepsy initiatives in Africa 1.
- Strengthening the technical capacity of the regional project management team
- Enhancing the capacity of African epilepsy organizations to influence health policy
- Strengthening the regional engagement and working relationship with WHO African Region, African Union (AU), ILAE Africa and Pan African Parliament (PAP).

Fundamental to the success of Phase II was investing in the capacity of the African Regional team. IBE Africa has engaged and trained advocates, provided educational resources across the continent, built and grown a network of advocates and organizations, funded meaningful projects, and influenced policy makers.

A notable accomplishment in Phase II was the development and implementation of the Advocate's Toolkit for Making Epilepsy a Priority in Africa. The engagement strategy used to design the toolkit (https://epilepsyafrica.org/advocates-toolkit/) and the implementation training helped to build knowledge and skills in 48 advocates. Additionally, the toolkit has been promoted on our website and through a webinar. Other IBE regions have requested to modify the toolkit for their unique settings and for translation to other languages. We are working with another possible donor to develop a similar resource for Latin America.





The timing of the toolkit training was ideal, since it aligned with a call to action from the Director General of the World Health Organization to develop a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (WHA73.10). The Brain Health Unit at WHO sought public opinion and input on the first draft of this plan and invited civil society to identify achievable global targets. With funding from the BAND Foundation, the project coordinator worked with IBE chapters in the African region to develop an engagement strategy to enhance the capacity of people with epilepsy to influence health policy and to ensure that their voice was represented at every stage of the WHO consultation process. People with epilepsy were encouraged to provide feedback on ways to strengthen service coverage and access to essential medicines. They were asked for recommendations to reduce stigma and discrimination. The project coordinator worked with the IBE Africa Regional Advisory Committee to develop written materials and letter templates for governments and Ministries of Health. IBE chapters in Africa sent letters to their Ministries of Health and had meetings requesting the WHO Secretariat to implement a 90-80-70 cascade target for epilepsy:

- 90% of all people with epilepsy in Africa are aware of their diagnosis as a treatable brain disorder;
- 80% of people diagnosed with epilepsy in Africa will have access to appropriate, affordable, safe anti-seizure medicines;
- 70% of those treated will achieve adequate seizure control through long term availability of treatment.

The IBE network in Africa was able to secure written commitments for the proposed 90-80-70 cascade target from 49 partners and stakeholders, including the Ministries of Health in Eswatini, Lesotho and Cameroon. They received the endorsement of 14 IBE affiliates with additional support from two key networks, namely the Pan African Network for Persons with Psychosocial Disability (PANPPD) and the South African NCD Alliance. The capacity that was built through our BAND Foundation partnership contributed significantly to this successful outcome.

To improve the visibility of epilepsy initiatives in Africa, BAND Foundation funding was used to develop a communications strategy

and to hire a communications support officer. The communications support officer maintained the website epilepsyafrica.org and organized 9 training webinars. These webinars were attended by 413 people representing countries acrossthe continent. In addition, the communications support officer established a YouTube Channel that was viewed by 393 people; and used Facebook, Twitter and Instagram to reach an audience of 1000+.

IBE Africa published a health laws mapping report (https://www. ibe-epilepsy.org/wp-content/uploads/2021/06/IBE-Africa-Reporton-the-21-States-copy.pdf) with legislation reviewed in 21 countries. This baseline data of existing legislation, particularly in the areas of health, education, driving, employment, marriage, and social inclusion, will be used to address and amend clauses that discriminate against people with epilepsy. It is notable that WHO Geneva asked for permission to circulate this mapping report, recognising its signifiance.

Over the course of three months, the initiative was able to train 40 journalists from around Africa about epilepsy and the Intersectoral Global Action Plan. Resulting from the training, 12 impact stories have been conducted across the African region since then.

Phase II monies were provided, through a competitive awards process, to six African nations. This modest grants fund was established to assist epilepsy organizations in implementing education and advocacy projects. The table below contains brief descriptions of the projects funded.

# **Edycs Epilepsy Group, Mauritius**

**Goal:** to train ECCEA pre-school teachers in epilepsy and seizure disorder

**Outcome:** 150 pre-school teachers' training using training tools and knowledge to support parents and other school staff

# **Epilepsy Association of Zambia**

**Goal:** Education survey in Lusaka - 'Children with Epilepsy (CWE) Out of School

Outcome: 40 stakeholders and authorities engaged to support education for CWE

# **Purple Bench Initiative, Uganda**

Goal: Creating epilepsy smart communities in the regions of Kyanamukaaka and Butego in Masaka

Outcome: 20 local government leaders trained in one-day workshop by epilepsy experts. 20 local leaders contributed to advocacy debates at district level and made recommendations for action

## **National Epilepsy Association of Malawi**

**Goal:** Fighting epilepsy silence in rural Malawi using technology Outcome: 6 volunteers trained to use drug audit/availability check tool on using a mobile phone

# **Epilepsy South Africa**

Goal: using WHA60.20 Resolution to make epilepsy a public health priority

Outcome: establishment of a National Epilepsy Taskforce

## Zimbabwe - individual youth grant

Goal: to creat an epilepsy campaign video

Outcome: musical video created to teach others about epilepsy

Project funded through a grant provided by BAND Foundation



Cameroon, Eswatini, Lesotho, Uganda, Malawi, Mauritius, Sierra Leone, Tanzania, Uganda, and Zambia also received minor funding to encourage people with epilepsy to join in the 50 Million Steps Challenge, a global epilepsy awareness project organized by the IBE around International Epilepsy Day. In South Africa, over the course of the project, a National Taskforce was formed and a person with epilepsy elected to chair the taskforce. In Malawi, a Taskforce was also established with the assistance of IBE Africa.

The project also engaged with AMREF to evaluate epilepsy work in which it is engaged in South Sudan. It was a huge success with the country now considering forming a National Taskforce on Epilepsy.

# Key lessons

We found in Phase II that putting epilepsy policies and plans into action required strong leadership and cross-cutting teamwork. Although the grassroots epilepsy movement has been mobilized and strengthened, thanks to BAND Foundation's partnership, there is still work to be done to ensure that policymakers, WHO, and elected officials prioritize epilepsy as a public health priority in their budgets and work plans for 2022 and beyond.

Many laws affecting the lives of people with epilepsy are outdated and fail to safeguard and promote their human rights in many nations. Where epilepsy legislation exists, it can deliberately violate the rights of people with epilepsy. As a result, there are unmet demands in the areas of education, healthcare, and the environment.

Health care that is adequate and inexpensive, as well as employment, housing, and community services. If epilepsy is not treated, it might lead to significant complications.



# Extra Support

In Phase II, the project management team appointed an External Advisory Committee which included a Trustee from the BAND Foundation and appointees from WHO Afro Regional Office, African Union, African Disability Alliance, IBE HQ, ILAE and Kenya Medical Research Institute. His Royal Highness Prince Bandazile of the Kingdom of Eswatini and Dr Joyce Banda, the Former President of Malawi were appointed Honorary Patrons.

### Photos:

Top: traditional healers, speakers at on of the project webinasr, picture with Mbutfo Masuku, support communications officer.

Below: Dr Joyce Banda, Former President of Malawi.





# President to President

Conversation with IBE Presidents Martin Brodie and Francesca Sofia



MORE VIDEOS







# An indepth discussion by IBE Presidents past and present

In July 2021, two months before the IBE General Assembly and the start of a new term for IBE's International Executive Committee, IBE's now Immediate Past President, Martin Brodie and President, Francesca Sofia, took part in an extended interview with the International League Against Epilepsy (ILAE).

In the 30 minute video they spoke about their roles and career achievements to date and shared their hopes for the future of epilepsy advocacy at a global level.

They also considered the value of the long-standing collaboration between IBE and ILAE.

You can watch the full video here:

# https://youtu.be/vHEhXoiAID4

or you can visit the President to President playlist on our YouTube Channel to watch seven shorter individual segments from the interview:

https://www.youtube.com/playlist?list=PL44aXXlaw9bkJd1JCzH3azrduOSUNpEoE





# WomenAndEpilepsy.org a special website for women with epilepsy

Being diagnosed with epilepsy is a significant moment in anyone's life and working out how to live with it takes time.

Women with epilepsy have to contend with additional issues, such as pregnancy, hormones, their sex lives and planning a health family.

To provide women of childbearing age with all the information they need, IBE has developed a dedicated website brimming with information and support tools, which will launch before the end of December 2021.

WomenAndEpilepsy.org is where you will find the answers to questions such as:

- Why is epilepsy different for women?
- What are hormones and how do they affect epilepsy?
- How does puberty affect epilepsy?
- Will epilepsy affect my sex life?
- **Epilepsy and contraception**
- Epilepsy and valproate
- Accidental or unplanned pregnancy
- What you need to know to have the healthiest pregnancy possible
- Risks to the foetus of an unmanaged pregnancy in a woman with epilepsy
- Questions for your doctor
- and much more!

# **Epilepsy and Pregnancy Group Members:**

Prof Gus Baker Chair, Mrs Ann Little Co-Chair, Mrs Tea Bobinac-Krivacic (IBE Youth Team), Prof Martin Brodie, Ms Elizabeth Cunningham, Ms Erin Davies (Golden Light), Prof Joanna Jedrzejczak , Mrs Barbora Jones (social worker), Dr Lieven Lagae, Ms Lorraine Lally (IBE Youth Team), Prof Janet Mifsud, Dr Barbara Mostacci, Dr Natela Okujava, Dr Francesca Sofia, Dr Janine Winterbottom, Ms Leonie Wollscheid (Youth Team).

The campaign has been developed with financial support from Sanofi. Sanofi has had no editorial control over the content of the materials.



# WELCOMING OUR NEW CHAPTERS

Thirteen chapters ratified by the General Assembly

IBE now has 149 chapters in 104 countries

With the world population estimated at 7.7 billion, this means that 7.0 billion people or 90% of the world's population live in countries now served by an IBE chapter

# Recently ratified chapters

# **African Region:**

- The Gambia: Foundation for Epilepsy and Stigma Support (FESS)
   Associate chapter
- Kenya: Foundation for People with Epilepsy (FPE)
  Associate chapter
- Mozambique: Associação Moçambicana de Apoio a Pessoas com Epilepsia (AMAPE)
   Full chapter
- Uganda: Purple Bench Initiative Associate chapter

# Eastern Mediterranean Region:

 Tunisia: Association AHMED d'aide aux enfants avec epilepsie
 Associate chapter

# **European Region:**

- Ukraine: Ukrainian Bureau for Epilepsy Full chapter
- UK: Ring 20 Research and Support UK Associate chapter
- Europe-wide: Dravet Syndrome European Federation Associate chapter

# Latin American Region:

Argentina: Fundación de Hemisferectomía (FundHemi)
 Associate chapter

# North American Region:

- USA: Epilepsy Alliance America Associate chapter
- USA: Epilepsy Foundation of Los Angeles Associate chapter

# South East Asian Region:

• India: India Epilepsy Foundation Associate chapter

# Western Pacific Region:

 Hong Kong: Epilepsy Foundation of Hong Kong Associate chapter



Argentina Australia Austria Bangladesh Belgium Brazil Bulgaria Cameroon Canada Chile China Colombia Congo, DR Costa Rica Croatia Cuba Cyprus Czech Republic Denmark Dominican Rep Ecuador

Albania

Egypt Estonia Eswatini Ethiopia Fiji Finland France Gambia Georgia Germany Ghana Greece Guatemala Guyana Honduras Hungary Iceland India Indonesia Iran Ireland Israel

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South Africa Spain Sri Lanka Sweden Switzerland Taiwan Tanzania Thailand Togo Tunisia Turkey Uganda UK Ukraine USA Uruguay Venezuela Zambia Zimbabwe

Monday, 14 February, 2022 is

# #EpilepsyDay





www.internationalepilepsyday.org