



# INTERNATIONAL EPILEPSY NEWS

ISSUE 3 - 2021

**Epilepsy & Pregnancy:  
survey report**

**International Golden Lights  
*Meet the Regional Executive  
Committees***

***IGAP Report***



# INTERNATIONAL EPILEPSY NEWS

## ISSUE 3 - 2021

### FROM THE EDITOR

Welcome to a bumper issue of IE News! Running to 37 pages, the magazine is almost twice the size of a regular issue and is bursting with reports and articles of interest to all.

We begin with the final President's Letter, with Martin Brodie looking back on his four-year term of office.

We celebrate the International Golden Light awards, with 19 worthy recipients due to receive their awards during the 34th International Epilepsy Congress. Eight of the awardees will also share their stories during one of the IBE Day sessions - you'll find a link to register for this free event in the magazine.

We also bring you an extremely interesting and important report on the epilepsy and pregnancy survey carried out in Europe in February. The information provided will now be used to inform a comprehensive toolkit being developed to address the knowledge gaps in this vital area.

Another important report is provided by Mary Secco on the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders, which deserves careful consideration.

And, as we draw close to the General Assembly, taking place on 3rd September, we introduce you to the newly elected members of the Regional Executive Committees. The International Executive Committee was featured in the last issue.

As always, happy reading!

Ann Little  
Editor



### CONTENTS

#### 3 PRESIDENT'S LETTER

A look back on  
four busy years



#### 11 IBE DAY INVITATION

Register free  
charge for this  
special event



#### 12 THE WAY FORWARD WHO global plan of action



#### 18 REGIONAL COMMITTEES Meet the newly elected REC members



#### 6 GOLDEN LIGHTS

Meet the  
international  
awardees

#### 14 IBE GENERAL ASSEMBLY

Don't forget to  
register!

#### 15 OBITUARIES Remembering three colleagues who have passed

#### 20 EPILEPSY & PREGNANCY Detailed survey report

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# PRESIDENT'S MESSAGE

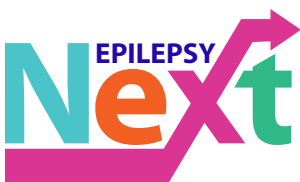
## DEAR FRIENDS

As I sit to write this, my last letter as IBE President, it seems like only yesterday that I penned my first attempt at communicating with the IBE chapters. Yet, looking back, I can see four years full of innovation and action. It has also been a very strange term of office – a term of two halves, the first ending two years pre-Covid and the last two very much affected by the worry, fear, and restrictions that the pandemic has brought to us all, and the rising, if cautious, belief that better days lie ahead.

In my election statement nearly 5 years ago, I stated that 'recognising the talents and drive within IBE chapters is vital if the organisation is to deliver the service and support that their clientele deserves'. We must move from 'top-down' to 'bottom-up' and be directed by the voices that matter - people with epilepsy and those who support and care for them'. This has been my driving goal throughout the last four years, as we slowly developed and introduced new initiatives that would include your involvement - our most important stakeholders.

Building confidence, recognising ability, and supporting capacity, both at national and international levels, is an essential element of the work of IBE. Our goal has been to improve unity, sustainability, and communication, not only among IBE members, but also with our chapters in 104 countries around the world.

### EPILEPSYNEXT focus on youth



The development of EpilepsyNext, a new modular youth platform, was created as a first step and this now represents a major element of our work programme. It helps young people to grow in inde-

pendence and develop the skills and qualities necessary to pursue happy and productive lives. Finally, it challenges them to use these attributes for their own betterment and that of the global epilepsy family. We now have three activities within the EpilepsyNext platform – YEAH, Youth Workshops, and Golden Light Awards.

YEAH – Young Epilepsy Advocates Hub is a Facebook page designed with teenagers in mind, covering those years that can be the most difficult for young people with a diagnosis of epilepsy, who are struggling to establish their identity in the challenging time between adolescence and adulthood. For young people with epilepsy, the desire to be the same as their peers, to be able to stay out late, to drink alcohol (in moderation!), to go



on dates, to enjoy nightclubs can bring extra stress. YEAH recognises the value of peer support at this challenging time in young peoples' lives.

There is wide recognition amongst IBE's chapters that young people are currently under-represented, posing the risk of undermining the future potential of our local epilepsy associations. In addition, the issues facing them are not always receiving the necessary public or political attention around the world. Recognising this, IBE developed youth workshops especially for young adults with epilepsy with the objectives of providing them with the skills to become epilepsy advocates in partnership with IBE's chapters. We held very successful youth summits in Bali and Costa Rica in 2018 and in Bangkok and Dublin in 2019. Unfortunately, Covid intervened in our plans to hold further face to face summits in 2020 and 2021. The third module of EpilepsyNext, which Covid failed to deter, was our regional and international Golden Light Awards! These are meant to honour young people with epilepsy, who have been



Hear my Voice Youth Summit held in Dublin, Ireland, October 2019

a 'shining light' for others and so are deserving of wider recognition. What they recognise is the fact that people with epilepsy should not be defined by their condition but, instead, embrace the longstanding call of IBE to 'bring epilepsy out of the shadows and into the light'. Each opportunity to bestow these awards provides IBE with new possibilities to identify many more young people who have the potential to become future leaders in their own communities and beyond. We launched these youth awards in early 2018 and since then have presented them at congresses in Bali and Bangkok and at the virtual Asian and Oceanian, Latin American and International Epilepsy congresses in 2021. A total of 43 young adults have now received their Golden Light trophies and lapel pins! There are plans to create an awards gallery on the IBE website to highlight the continuing achievements of all those young people who have shared their remarkable stories with us. Congratulations to all of you!

## Our Teams

IBE is its people as well as its chapters and in line with our Strategic Plan we recognise the need to place people with epilepsy and their care providers central to all our decision making. Involving our stakeholders in all IBE's activities is vital if they are to become the motivators of tomorrow. Our objective is to see an expanded IBE board emerge over the next decade, whose membership consists of people with a wide range of knowledge, experience, expertise, and skills. The IBE Teams is a step towards achieving this objective. I was delighted to see a positive response from the chapters to the creation of our Teams, with many chapters sending nominations or promoting this initiative to their membership.

At present, we have four Teams in place:

- **Youth Team:** which aims to increase the participation of young people in decision-making processes within IBE, to identify advocacy opportunities in which they can become involved in our agenda, and to support their self-empowerment to make a difference in society.

- **Professional Development Team:** enables the sharing of good ideas and best practice among chapters; connects individuals and teams from IBE chapters to identify areas of common interest and collaborate in achieving our goals; and identifying opportunities for joint learning and capacity-building within chapters.
- **Research Team:** identifies research priorities of the IBE; engaging in identified projects; and working to provide information to people with epilepsy and their chapters in easy to understand language.
- **Academy Team:** is structured to support the building of the planned IBE Academy through the provision of feedback on modules, pilot-testing and helping with translation work when required.

## IBE in Africa

While IBE's structure recognises seven regions, broadly in line with WHO regional boundaries, with an elected Executive Committee for each region, some of our regions are more energetic than others, for a variety of reasons. Over the past term, our African region has been particularly active, thanks in no small measure to the provision of substantial financial support from the BAND Foundation, which has made possible a number of initiatives with its generous funding to a number of our chapters in the region.

Over the past two years, an African Advocacy Toolkit has been developed, which aims at providing chapters and other groups in the region with the tools necessary to support their advocacy efforts, to encourage national health departments, and to create management plans for epilepsy. A support document is freely available for downloading and regional chapters were provided with online training, the modules of which are also now available. Following the call for proposals, a number of chapters were also provided with funding to support relevant initiatives at a local level.

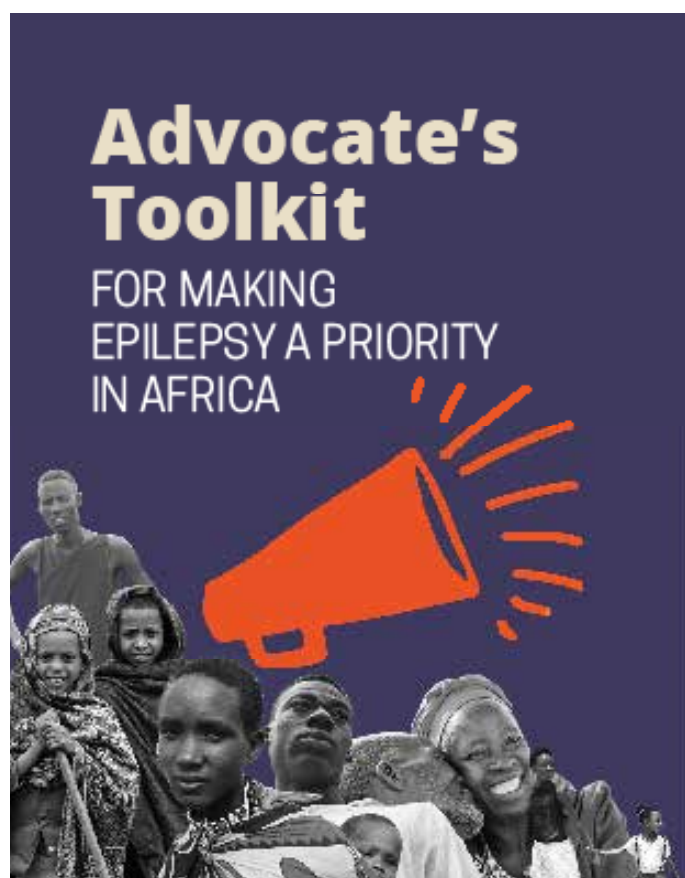
Monthly webinars have played an important role in all this work, most of which have been attended by more than 100 participants. Each of these has addressed a particular aspect of the current climate for people with epilepsy in Africa and the need for better care, easier access to medication, and public education to reduce stigma in the region. Important to all this work is the employment of dedicated full-time administrator and part-time communications officers, with these costs also covered by BAND Foundation funding.

Many of the activities that have been successful in Africa would be suitable for rollout in other regions with minor adjustments. To find out more about these efforts and the accomplishments of this region please visit our dedicated website at [epilepsyafrika.org](http://epilepsyafrika.org).

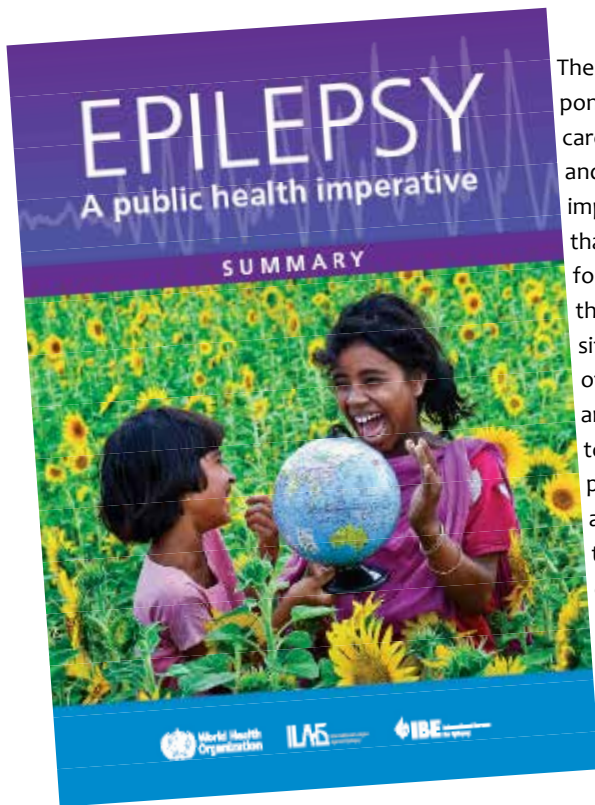
## Epilepsy and Pregnancy

Another initiative, that is being piloted in Europe, but which will be rolled out at an international level, is our Epilepsy and Pregnancy campaign. A working group has been developing this project since early 2021. The group comprises a number of young women from across Europe, as well as medical and other professionals.

As a first step, a survey was carried out, to which just under 900 women of childbearing age from across Europe responded. The main theme of the survey was to establish to what extent women are aware of the risks associated with epilepsy and pregnancy; where they access this information; what support they have received in making choices; at what point did they look for this information and how does it impact on subsequent decisions.







The survey responses have been carefully analyzed and form an important report that is available for download on the IBE website. The results of the survey are being used to inform the production of a multi-faceted toolkit with its own dedicated website. Future plans include having this information available in a

number of languages. While this campaign has been developed with financial support from Sanofi, the company has had no input in the undertaking of the project, nor has it contributed to the content of the material.

## Global Outreach

Twenty-four years ago, in 1997, I took part in the ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows' project, which was launched in Geneva and Dublin. In the intervening years, the working relationship of the three partners has remained strong, with the introduction of a number of initiatives and interventions. The impetus moved up a notch in 2015 with the approval by the World Health Assembly of Resolution WHA68:20 on the 'Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications'. Reacting to the initially slow response of national health departments to the resolution, the first global epilepsy report: 'Epilepsy: A Public Health Imperative' was launched by ILAE/IBE/WHO in 2019 at the time of the 33rd International Epilepsy Congress in Bangkok in 2019.

This momentum has continued thanks to the dedicated efforts of the global outreach group drawn from members of IBE and ILAE, which led to the production of a second resolution in November 2020 on 'Global Action on Epilepsy and other Neurological Disorders'. This resolution called for the development of an Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Disorders in time for consideration by the WHA during its 75th session in 2022. Work on this important initiative is ongoing. I am grateful to all the chapters who played an active part in reviewing the first draft of the IGAP document and in promoting the Out of the Shadows media campaign and Round Table Discussion webinar, which were developed to support epilepsy as an entry point in IGAP for strengthening care and treatment for many neurological disorders including, of course, epilepsy.

Like so many of our other efforts via global outreach initiatives, our aims include to reduce stigma and improve inclusion, to increase awareness through education, and to bring epilepsy into wider public and political focus.

## International Epilepsy Day

International Epilepsy Day has been celebrated annually on the second Monday of February since 2015. A joint initiative of IBE and ILAE, it is a global event geared to promote awareness around the world; a powerful opportunity to highlight the problems faced by people with epilepsy, their families and care providers; and a platform to advocate for appropriate legislation guaranteeing the human rights of people with epilepsy in every corner of the world. In 2021, despite the restrictions imposed by Covid-19, 146 countries in every region of the world organised events to celebrate the day, including the lighting in purple of important public buildings in a high number of major cities across the globe.

New for 2021 was the 50 Million Steps for Epilepsy challenge, encouraging people "to step out for epilepsy" and providing a website with supporting materials and the ability to log all the steps walked. The response by chapters, individuals and other stakeholders to this initiative was tremendous and, by the time the four-week event closed, the counter on the website showed a total of 164,817,721 steps – more than three times our target! The photos, videos and reports from our chapters have shown that the 50 Million Steps challenge has provided them with the opportunity of raising both awareness and critical funds.

Already we are looking at new ideas and opportunities to add to the campaign for 2022!

## Other activities and initiatives

While these were the main initiatives in which I was privileged to be involved over the last four years, there have been many other activities along the way, either newly introduced or ongoing, including our joint congresses with ILAE; our Promising Strategies Program that has supported a number of chapters in creating projects to address local issues and which, to date, has provided almost US\$400,000 in funding since its creation in 2007; our membership development with 17 new chapters added since 2017; and this magazine that has now been in continual production for 58 years, since 1963!

## Remembering those we have lost

In closing, I would like to remember those friends and colleagues who are now longer with us and whom we have lost during the last 4 years. They will forever remain in our memory, and we celebrate their efforts working with IBE to improve the quality of life of all people with epilepsy around the world. May they rest in peace:

- Anthony Zimba: Treasurer 2017-2020
- Robert Cole: Treasurer 2013-2017
- Vinod Saxena: Vice President South East Asia 2009-2013
- Judy Cochrane: Vice President 1993-2001
- Anastasia (Tata) Vassou: Chair, European Regional Executive Committee 2013-2017
- Margaretha (Maggan) Andersson: Member, European Regional Executive Committee 2013-2017
- Mbusumuni Mahlalela: Member, African Regional Executive Committee 2017-2021
- Rosie Panelli: Member IBE Research Commission
- Henry Stokes Brown: IBE Chapter in Guatemala
- Augustine Mugarura: IBE Chapter in Uganda

Please forgive me if I have inadvertently omitted anyone from this list. With best wishes

Martin Brodie  
President

# International Golden Lights 2021

The IBE International Golden Lights awards reward young people affected by epilepsy who have made a significant positive impact on the lives of others who have the condition. The aim is to show that people with epilepsy do not have to be defined by their epilepsy but who embrace the call of the International Bureau for Epilepsy to 'bring epilepsy out of the shadows and into the light'. These 19 worthy candidates, nominated by their chapters, will receive their awards during the Awards Ceremony at the 34th International Epilepsy Congress in late August. You can also meet them and to hear the remarkable personal stories seven of these wonderful people, one speaker from each IBE region, during the IBE Day on 1st September. The IBE Day is free of charge for delegates but you must register in advance. You can find full details on IBE Day on page 9 of this issue of IE News. **Register for IBE Day:** <https://www.surveymonkey.com/r/C9MV3FR>

## Lynna Held, Germany

Lynna is a board member (Vorstandsmitglied) and secretary of Deutsche Epilepsievereinigung (DE). She is dedicated to the development of the self-help group, "Junge DE", for younger members within Deutsche Epilepsievereinigung. She involves other young members in this work without splitting the organisation. The effects are absolutely positive: More young people than ever are getting involved in the activities of the DE and are confidently spreading their knowledge!

[Read Lynna's story here](#)



## Luiza Gatto, Brazil

Luiza was diagnosed with epilepsy four years ago. She has since been using her YouTube channel to reach out to other young people affected by the disease. Luiza is a member of the ABE (Brazilian Epilepsy Association) and now leads a youth group.

Luiza says "I want to say for the people with epilepsy: 'be brave and fight for our rights'." My work teaches me a lot, not only about epilepsy, but about people, about life, but most of all, about how helping others, is always going to be the right way to live."

[Read Luiza's story here](#)



## Mohan Dike, Nigeria

Dr. Mohan Dike joined the Epilepsy Association of Nigeria in July, 2016. Together with Dr S.E. Nwakwue he created a group for youth action against epilepsy which helps to raise awareness among young people and medical students and has since gone on to establish multiple epilepsy centres in his country.

Mohan has been involved in many presentations and support groups to make sure that epilepsy is pushed up the political agenda in Nigeria and in order to bring about change at government level.

[Read Mohan's story here](#)





## Meng-Leo Chou, Taiwan

Meng-Leo has struggled through epilepsy diagnosis, drug dose adjustment and the recurrence of seizures after a seizure-free period in his early epilepsy journey. He has achieved great academic success and has a positive attitude and indomitable spirit toward his epilepsy. Meng-Leo is both a person with epilepsy and a physician training to be a neurologist. Despite the culture of social stigma around epilepsy in Taiwan, he accepted the invitation to lead a six-member group of young adults with epilepsy as speakers at a national conference as part of the Taiwan State Party's implementation of the UN Convention on the Rights of Persons with Disabilities, demonstrating excellent leadership skills.

***[Read Meng-Leo's story here](#)***



## Mohsen Fariborzi, Iran

In 1997 Mohsen had a bone marrow transplant surgery- surgery which was fortunately successful. However, following the surgery Mohsen began having seizures. His physicians said the cause of the newly onset epilepsy was possibly a side effect of different medicines which were used for the bone marrow transplant surgery.

Mohsen is a Member of Institute of Public Law Studies, University of Tehran, a Member of Iranian Constitutional Rights Association and a Member of Iranian Association of Administrative Law.

***[Read Mohsen's story here](#)***



## Praise Bessong, Cameroon

Praise's epilepsy originated as a result of falling and hitting her head at the age eighteen months. Praise describes the negative impact that epilepsy has had on her life and her mental health: "Epilepsy brought me low self-esteem, lack of confidence, stigmatization, abandonment, traumatization and demoralization a lot." Through careful management, Praise has been able to turn this around. There has been a huge improvement in her seizure frequency and severity, and she is now studying English Modern Literature at university.

***[Read Praise's story here](#)***



## Sophie Nabukenya, Uganda

Meet Sophie Nabukenya from Uganda, a volunteer with the Purple Bench Initiative.

"My dream is the whole world to understand that epilepsy is a disease like any other; people living with it are not bewitched, demon-possessed or insane. They can achieve every one of their goals if they seek and adhere to their medication, stop pity-parties, work hard and believe in themselves like I do."

***[Read Sophie's story here](#)***





## Valentina Khan, Chile

When Valentina was a child, she had a rare kind of epilepsy, with an abnormal electroencephalogram and had seizures very often, sometimes many in the same day. With the support of her family and neurologist, Valentina's began to have less seizures and by age 18 she had none at all. The experiences of her childhood paved the path towards her becoming a professional who could help children with motor problems due to neurological causes. Valentina has now been working as a neuro pediatric physiotherapist for more than 7 years. Read Valentina's story here.

**[Read Valentina's story here](#)**

## Veselka Šoštarić, Croatia

Veselka Šoštarić, from Croatia, was diagnosed with epilepsy at 14. Sadly, in Croatia there was, and remains, a common misconception that epilepsy is a mental illness. Veselka experienced a lot of prejudice and stigma. Now 32, Veselka is married with three beautiful, intelligent and completely healthy children: a daughter and two sons. She explains "There are a lot of fears when starting a family when you are diagnosed with epilepsy. But in collaboration with a neurologist, I adjusted my medication during the family planning period, and with the help of a doctor, gave birth without significant problems."

**[Read Veselka's story here](#)**



## Adi Vaknin-Aviram, Israel

Adi Vaknin-Aviram is an Israeli writer, bibliotherapist and a PhD doctorate in literature. Her first book, "Aura" was published last March. The book tells the story of Gabi, a young woman living with epilepsy. The story of Gabi was inspired by Adi's own experience of epilepsy. She was diagnosed with epilepsy at 7 years old, with tonic clonic and absence seizures. Adi hopes her book will offer a personal point of view and raise awareness about the topic.

**[Read Ad's story here](#)**

## Alison Kukla, USA

"Epilepsy was a big part of my life and I often felt misunderstood and unable to connect with others who could relate. This sparked my volunteering in the epilepsy community to help find other people who could relate to my experiences..."

I use my platform and experiences living with epilepsy to help others. It took me years to connect with others living with epilepsy, so I frequently mentor others, so they don't have the same experience I did. While I certainly didn't choose my diagnosis, I am thankful it helped me find my calling."

**[Read Alison's story here](#)**





## Bright Bwalya, Zambia

Bright M Bwalya is a 29 year old epilepsy and mental health advocate, poet, innovator and entrepreneur living with epilepsy. Bright was diagnosed in 2016, a year before finishing university. Multiple daily seizures placed a huge strain on his studies but as his dissertation Bright developed a mobile application for people with epilepsy or convulsive disorders and for the general public.

A passionate advocate, Bright explains, “Even if I am not cured, I am proud to have the strength and be a beam of light to those still in the dark about this condition, for them, I will be strong and be Bright.”.

***[Read Bright's story here](#)***



## Cassidy Megan, Canada

In 2008 Cassidy founded Purple Day, an epilepsy awareness day that is now celebrated globally every year on March 26th. Cassidy started Purple Day motivated by her own struggles with epilepsy and the discrimination and stigma that came with it. Her goal is to get people talking about epilepsy in an effort to dispel myths, reduce stigma and let those living with epilepsy know that they are not alone

***[Read Cassidy's story here](#)***



## Emily (Ka Yan) Kwong, Hong Kong SAR

Emily is a young member in the Hong Kong Epilepsy Association. Emily has had epilepsy since her childhood. Epilepsy has been devastating for her both physically and psychologically. Her study and school life were affected adversely. Nevertheless, she has a motto to support herself and others: ‘Never give up’. Emily has now completed her academic pursuits with a diploma. She has demonstrated her perseverance in leading a positive life and is a great example for other people living with epilepsy.

***[Read Emily's story here](#)***



## Lai Siew Tim, Malaysia

Siew Tim is a mindfulness-based therapist under the Epilepsy Research Programme at the University Malaya Medical Center, Malaysia. During the process of history taking, Siew Tim utilised psychotherapeutic techniques and assessments to understand the needs of people with epilepsy (PWE). This allowed her to provide individualised interventions for PWE to relate to their diagnosis and learn to cope with stressful life events.

Siew Tim received an award from the ILAE Young Leadership Development program, and subsequently joined the Young Epilepsy Section.

***[Read Siew Tim's story here](#)***





## Vinay Jani, India

Vinay resides in New Delhi. He is an Ultra Randonneur, 4 Times Super Randonneur, a Marathoner and attempted Paris-Brest-Paris in 2019. In July 2005 Vinay was diagnosed with focal seizures due to a cyst in the left temporal region of his brain. This affected his lifestyle and daily routine in a massive way. Recently, Vinay spoke on a webinar conducted by Indian Epilepsy Society and become a member of epilepsy support group Ekatwam. Vinay is currently fund raising for the Child Raise Trust through participation in the Tata Mumbai Marathon 2021 which will be utilized for medicines for underprivileged children with epilepsy..

[Read Vinay's story here](#)

## Camila Herzberg Cuetu, Cuba

Camila Herzberg Cuetú is a young Cuban girl who has addressed epilepsy issues and made them visible through the arts, in a creative and transversal way. Camila is one of the founding members of the first group of teenagers with hemispherectomy on the social media, a tool that she applies to teach the techniques and resources she has acquired to live in our world with the use of one hand and just half a brain. Camila's first book was published in 2013. To date, she has published 6 short stories and is currently working on another

[Read Camila's story here](#)



## Oliver Kilmartin, Ireland

Oliver explains: "Like many people with epilepsy, I have had negative experiences associated with living with the condition but in so far as possible, I have used those experiences to try and help increase understanding and awareness. My participation in the 2020 International Epilepsy Day campaign was one such example of this."

[Read Oliver's story here](#)

## Fred Beuchi, Kenya

Fred is the secretary of the National Epilepsy Coordination Committee in Kenya. He is inspired by his youngest sister Mercy Kwekwe Mboya, who was diagnosed with epilepsy at the age of 2 years following cerebral malaria. Fred is also a counselor and his background in theology has enabled him inspire and give hope to hundreds of youth living with epilepsy. Recently, Fred organized and participated in an Epilepsy Awareness Challenge involving a 3 day, 327km cycle and climbing Mt. Kilimanjaro.

[Read Fred's story here](#)







**Wednesday 1<sup>st</sup> September 2021**

## **IBE Day at the 34<sup>th</sup> International Epilepsy Congress**

**Time: 07:00 EST, 13:00 CET/CAT, 16:30 IST, 19:00 CST, 21:00 AEST**

*If you are unsure about the start time for where you live, contact us at [annlittle@ibe-epilepsy.org](mailto:annlittle@ibe-epilepsy.org) for help.*

### **Three (3) two-hour virtual sessions:**

1. Making Epilepsy a National Health Priority - intersectoral collaboration

*Chairs: Mary Secco, IBE Secretary General and Action Amos, IBE Vice President Africa*

2. Empowering Youth to Raise their Voices

*Chairs: Lorraine Lally (Ireland) and Scarlett Paige (Australia), co-chairs of the IBE Youth Team*

3. Best Practices to address the Psychosocial Impact of Epilepsy

*Chairs: Gus Baker, IBE Secretary General-elect*

**Plus** presentation of the International Golden Light Awards

More information on speakers coming soon.

**REGISTRATION IS FREE BUT YOU MUST REGISTER TO ATTEND!**

To register, please click **HERE**

# The 'Way Forward': WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031)

by Mary Secco, Secretary General



As you read this article I encourage you to go to the global advocacy pages on our IBE website. On these pages we have uploaded many different documents related to our advocacy efforts to improve the social condition of people with epilepsy in all regions of the world.

To understand the 'way forward' it is important to put into context some past successes at the international level, beginning on May 26, 2015, when 194 countries from all regions of the globe approved a Resolution known as WHA68.20. The wording in this Resolution recognized the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications. This was the first time the World Health Assembly had formally recognized epilepsy as a public health priority and the first step in putting 'epilepsy' care on the radar of countries around the world! This was an enormous accomplishment for our global epilepsy community and demonstrated the power of leveraging our collective voice. Congratulations!

Following the passing of the Resolution, WHO invited IBE and ILAE to co-develop a global report to provide guidance to governments on 'why' epilepsy is a public health imperative and to provide recommendations to strengthen leadership and governance, citing possible solutions to improve epilepsy care. The report titled *Epilepsy: a public health imperative* was published in 2019. The report reinforced the importance of developing access to safe and affordable antiseizure medications, recommended cultural approaches to reducing stigma, and ways to reduce preventable cases of epilepsy. It also recommended cost effective and scalable strategies to improve care. The report is a 'must read' for global advocates. While these two documents provided guidance for countries, what was missing was an action plan – a specific set of details and indicators to guide this important work.

So, in February 2020, IBE and ILAE returned to Geneva to advocate for a formal action plan to improve epilepsy care. During this meeting a draft decision received strong support but many countries wanted to increase the scope of the action plan and added other neurological disorders to the plan citing the burden of all neurological conditions and the potential synergies in developing care pathways. With so many other neurological conditions engaged in the process our IBE goal was to ensure that 'epilepsy' was maintained as a priority condition in the action plan.

On November 9, 2020 a virtual meeting was held (due to COVID) where countries from around the world requested that WHO develop a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. These countries stated that the 10-year plan should address the current significant gaps in promotion of physical and mental health, prevention, early detection, care, treatment and rehabilitation as well as the social, economic and educational needs of persons with epilepsy and other neurological disorders. The plan was to include ambitious, but achievable, global targets on reducing preventable cases and avoidable deaths from epilepsy and other neurological disorders; strengthening service





coverage and access to essential medicines; improved data collection on the incidence at the country level; and critical research in addressing discrimination and stigma.

In March 2021, the WHO Brain Health Unit distributed a discussion paper asking member states (governments), United Nations agencies, relevant non-state actors (like IBE and ILAE) and people with different neurological conditions to provide formal feedback on a draft plan of action. At this time, you may recall that IBE sent a survey asking our chapters from every region in the world to identify their priorities. After consolidating your priorities, IBE submitted a formal response. Our comments were considered alongside others from many sectors and multiple stakeholder groups.

In June 2021, the WHO Brain Health Unit circulated the first draft of the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (2022 – 2031). This first draft can be found on our IBE website. The IBE executive was very pleased, as the plan has many strengths, and we are beginning to see the ‘way forward’ for improving care in epilepsy, especially in regions of the world where there is the greatest burden. The first draft recommends that countries leverage epilepsy prevention, treatment and care as an entry point to reduce the stigma, impact and burden of neurological disorders. The IBE executive applauds this recommendation. The first draft includes five measurable strategic objectives, all with global targets. Global target 5 is specific to epilepsy and recommends that, by 2031, countries will have service coverage for epilepsy increased by 20%. Is 20% good enough? Is it OK to have a 10-year plan where over 30 million of the 50 million people with epilepsy will still not have access to care? We think not. For this reason, we are recommending that the WHO amend global target 5 to include a more ambitious target:

1. 90% of people with epilepsy are aware of their diagnosis as a treatable brain disorder
2. 80% of people diagnosed with epilepsy can access appropriate, affordable, safe antiseizure medicines and

3. 70% of those treated achieve adequate seizure control. We are working with the ILAE to demonstrate to the WHO Brain Health Unit and to governments that this cascade target (90-80-70) is achievable.

IBE is also recommending a second target (5.2) be added to address stigma and discrimination. This proposed target would request countries review their existing legislation, particularly in the areas of education, driving, employment, marriage and fertility, with a view to addressing and amending clauses that discriminate against people with epilepsy and other neurological disorders. It is the IBE position that reducing stigma is essential for improving access to quality care.

These two recommendations will be considered by the WHO Brain Health Unit in the upcoming months as they develop a second draft of the global action plan. We will post this second draft on our IBE website when it is released in September. We will also circulate it to you - our chapters. Some important thoughts - as people with epilepsy and those who care for them, it is essential that you send us your comments on this second draft plan of action. You are the experts and know your community well. You also know the names of local policy makers and government officials, so, please meet with them as your voice will resonate loudly.

To learn more about global advocacy and our work with the WHO, please join the IBE virtual session on September 1st where a distinguished list of speakers will speak about the action plan and recommend tools for advocacy and strategies to develop Intersectoral Collaboration.

**Link to the IBE website page to find out more:**

<https://www.ibe-epilepsy.org/initiatives/global-advocacy/>

**Link to register for the IBE Day session (free of charge but registration is mandatory):**

<https://www.surveymonkey.com/r/C9MV3FR>



## International Bureau for Epilepsy **GENERAL ASSEMBLY 2021**

**Date:** Friday 3rd September 2021

**Time:** 07:00 EST, 13:00 CET/CAT, 16:30 IST, 19:00 CST, 21:00 AEST

**Duration:** The meeting will run for no longer than two hours

All IBE Chapters (Full, Associate and Provisional), Regional Committees, Team Members and other interested stakeholders are invited to attend.

**Prior registration is mandatory.**

If you wish to attend the assembly, please email Ann Little, Executive Director, at [annlittle@ibe-epilepsy.org](mailto:annlittle@ibe-epilepsy.org), in order to receive a link to the meeting.

*EST (Eastern Standard Time, USA), CET (Central European Time), CAT (Central African Time), IST (India Standard Time), CST (China Standard Time), AEST (Australian Eastern Standard Time).  
Still unsure of the start time for where you live? Then please email us for help.*





# JUDY COCHRANE

3 April 1940 – 14 June 2021

Judy Cochrane began her working life as a teacher, initially of English and history in high schools in England and Australia, then in the English Department of the University of Queensland, where she also completed her master's degree. On returning to the UK she taught at the University of Glasgow and then worked with Quarriers, where she was responsible for overseeing the education of 500 children in residential care.

Judy's long and successful career in epilepsy began in 1984 when she joined the Epilepsy Association of Scotland. From the beginning her belief that people with epilepsy should live a full and meaningful life, and have access to the same opportunities as everyone else, informed everything that she did and led to improved services for people with epilepsy in Scotland and beyond.

As Head of Epilepsy Support Services, she launched a number of initiatives to support people with epilepsy and their carers including a phone helpline, a network of community-based epilepsy fieldworkers, and a national epilepsy befriending service. A key focus of her work was the education of a wide range of health care and other professional groups including social care and housing staff, as well as police, ambulance, and prison staff, providing them with the knowledge and skills needed to inform their professional practice in relation to epilepsy.

Judy saw information as critical to empowering people with epilepsy and their families come to terms with and to manage their condition and she oversaw the development and distribution of comprehensive information resources on a wide range of topics and formats to ensure accessibility. She saw the benefits of working with others to produce standardised, high-quality materials and as an active member of the Joint Epilepsy Council of the UK and Ireland (JEC) she led the development of shared resources for all JEC member organisations to use. These included, among others, ground-breaking resources about epilepsy and sexuality, men's lived experience of epilepsy, and the UK's first information leaflets about childhood epilepsy syndromes.

In 1992 Glasgow hosted the 3rd Epilepsy and Society Conference with Epilepsy Association of Scotland as the host organisation. Judy played a significant role in developing the programme for and running this successful event. In 1993 she was elected Vice President of the International Bureau for Epilepsy and during her two terms in this role she chaired the IBE's Public Education Commission, leading the global development of public awareness raising and epilepsy training programmes, and nurturing the Youth Commission for young adults with epilepsy.

The impact of Judy's work extended throughout Scotland, the UK

and beyond. Her contribution was recognised with the Ambassador for Epilepsy Award in 1993.

Judy's commitment to making life better for people with epilepsy continued after her retirement in 2000 and in that year she set up a new charity with a local focus, Epilepsy Connections, to support people with epilepsy and their families in Glasgow. During her 15 years as a Trustee of the charity, Judy freely gave of her time, knowledge, wisdom and example, and after she stepped down she retained her interest in the charity's progress and remained a much loved and respected source of inspiration, advice, and encouragement. Under her guidance, Epilepsy Connections thrived from the start and today provides epilepsy information, support, counselling and training to thousands of people in Scotland every year.

Over her long career Judy established relationships with people throughout the world, and many professional relationships became long standing friendships too. She will be remembered for her formidable intellect, her warmth, hospitality, compassion, and capacity for fun. Those who knew her well will also remember her devotion to her family, her love of gardening and of Scottish country dancing, and her lifelong passion for Manchester United Football Club.

As colleagues and friends we were privileged to know Judy, and we miss her.

*Shirley Maxwell & Christine McGarvey, Epilepsy Connections, Scotland*

## **Contribution from Shona Scott, Vice President, Epilepsy Research UK**

*Judy made a really significant contribution to the development and running of the charity in her time as a founding trustee and vice chair of Epilepsy Research Foundation (now Epilepsy Research UK). She was passionate in her commitment to improving the lives of people with epilepsy through research, and to working collaboratively with others to achieve that. A great supporter of the staff team and a positive instigator of and contributor to new initiatives. Appreciative always of the efforts of the charity's supporters to fundraise for research, and generous with her time in turning out to meet and thank people, such as meeting the Edinburgh Marathon runners.*

*She was a great encourager of collaboration across the epilepsy community – both to achieve more together, and to avoid wasteful duplication of resource and effort - and embraced the opportunity the internet offered for the sharing of high-quality information resources to support people with epilepsy.*

*A lovely lady – positive, efficient and effective, warm, saw the funny side in life and people – always good to be around."*



# Anastasia (Tata) Vassou

*26 December 1956  
to 25 June 2021*

## Remembering a remarkable woman

Anastassia Vassou, better known to everyone as Tata, was born in Athens. Through generations she had family connections with Monopoly-Italy on her mother's side and Malta on her father's side. She began working as an EEG technician at the age of 24 years, and was particularly involved in recording brief or long duration sleep-awake video EEGs of children with a variety of paroxysmal events. She would take detailed histories, not only of the recording events, but also of the background family anxieties and morbidities.

In her work as an EEG technician in the Neurology/Neurophysiology department at the Children's Hospital Aghia Sophia in Athens, she met children who were not old enough to understand what was happening to them; children who had learning difficulties and did not like school; children who had difficulty socializing at school and wanted to stop attending; children who refused to take their medication; parents who collapsed on hearing a diagnosis of 'epilepsy'; parents who did not accept their child's problem; or parents who were overprotective and anxious about their child's future.

She soon became a key person of both the IBE and ILAE Greek chapters, initially devoting most of her free time to them and, when she retired and became a pensioner, her time was totally occupied with the activities of epilepsy in Greece. She was the person taking phone calls and answering messages sent to the office from all over Greece from people with epilepsy, caregivers and parents. She organized speeches on epilepsy in schools and for society at large in order to improve awareness and educate people about the real facts on epilepsy. Together with the epilepsy specialist nurse they created groups of people with epilepsy giving them psychological and social support. It was very emotional when people with epilepsy managed to get out of the "dark tunnel" and wanted to offer their help to others by sharing their experiences and explaining the way they had found to have a normal life.

She became an important figure in the organization of the annual Pan-Hellenic epilepsy congresses and workshops. Tata made the ILAE and IBE Greek chapters her second family and fought to inform and raise public awareness about epilepsy; we are eternally grateful to her.

The president and the Board Members of the two chapters, as well as the epilepsy society in Greece and abroad are devastated by the death of our beloved Tata, who consistently served the purposes of the chapters and stood by people with epilepsy, with love. She offered her services for over 30 years, to a special category of children and later to all people with a particular neurological problem for which they are often stigmatized. Her exceptional character and her wonderful way of communication soon made her well known and she gained excellent friends and communication channels not only in Greece but also abroad.

A journalist wrote of Tata: "Tata left early, spreading immense sadness to all those who in recent years had the pleasure of working with her. She consistently served the purposes of the Greek chapters and was on the side of people with epilepsy, with love. We thank her, we are grateful to her, and we commit that we will continue to work for a world without prejudices and stigma".

With great sadness, with our hearts heavy from the unfulfilled loss, we say goodbye, shocked, one of our own people, a collaborator, who passed away prematurely.

Those we love do not leave, they will remain in our hearts for many years to come. Have a good journey dear colleague and friend.

*Thanos Covanis on behalf of the member of the Greek IBE/ILAE chapters*

### **Note from IBE:**

Tata was well-loved by all who came to know her at IBE. Her first involvement was at the time of the Epilepsy & Society Conference held in Athens in 2020 where she played a large role in ensuring that everyone was well looked after.

She would later serve on the IBE European Regional Executive Committee, becoming its Chair for the term 2013-2017. Her laugh was infectious, her caring generous personality was unrivaled and her collection of silver bangles, for which she was famous, much coveted!

Her friends in IBE in Europe were greatly saddened to hear of Tata's sudden death but her kindness will be long remembered. May she rest in peace.





# ROSEMARY PANELLI

*30 June 1952 – 27 April 2021*

Rosemary Panelli's professional life began as a registered nurse in the 1970s, with a job with the Arthritis Foundation of Victoria her first experience in the community service welfare sector. She later moved to the Epilepsy Foundation of Victoria playing a pivotal role in the reinvigoration of the Foundation's engagement with its community - people with a lived experience of epilepsy and those who wished to support them.

Learning from the Multiple Sclerosis Society and the St Vincent de Paul, she developed the Foundation's shops program, which became a profitable and highly valued part of the Foundation's outreach to the community.

Rosy also provided training and support volunteer speakers, which produced a number of outstanding public speakers who were further supported in training as counsellors with accredited training in solution focused counselling.

To increase her knowledge and expertise, Rosey undertook a Masters degree in Public Health and went on to study for a PhD.

A turning point in her epilepsy focus came about through contract with Jennifer Preston and Jane Hanna, who had lost loved ones with epilepsy to SUDEP and who had set up the UK charity Epilepsy Bereaved (now SUDEP Action). This would lead to a lifelong drive to increase knowledge about and research in SUDEP.

In 2005, Rosey along with Denis Chapman from Epilepsy Australia, Brendon Moss, and Russell Pollard, produced "Sudden Unexpected Death in Epilepsy: A Global Conversation" with funding support from IBE. It contained inputs from 14 nations, giving voice to what both experts and ordinary people with lived experience knew about SUDEP and looking at the work that needed to be done. The book was hugely successful, leading to second and third editions.

This was a truly groundbreaking book as it clearly demonstrated that the global conversation about SUDEP, and indeed about epilepsy, was one that appropriately engaged people all over the world from both the medical profession and from those engaged in public health including ordinary members of the community with lived experience. It also demonstrated very clearly that many

people living with epilepsy wanted to talk openly about the condition with which they were living and they wanted to be engaged in conversations about all aspects of it. By the time of its third edition, Rosey had become the International Research Officer for the UK's SUDEP Action. At the 10th Asian and Oceanian Congress of IBE and ILAE held in Singapore in 2014 she told more than 1,000 delegates that "By working together we can push forward the global conversation on SUDEP which is vital to research and action on SUDEP and epilepsy-related deaths wherever we are in the world."

Rosey also organised dragon boat racing teams involving doctors, nurses, EEG staff from hospitals and epilepsy volunteers, to further raise epilepsy awareness in Victoria.

At an international level, Rosey was a member of a number of IBE commissions and working groups, most notably the IBE Research Commission. To recognise her contributions to the epilepsy community, we were awarded the IBE/ILAE Ambassador for Epilepsy Award in 2011. In 2016 she won the BMJ community neurology award for The SUDEP and Seizure Safety Checklist.

People who knew Rosey knew that she was a woman of extraordinary energy and commitment. A woman with a first class intellect, a gifted communicator, a warm human being with a broad inclusive smile and a winning sense of humour. She was a very good listener and a sharer of ideas..

In her short life she went from university into nursing and to horticulture moving to the public health sector. Her academic accomplishments while richly deserved were hard won - she had to work for them, while raising a family and tending to demanding jobs involving contact with many people across many different communities, all the while studying and learning to become a first class researcher. Rosemary Panelli was widely respected around the world for her work in public health where her legacy will live on. May she rest in peace.

*Text: adapted from a longer obituary provided by Pauline Brockett, Maree Kearton, Russell Pollard and Terry O'Brien*

*Photo: LARRY PITT PHOTOGRAPHY*

# Meet the Regional Executive Committees 2021-2025

## AFRICAN REGION



Action Amos, Malawi  
VP/Chair



Youssouf Noormamode,  
Mauritius, Vice Chair



Betty Nsachilwa, Zambia  
Secretary

## EASTERN MEDITERRANEAN REGION



Hassan Hosny, Egypt  
VP/Chair



Najib Kissani, Morocco  
Vice Chair



Fatma Kamoun  
Tunisia, Secretary

## EUROPEAN REGION



Natela Okujava  
Georgia, VP/Chair



Thomas Porschen  
Germany, Vice Chair



Erin Davies, UK  
Secretary



Claudine Aitken, Malta  
Member



Ana Sruk, Croatia  
Member



**The term of the incoming regional committees will begin at the time of the General Assembly on Friday 3rd September and run until 2025. However, the term of office of the Vice President (VPs) will end in 2023.**

**The members of the International Executive Committee were announced in the last issue.**

## **LATIN AMERICAN REGION**



Tomás Mesa, Chile  
VP/Chair



Alicia Bogacz  
Uruguay, Vice Chair



Mauricio Olave  
Colombia, Secretary

## **NORTH AMERICAN REGION**



Deirdre Floyd, Canada  
VP/Chair



Vice Chair  
to be announced



Secretary  
to be announced

## **SOUTH EAST ASIAN REGION**



Man Mohan Mehndiratta  
India, VP/Chair



Muzharul Mannan  
Bangladesh, Vice Chair



Secretary  
to be announced

## **WESTERN PACIFIC REGION**



Ding Ding, China  
VP/Chair



Anchor Hung,  
Hong Kong SAR, Vice Chair



Chris Dougherty  
Australia, Secretary



# Epilepsy & Pregnancy Toolkit SURVEY REPORT

As part of the IBE Epilepsy & Pregnancy Campaign, which is running as a pilot in Europe, a survey was carried out in February/March to establish the level of knowledge of women of childbearing age about the risks associated with epilepsy and pregnancy.

Beginning on International Epilepsy Day, 7th February, and ending on International Womens' Day, 8th March, almost 900 women responded to the survey, which was available in 10 European languages - English, Spanish, French, Italian, Croatian, Czech, Polish, Russian, German, Greek and Georgian.

The campaign working group has now completed its report on the survey which is being widely circulated. Of particular significance are the open comments provided by a large number of respondents which will play an important role in directing the focus and content of the multi-faceted toolkit, which is the major output of the campaign.

The campaign working group would like to thank all those who took the time to answer the survey and share their personal experiences. The survey was totally anonymous.

A summary report is also being prepared, which will be made available in the coming weeks.

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





## INTRODUCTION

1. While the majority of women with epilepsy will have successful pregnancies, it is vital that women of childbearing age are fully informed on all issues relating to epilepsy and pregnancy. The use of anti-seizure drugs (ASDs) has been associated with an increased risk of birth defects such as cleft palate, spina bifida, autism spectrum disorders or a lower IQ. Nevertheless, seizure control during pregnancy is vital because the risks involved from having uncontrolled seizures can be greater than the risks from ASDs themselves. There is a 25% risk of seizures become more severe during pregnancy and seizures can cause miscarriage, premature labour or affect the baby's heart rate by lowering it to a dangerous level. However, ASDs can also cause issues for pregnant women with epilepsy, with drug levels falling during pregnancy and then rising post-partum so that it is very important for continuous monitoring of levels at this time.
2. Given that up to 50% of pregnancies are unplanned, it is very important for women with epilepsy to talk with their doctors before they consider becoming pregnant so that they are fully informed on the risks involved and, together, they can work to ensure the best possible outcome to a pregnancy. Informing women of child-bearing age about the problems that might arise in a pregnancy, due to their epilepsy, is vital for both the mother and her unborn child. Getting the right message, to the correct audience, in the most appropriate format, is vital.
3. A public hearing, hosted by the European Medicines Agency (EMA) in 2017, reviewed the prescription of medicines containing sodium valproate for women and girls who are of childbearing age. The discussion among the 65 stakeholders who attended the hearing, 28 of whom were people with epilepsy, also looked at the wider issues around epilepsy and pregnancy. At the hearing, IBE emphasised the need for improved public information and health education on all matters relevant to women of childbearing age and pregnancy, advancing advocacy and the exchange of international best practice. It was proposed that a well-organised education campaign was required, in all EU languages, to ensure that as wide an audience as possible was reached. Following on from the public hearing, a stakeholders meeting was organised at which it was agreed that, in ensuring the women of childbearing age were fully informed on the risks associated with epilepsy and pregnancy, personal communication and trust with healthcare professionals should be the basis of the dialogue, with positive messages and explanations as part of this communication.
4. There was agreement that improved information resources had been developed in a number of EU member states. However, these were not reaching the right people at the right time. The distribution and use of these materials, as well as the acceptance of the need for change, had not happened as had been hoped. In addition, risk minimisation had not always been apparent. The consensus was that the status quo was not acceptable, and it was clear that things could, and should, be done better. Two years later, it appeared that there was still little success in getting the message on the risks associated with epilepsy and pregnancy to the right people.
5. This problem was raised by young adults attending an IBE Epilepsy Next workshop in Dublin in 2019. The partici-

pants, from 12 different European countries, highlighted the lack of knowledge among many young people with active epilepsy around the issues of contraception, pregnancy and childbirth. They were particularly concerned that young people were often unaware of the associated risks for those with active seizures. The participants discussed how knowledge around this topic differed greatly across Europe and, indeed, even at a country level. The willingness of some doctors to discuss contraception, family planning and pregnancy, national legislation and religious teachings that impacted on safe family planning for people with epilepsy, and the need to support self-empowerment of people with epilepsy to be able to discuss these matters with their care providers were also discussed.

## FOCUS OF THE SURVEY

6. The main theme of the survey reported on here was identified as to establish to what extent women with epilepsy of childbearing age are:
  - Aware of all of the risks associated with epilepsy and pregnancy
  - Informed of such risks by their GPs and healthcare specialists
  - Supported by their healthcare providers in making informed choices
  - Where the patient is not provided with information by their healthcare providers, where do they look for this information – internet, social media, epilepsy association, other sources
  - At what point do they look for information – before considering pregnancy, when considering pregnancy, when they become pregnant?
  - How does the information they receive impact on their decisions?

## PROPOSED SOLUTION

7. IBE would like to address the knowledge gap around epilepsy and pregnancy by working with its Global Youth Team and with key professionals, including medical professionals:
  - to establish why key messages are not reaching young adults at the time of their lives where information on epilepsy and pregnancy is most urgent;
  - to identify the type of information and the format in which it is delivered that would be effective in closing the gap;
  - to create and deliver key messages in those formats to the widest possible audience.
8. Vital to delivering the message will be the young people themselves. While stigma and medical paternalism have been barriers in the past in involving the most important stakeholder group in raising awareness about epilepsy – persons with epilepsy themselves – the barriers are beginning to come down and there is a rising confidence in this age bracket to discuss their epilepsy and what they need to enjoy the best possible quality of life. They are the most powerful advocates for epilepsy.
9. A key reason for involving the IBE Global Youth Team is because of the importance of informing women about the risks around epilepsy and pregnancy before they reach the stage of planning a family. Once they are aware of the

risks and how best to minimize such risks, they are then forewarned and forearmed for the duration of their child-bearing years. Peer to peer messaging will be important in this work.

10. The organisers of this project agreed that in the initial stage there would be a need to conduct a survey to determine what women with epilepsy and their families knew and understood about the risks associated with antiepileptic drugs and pregnancy.
11. The results of the survey would inform the development of a toolkit. Such a toolkit, which will act as a guide for advocacy planning and an aid to build capacity of the user, will be central to the campaign. It will be developed to be user-friendly, culturally relevant and visually engaging. It will be produced with print, web and social media in mind and with any medical information validated by the medical members of the project team.

## PROJECT GROUP

12. Collated responses from each survey provided an overall picture of the situation across Europe and provided the basis to consider where the knowledge gaps lie and which knowledge areas are falling short. A project group, drawn from all relevant stakeholder groups, will then be tasked with developing a programme of materials in a format that is likely to reach its target audience.
13. The group is comprised of members of the IBE Global Youth Team (members drawn from across Europe to ensure a wide focus), IBE President (Prof Martin Brodie), members of Epilepsy Alliance Europe (the joint task force in Europe of IBE and ILAE [epilepsyallianceeurope.org](http://epilepsyallianceeurope.org)), IBE Executive Director Ann Little, President-elect Francesca Sofia and Secretary General-elect Professor Gus Baker.

## METHODOLOGY

14. In the first instance the survey was conducted in 9 countries in Europe, with involvement of a number of IBE chapters. In order to ensure maximum take up of the survey, it was necessary to have the content translated to a number of different European languages for those countries where English is not the primary language.

15. The survey ran for eight weeks using SurveyMonkey software, which gathered information on the extent of information available across Europe, and its uptake by all relevant stakeholders. IBE chapters were involved in rolling out the survey at local level to capture data on the knowledge gap that exists.
16. The sampling frame for the study was social media, mailing and IBE databases, website promotion. A self-completion questionnaire addressing a number of epilepsy and pregnancy issues was developed.
17. The questionnaire contained information relating to the following areas:

### Demographic details

18. Information was obtained about respondent age, marital and employment status, education, country of origin, and membership of an epilepsy organisation.

### Clinical Information

19. This included information in relation to number of years since diagnosis, whether under the care of an epilepsy specialist, pregnancy history, and history of anti-seizure medication.

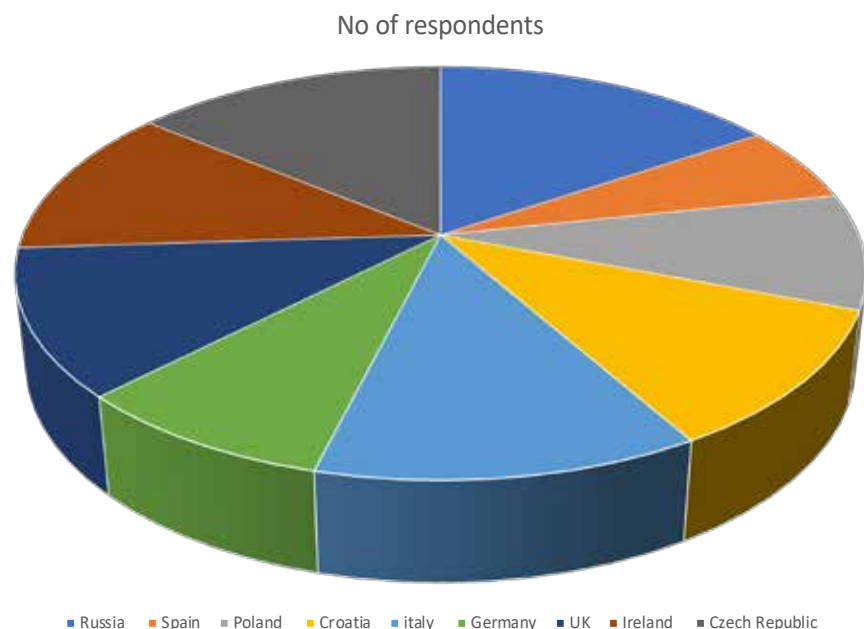
### Access to Information about Pregnancy and Epilepsy

20. Information was obtained about access to information about epilepsy and pregnancy. Information was obtained in respect of the source of the information and its value to the respondent. Respondents were asked to consider their level of knowledge of the risks of epilepsy and pregnancy and their decision-making as to whether to have a family or not.
21. Respondents were given the opportunity to provide free comments on many of the aspects covered in the questions.

## RESULTS OF THE SURVEY

22. In all, 890 questionnaires were registered on the SurveyMonkey survey. The breakdown by country is shown in figure 1. The majority of respondents (66%) were drawn from four countries, Ireland (11%), United Kingdom (11%), Russia (15%), Czech Republic (14%) and Italy (15%). The other participating countries each contributed <10% of respondents.

**Figure 1 Questionnaires completed by country**



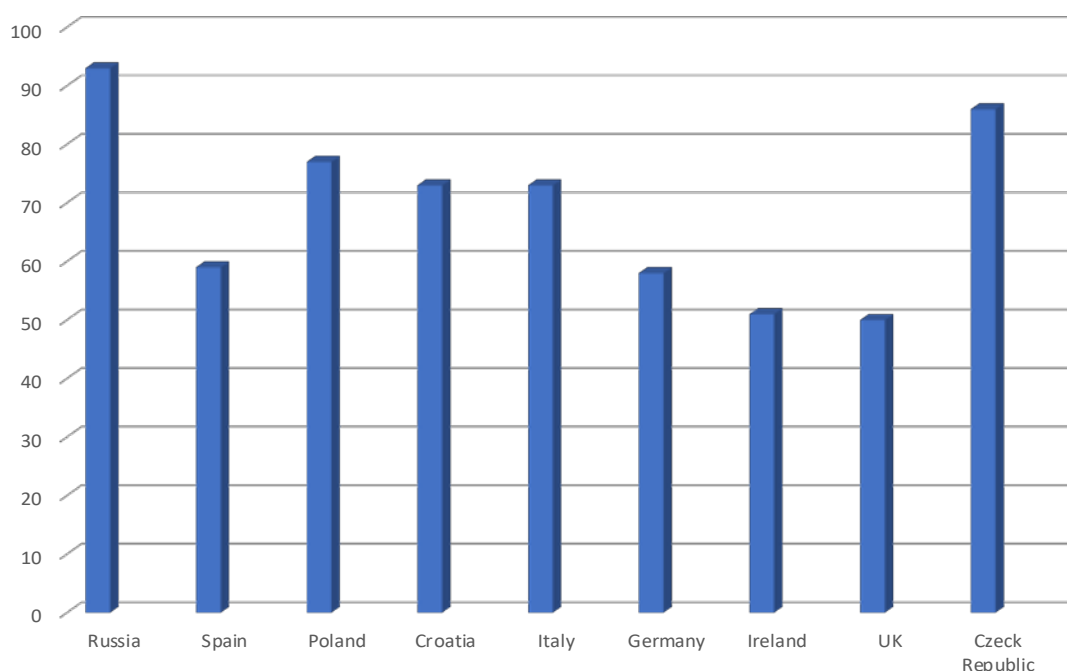
**Table 1. Number of respondents by country included in the report**

Country	No of Respondents
Russia	136
Spain	52
Poland	78
Croatia	94
Italy	107
Germany	74
UK	99
Ireland	102
Czech Republic	123



**Figure 2. Membership of Epilepsy Organisations**

**Not** being a member of an Epilepsy Organisation or Epilepsy Support Group by Country



### Demographic and clinical characteristics of respondents

1. The majority of respondents were between 20 and 39 years of age. Twenty-one percent (22%) were single, 71% were married or cohabiting. Sixty-one percent (61%) were educated to college/University level. In terms of employment 60% were currently in employment, of whom the majority working in paid positions as opposed to self-employment.
2. The majority of respondents had been diagnosed with epilepsy for more than two years with 90% reporting a history of epilepsy spanning between 3 and 10 years.

### Membership of an epilepsy organisation or epilepsy Support Group [Q8]

3. Membership of an epilepsy support group or epilepsy organisation varied across countries with a mean response of only 37% and the respondents having no membership ranging from 26% to 93%.

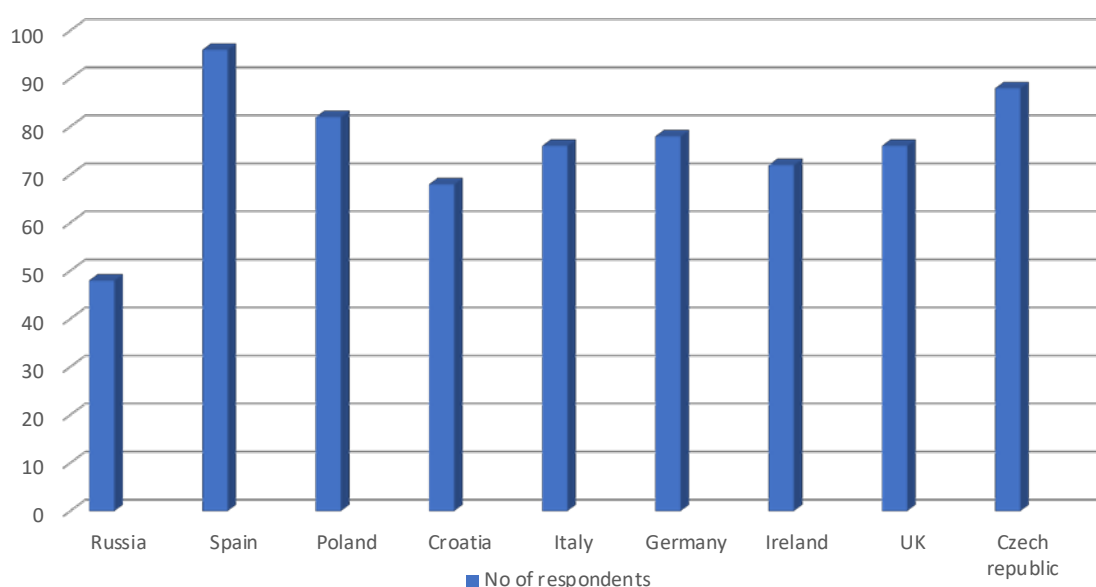
### Under the care of a neurologist/epilepsy specialist [Q9]

4. Respondents were asked to report whether or not they were under the care of a Neurologist/ specialist professional in epilepsy or a GP with special interest in epilepsy. Ninety-one percent of respondents on average reported that they were under the care of an epilepsy specialist with a range across the countries from 79-100%.

### Information in relation to pregnancy history [Q10-12]

5. A number of questions were addressed to respondents in relation to their experience of pregnancy. Respondents were asked whether they had been pregnant. The mean response across the countries sample was 52% with a range of 44-74%.
6. Respondents were asked to report on whether they were taking antiepileptic medication at the time of the pregnancy [Q11]. There was a significant variation across the countries with Russian respondents reporting as low as 50% and Spanish respondents reporting as high as 96%.

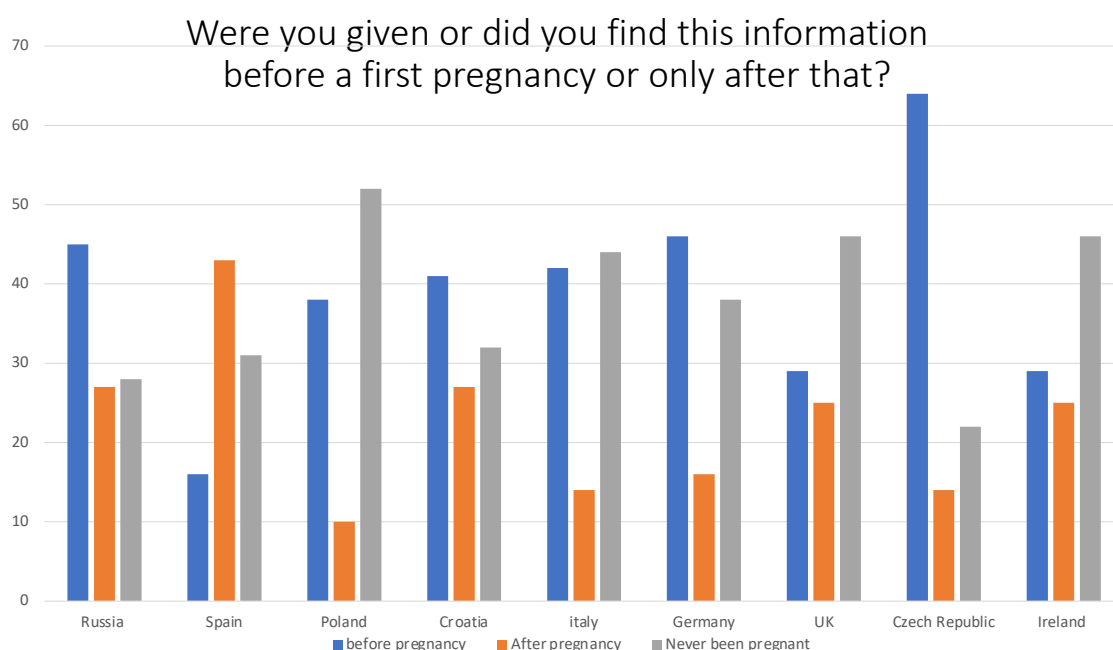
**Figure 3. Number of respondents taking anti-seizure medication at the time of their pregnancy**





7. In respect of planned or unplanned pregnancy, the mean percentage of respondents reporting a planned pregnancy across the countries was 66% with a range between 46% and 78%. Among those who described their pregnancy as planned, respondents were asked whether the pregnancy reached full term. Responses by country ranged from 78% to 89%. If the respondent answered NO they were asked whether the pregnancy was terminated electively. Responses by country saying NO ranged from 64-100%.
- Information relating to advice about epilepsy and pregnancy [Q16-21]**
8. A series of questions were provided in relation to information about becoming pregnant while living with epilepsy. Respondents were asked: "Have you ever been given by someone else, or found for yourself, information about becoming pregnant while living with epilepsy?" [Q.16] Respondents providing a YES response ranged from 51% [Russia] to 79% [Czech Republic].
  9. Respondents were asked "Were you given or did you find this information before a first pregnancy or only after that?" [Q17]. The results varied across countries and are presented in figure 4.

**Figure 4. Timing of information re risks of epilepsy and pregnancy**



1. Respondents were asked “In respect of the information you have received, how easy was it to access?” [Q18]. The responses are tabulated in Table 2 below:

**Table 2. Access to Information [% responses]**

Response	Russia N=136	Spain N=52	Poland N=78	Croatia N=94	Italy N=107	Germany N=99	UK N=99	Czech Rep N=123	Ireland N=102
Very easy	21	10	9	16	15	16	32	18	29
Somewhat easy	29	21	28	22	34	22	27	35	28
Neither easy nor difficult	32	35	46	48	30	48	23	27	26
Somewhat difficult	14	26	14	10	20	10	14	17	14
Very difficult	4	8	3	4	1	4	4	3	3

2. Respondents were asked “In respect of the information you have received, how easy was it to understand?” [Q19]. See table 3

**Table 3. Understanding of Information [% responses]**

Response	Russia N=136	Spain N=52	Poland N=78	Croatia N=94	Italy N=107	Germany N=99	UK N=99	Czech Rep N=123	Ireland N=102
Very easy	26	15	16	16	21	17	36	21	31
Somewhat easy	32	28	50	29	43	29	29	39	34
Neither easy nor difficult	31	33	26	40	16	40	21	32	21
Somewhat difficult	9	18	8	15	20	14	12	4	13
Very difficult	2	5	0	0	0	0	1	4	1

3. Respondents were asked “In respect of the information you have received, how helpful did you find it?” [Q20]

**Table 4. Ease of usefulness of information received [% responses]**

Response	Russia N=136	Spain N=52	Poland N=78	Croatia N=94	Italy N=107	Germany N=99	UK N=99	Czech Rep N=123	Ireland N=102
Very easy	39	15	16	38	21	12	30	21	35
Somewhat easy	36	28	50	42	43	33	47	39	38
Neither easy nor difficult	20	33	26	18	16	39	14	32	19
Somewhat difficult	4	18	8	2	20	12	5	4	6
Very difficult	1	5	0	0	0	4	4	4	2



4. Respondents were asked “Did the information make a difference to your decisions about pregnancy and, if so, what?” [Q21]  
Comments are tabulated below.

**Table 5. Comments from respondents on their experiences of receiving information in respect of epilepsy and pregnancy**

COMMENT
No, I’m still confused as to whether it is safe for me to get pregnant especially risks around SUDEP, and congenital malformations when taking newer anti-epileptic medication. I do think, it is important to carry out more research in this area even though there is an Epilepsy Pregnancy Registry, there remains unanswered questions around new drugs for example Rufinamide, and Lacosamide. I think there are also concerns about an increase in seizures due to extra hormones when pregnant. [UK]
The information made it easy to monitor certain things happening with and to my body. Made me feel a lot more comfortable knowing that my epilepsy wasn’t a problem during pregnancy. [Italy]
Yes, I fear pregnancy because of my medications [Italy]
Yes, it did. Prepare for it more thoroughly [Russia]
Yes, I have had to come off and change seizure medication twice before planning pregnancy, have also had to have abortion as became pregnant once on Epilim, decision may have been different if Epilim was not dangerous.[UK]
I postponed the planned pregnancy for several years after the start of treatment [Russia]
It’s fundamental to know that pregnancy needs to be planned and that my life-saving medication would be extremely harmful for the foetus. Any decisions about having or not having a child cannot be taken light-heartedly anymore!!! Lots of aspects must be factored in for oneself and the prospective newborn! [Italy]
One doctor advised against getting children. Another doctor said it’s no problem. [Germany]
Yes, it was not so scary for my children that they could inherit epilepsy or not! [Russia]
More than anything the information given by my epilepsy nurse team was frightening. A lot of ‘Do not’ ‘you can’t’ ‘you shouldn’t’ without offering alternatives. The information was valid and worth knowing but daunting for an expectant mother when offered with no ‘Instead try..’ [UK]
“I am afraid of getting pregnant. I am afraid that the child will be” damaged” or will not survive.” [Poland]
The information received is too little for making decisions: breastfeeding, taking vitamins and additional medications, which doctors to visit. I’m afraid to face the negative. I will go specifically for a consultation before becoming a mother. [Russia]
After the clarification with a specialist for epilepsy the decision to get pregnant was strengthened in a positive way. [Germany]
I found out what medications I can take, that I need to take folic acid. I know that I can breastfeed and give birth naturally. I’m not afraid of getting pregnant. [Poland]
There is very little information on this matter, the doctors themselves know very little (Russia)
The low, non-absent, risk of teratogenicity caused a sort of psychosis in me that made me consider to voluntarily interrupt the pregnancy. Luckily, everything ended up well. [Italy]

## COMMENT

It was reassured that a pregnancy isn't a problem while taking lamotrigine. It strengthened my decision to get pregnant. [Germany]

No it didn't, but in some ways it made me more apprehensive and worried about pregnancy and being a mum because of all the risks of seizures etc. [UK]

When I first found out about the risk, I was in a deep emotional depression and I was seriously considering with my partner that we would never have children (or adopt) because it could be too dangerous. [Poland]

The information I received has been fundamental in deciding not to have children. [Italy]

It made me aware I had to take a higher dose of folic acid and the possibility of risks [UK]

I don't want children because I'm scared and I have a lack of trust in my neurologist. [Germany]

The information I received made me feel more secure in myself and about the pregnancy, ESPECIALLY the pregnancy. I had several "fears", since the father of the baby was not by my side, but thanks to my family and to my physicians some of the biggest fears gradually disappeared! [Italy]

Yes I had been taking sodium valproate and while I was doing a research proposal for my degree I decided to do it on the effects of anticonvulsants during pregnancy. After my findings I asked GP for a referral to neurologist. I discussed my plans with him and he changed me over to Keppra. [UK]

The information had impact on the decisions to be pregnant. They made me realize how important it is to properly plan and manage pregnancy in a correct and responsible way. [Poland]

I've always wanted several children. I discovered I suffer from epilepsy at the third month of gestation and I immediately started a treatment with Keppra, which is still ongoing. I carried the high-risk pregnancy to term giving birth to a healthy baby. With the information I have now I don't think I'll opt for a second child. I'm too scared of the outcome. [Italy]

The information that women with epilepsy can give birth to healthy baby made me decide to become pregnant. [Poland]

Since been diagnosed at age 11, I have always taken folic acid and have been on Keppra which is safe to use at child bearing age. I was reassured when epilepsy nurse told me that 94% of women with epilepsy do not have a seizure during labour/birth. I was told to bring additional medication in case I vomit through birth. Told not to bathe baby alone, wear a sling with baby alone. All common sense but helpful all the same! [UK]

Yes, because my neurologist reassured me that given my non-severe form of epilepsy and with appropriate treatment and a good gynaecologist my pregnancy would run its course peacefully. [Italy]

I was terrified, it reassured me that all would be okay which it was [UK]

I decided to have an abortion, before I got married my husband had a brother and a cousin who died from leukaemia. I didn't want children with possibly two diseases, especially leukaemia. I received information about epilepsy and pregnancy 12 years later. If I had had the opportunity of talking about this with somebody I probably wouldn't have interrupted the pregnancy. [Italy]

Information was hard to get from doctors on this. It was also difficult to even get appointments to see the neurologist without waiting months [UK]

## COMMENT

I was always unsure if I would have children but thought someday I would. I changed Neurologist to an epilepsy specialist recently and the discussion came up around Epilim as I was on it when I was 15/16. Given recent reports of the effects of Epilim on pregnant woman my new neurologist was keen to know how long I was on it for. The only reason I was taken off it was due to weight gain. I'm still not clear on what effects Epilim can have if you were on it in the past but I have also been informed that my epilepsy is hereditary and there's approximately a 17% chance that my child would get it. I'm currently on Lamictal, Keppra and Frisium and still having seizures. If I was someone who really wanted children I would potentially take the risk, however given that I was unsure it's highly doubtful that I will have children. I am 30 years old. [UK]

I received the information from my epilepsy nurse and neurologist and it made a difference as it made me plan ahead to talk to my neurologist to plan each pregnancy with regard to the medications I was on and the dosage. During my last pregnancy I was hospitalised as I had pre-eclampsia and low sodium levels and as a result I had to monitor my fluid intake and output. My medication was also reduced due to this issue. I was induced at 36 weeks due to issues with blood supply to the baby as a result of pre-eclampsia. [UK]

Yes, it reassured me I don't know any other epileptics so knew nobody who was pregnant and have birth so I liked to read success stories to know it is possible [UK]

I was on an old epilepsy drug and had to come off it as one of the side effects was birth defects so came off it before I got pregnant and went on a lighter dose of a completely different drug. [UK]

Yes. The sodium valproate scandal meant that I was aiming to cut my AED medication (Lamictal) and be off it completely for at least 6 months before trying to become pregnant. A combination of information that I received from 1. a presentation for women run by Epilepsy Ireland, 2. an appointment that a specialist nurse kindly gave me after the presentation when I asked to speak with her (the appointment was a phone call to answer all the questions my husband and I had), and 3. the MHRA report from January 2021 'Antiepileptic drugs: review of safety of use during pregnancy' (it was mentioned in the presentation), resulted in me deciding to stop doing this, as I learnt that actually having any sort of seizure is far more dangerous for the baby than taking Lamictal could have been." [UK]

Yes, being better informed meant I could make better choices and was prepared if/when my seizures returned. My epilepsy nurse specialist and consultant were outstanding in the care and guidance given pre pregnancy. They did everything in their power to keep myself and baby well and as safe as is/was possible. [UK]

I decided to terminate my pregnancy because I had not been taking folic acid and was currently taking a med that is not safe for pregnant women. I was also finishing school and thought it would be too much for my body in regardless to controlling my seizures. So with all that information, I was able to make an informed decision for my abortion. [UK]

It made me realise it's not a decision I can just make easily and quickly like many women can, it takes a lot of planning with healthcare providers to make sure risks are minimised. [UK]

Information I've accessed made me question whether I'd ever want to become pregnant due to the risks involved, though that might be more of a personal thing. Although you see examples of pregnancies going to full-term and hear of good experiences, it's very hard to trust that my experience will be the same. Each person's experience of epilepsy as a condition is different, so how would I know if I was going to be ok? Looking at the facts and figures that are out there, I should feel reassured. I can tell that my consultants are always trying to approach the topic in a reassuring manner but don't find this all that encouraging. I don't know if I'd be brave enough to take the risk of becoming pregnant after recently seeing the figures related to epilepsy and pregnancy, I've thought about adoption instead. It feels as though the chances of a successful pregnancy are half science and half luck. The luck being who your healthcare provider is, how long waiting lists are, capacity and understanding. [UK]  
Yes. I'm afraid to have children now. This was when I was on Epilim this was the only time I was given information about pregnancy. I know no information about getting pregnant and the medication I am on now. [UK]

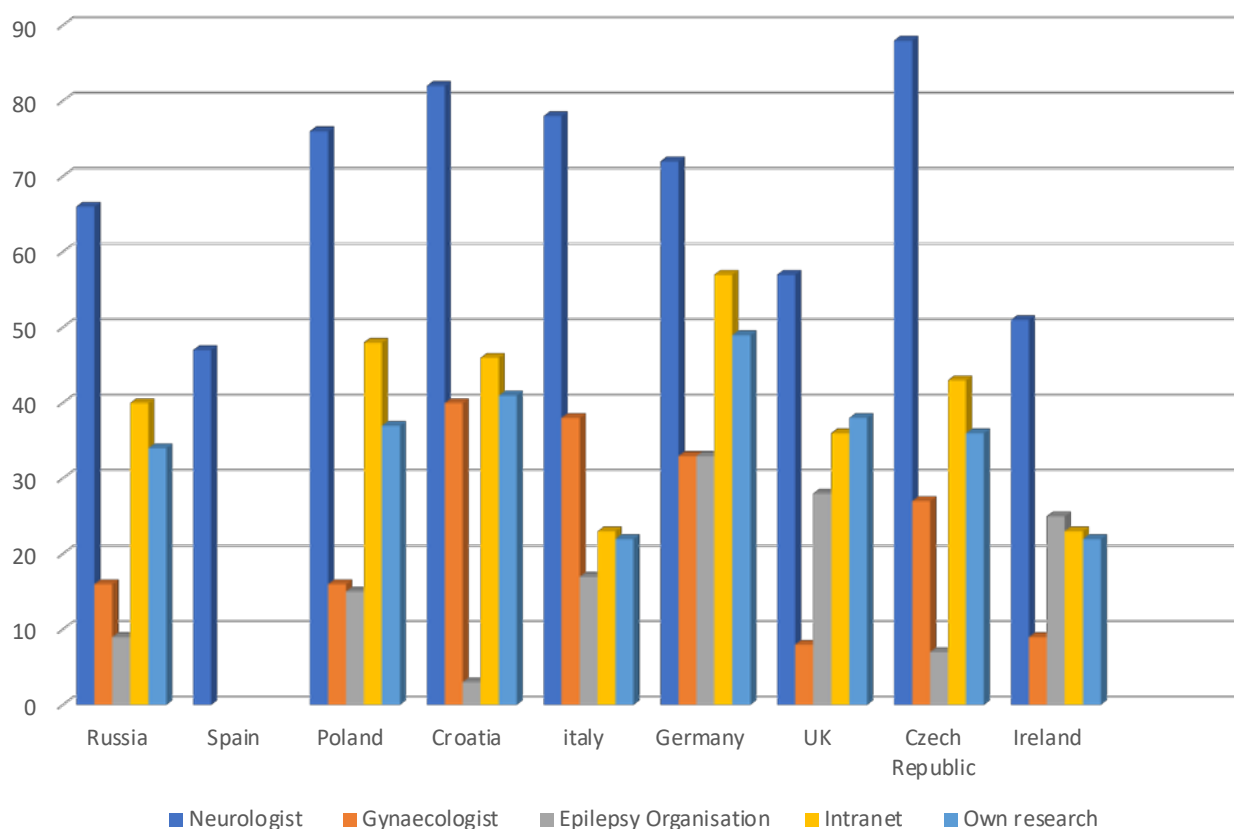
I made a decision to become more insistent on reducing Epilim which my neurologist and nurse were happy to go with. I understand Keppra is slightly safer but will consider these risks. I want to reduce my Vimpect also. Overall, the information has probably caused more concern and frustration because my wish for children is strong but has certainly made me think what the best decision for me and potential children would be.  
[UK]



## Who provided the information in respect of epilepsy and pregnancy [Q22-27]

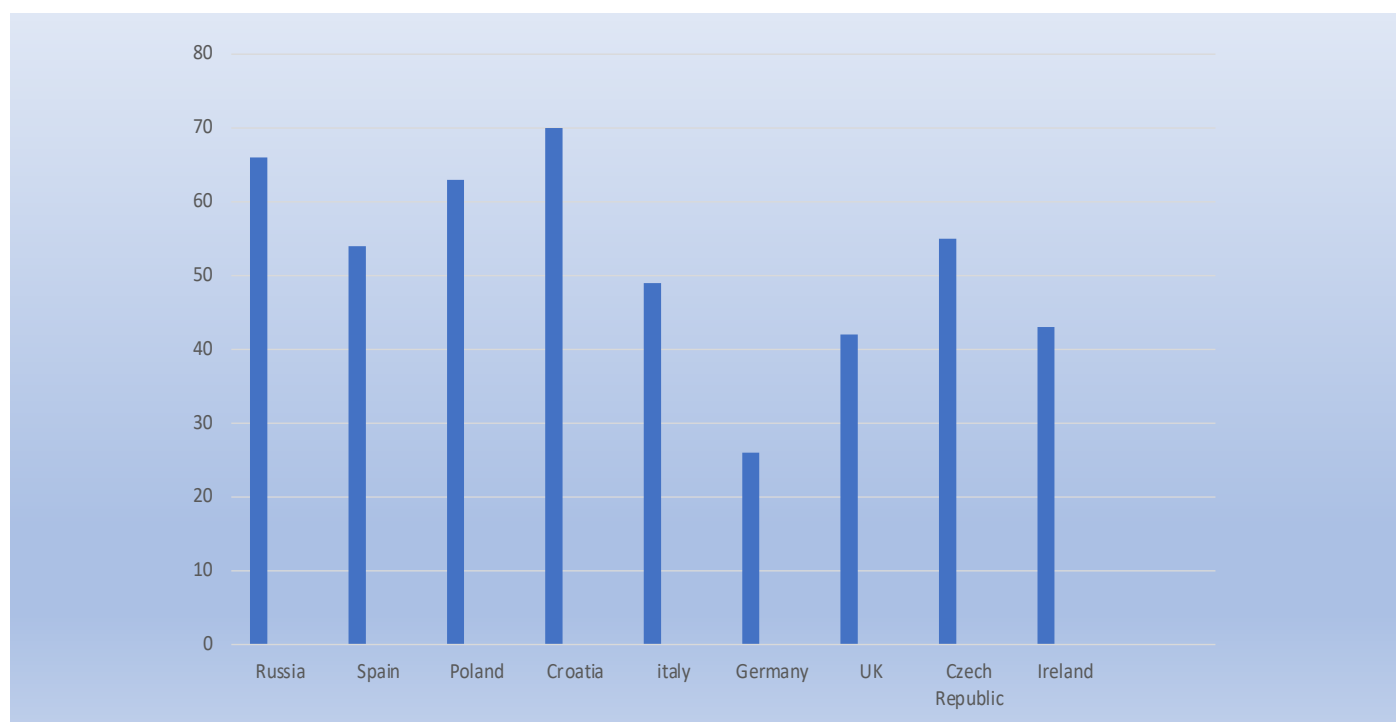
1. The respondents were asked to comment on who provided the information [Q22]. A list of professions were provided. The majority of the respondents identified that neurologists were likely to be the main provider, followed by gynaecologists, the internet or they found it for themselves [see figure 5].

**Figure 5. Sources of information regarding epilepsy and pregnancy**



2. Respondents were asked whether they had ever received information from a medical practitioner in relation to the need to consider contraception while taking anti-seizure medication [Q23]. The majority of respondents were either provided by a neurologist, gynaecologist or individuals found the information for themselves or via the internet. Epilepsy organisations, in the main, was not a frequent source of information.

**Figure 6. Number of respondents who reported that they were not provided with information in respect of contraception**

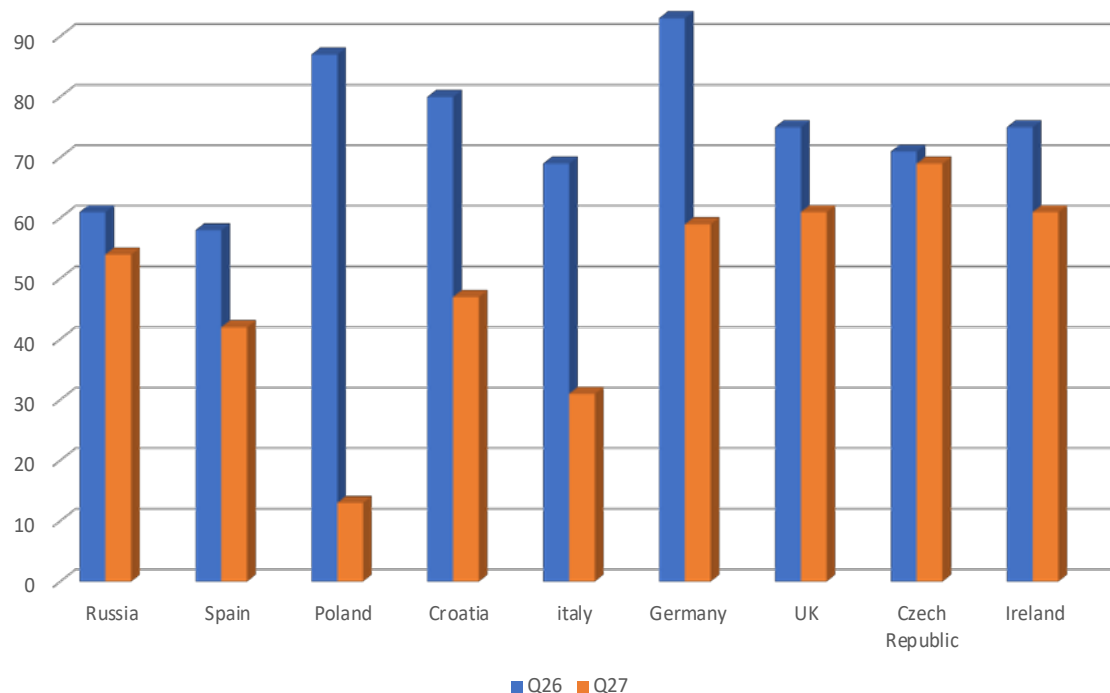


3. Respondents were asked “Have you ever been referred by a neurologist or GP to additional social and medical supports available in your community for women with epilepsy?” The response rate varied from 76% to 93% of respondents reporting that they had not been referred for additional support.
4. Respondents were asked to address the following questions in respect of the risk of pregnancy and planned pregnancy:
  - Have you been made aware of the risks associated with taking some anti-seizure medication while pregnant? (Q26)
  - Have you been advised to plan pregnancy by a medical professional? (Q27) There was a significant variation by country as displayed in the following figure.

**Figure7. Responses to the risks of pregnancy and whether respondents had been advised to plan their pregnancy**

Q26. Have you been made aware of the risks of taking AEDs while pregnant? [Yes]

Q27. Have you ever been asked to plan your pregnancy by a medical specialist? [Yes]



5. Respondents were asked if they were provided with advice about planning their pregnancy, who provided such advice. The majority of respondents reported that their neurologist was the person to have given them advice, with a range across the countries from 72% to 96%. The second most commonly cited professional involved in advising about pregnancy was the gynaecologist, with a wide range across the countries between 10% and 70% of respondents. [Q28]
6. Respondents were asked “If you were pregnant tomorrow would you contact a medical professional before making any decision about whether or not to stop taking medication?” [Q29]. The following table provides individual country responses:

**Table 6. Response in respect of medication decisions if pregnant**

Country	% response answering YES
Russia	84
Spain	100
Poland	74
Croatia	82
Italy	91
Germany	74
UK	90
Czech Republic	92
Ireland	92

1. Respondents were asked to document their responses to the following question, “Are you aware of the registries that exist in Europe/UK for women with epilepsy who are pregnant?” [Q30] A significant number of respondents reported that they were not aware of such registries.
2. Respondents were asked “In your opinion, is clear and concise information available for women with epilepsy who are considering becoming pregnant? [Q31]. There was a wide range of responses from the countries with between 18 to 75% responding that no there is not enough clear and concise information available.

**Table 7. Responses to availability of clear and concise information by country**

Country	% response answering YES	% response answering NO
Russia	35	65
Spain	25	75
Poland	41	59
Croatia	82	18
Italy	37	63
Germany	48	52
UK	40	60
Czech Republic	65	35
Ireland	32	68

3. Respondents were asked to respond to the Question “Would you avoid becoming pregnant if you were on anti-seizure medication?” [Q32]. The responses are tabulated below.

**Table 8. Responses to decisions about becoming pregnant if on anti-seizure medication**

Country	% response answering YES	% response answering NO
Russia	43	57
Spain	53	47
Poland	41	49
Croatia	38	62
Italy	41	49
Germany	28	72
UK	34	66
Czech Republic	16	84
Ireland	36	64



4. Respondents were asked “Would you consider the information given to you on the issue of epilepsy and the risks associated with pregnancy has helped you to decide whether to become pregnant?” [Q33]. The responses are tabulated below with a wide variation of responses from 17-50% of respondents reporting that they had never been provided with information about the risks associated with pregnancy. .

**Table 9. Responses to adequacy of information provided in respect of planned pregnancy by country**

Country	% response answering YES	% response answering NO	% response answering Information has never been provided
Russia	48	18	34
Spain	29	21	50
Poland	70	17	13
Croatia	56	17	27
Italy	51	29	20
Germany	62	20	18
UK	62	16	22
Czech Republic	63	20	17
Ireland	54	18	28

5. Respondents were invited to comment on whether there was any other information that they had found helpful and if so what?

**Table 10 Comments by respondents on whether other information had been helpful**

COMMENT
I think looking on the SUDEP Action website has been a useful resource and their research around pregnancy in women, as I think a lot of neurologists are scared (understandably so) to discuss this openly with women. There is also a section on the Epilepsy Action website which includes stories from women with Epilepsy and their experiences of pregnancy which I found helpful. [UK]
This information led me to choose a physician who would explain things thoroughly to me. [Italy]
Today I want to be a mother and I can't get anyone to guide me [Spain]
There is no clear understanding of which drugs can be taken and which cannot be taken. There is also no clear understanding of what the use of drugs can lead to during pregnancy and lactation. (Russia)
I didn't receive much information on epilepsy from my neurologist. The yearly follow-up visit is used mainly to have updates on my health status. [Italy]
I think there is a lack of positive stories, attitudes and information concerning epilepsy and pregnancy and parenting. Parenting specifically. [UK]
It gave me some peace of mind knowing that despite epilepsy I can have a normal pregnancy and a healthy and beautiful baby [Spain]
The information that women with epilepsy can give birth to healthy baby made me decide to become pregnant. [Poland]

## COMMENT

Unfortunately, there are very few qualified doctors in our country. I found my epileptologist, who has been leading me for many years, only 2 years after the onset of seizures. In hospitals (DIFFERENT!) I was told that I was in my puberty age and everything would go away by itself. Articles on the topic of epilepsy are very necessary and important, how to identify it, to which medical centers to run for help. In fact, only such sites helped me find the right people who made the correct diagnosis and treatment. Now it is not so scary to become pregnant with epilepsy and appear with unqualified specialist. [Russia]

"I had my first tonic clonic seizure 5 years ago and my second whilst heavily pregnant a week before my due date. I was diagnosed a week before birth and was told to start taking AED's. I felt I didn't know enough about it, was in shock and didn't plan on taking them until baby was here as I wanted to breastfeed and I wasn't aware of any risks (or no risks) regarding the AEDS and breastfeeding. When in labour, I was told I must start taking the medication right then and now, my partner had to go home and get the medication and I started in labour. This was awful adjusting to AED's whilst going through a traumatic birth. Hospital doctors wanted to give me an epidural straight away as they were worried pain would cause another seizure, this was the total opposite of the birth I had imagined and unfortunately the whole experience has left me totally traumatised and I plan on having no more children." [UK]

There is a lack of reputable information online. Often you found discussion forums and they are very different/subjective. [Germany]

List of antiepileptic drugs that are safe or less harmful to the unborn child. I understand that research on pregnant women is not carried out, but nevertheless, a lot of women give birth, taking different drugs. Are there any drug statistics? (Russia)

"It is a very small percentage that the child is born with a deficiency compared to other women. Taking the precautions of the neurologist and gynaecologist, I see that there is not too much problem." [Spain]

All information is very important. I still wish I had more children. Unfortunately, drug-resistant epilepsy is the barrier. I am waiting for a miracle or a drug that will guarantee no seizures. I would like to have the comfort of life and know that if I take this drug I will not have seizures - I will be able to get a driving license and at least partially become independent and function more freely ... [Poland]

I'm lucky to be followed up at a regional epilepsy centre. However, gynaecologists are not informed about all this and should interact with epileptologists. [Italy]

I would love to know how to get pregnant with a diagnosis of epilepsy (Russia)

My neurologist and gynaecologist examined me good/often and make me aware of everything before and during the pregnancy. [Germany]

"The neurologist informed me that the pregnancy had to be planned, a higher dose of folic acid was ordered, but I did not receive full information about the risk of my medications, the dose was not reduced. I gave birth to a child with a neural tube defect - spina bifida. In my opinion, I was not properly guided by a neurologist before and during pregnancy." [Poland]

"I was told if I got pregnancy I would want an abortion which was inappropriate." [UK]

Complete terror of dying and malformations, total ignorance of what pregnancy would be like [Spain]

"I'd like to point out that I hold a degree in Neurosciences, for me it's been easy to understand what the neurologist says and finding information on medications and their effects. For other women it's probably not the same because epilepsy is scarcely, and often poorly, discussed." [Italy]

No all medication will affect pregnancy. Having a good doctor and epilepsy nurse and neurologist makes a huge difference - nothing is impossible. [UK]

"I found looking on websites where children are impacted by anticonvulsant medications very informative. They give out clear information on what may happen to the unborn child." [UK]

## COMMENT

"Yes, my neurologist and my gynaecologist explained to me that I should take care with contraceptives until the day I want to have a baby because it must be very planned. My neurologist also told me the risks of medication in a baby, but on my own I wanted to know more in detail, and I decided to search a lot in books, and on the internet to know exactly what the risks were for the baby and for me. And I was able to find the answer. I suppose that they would explain it to me when it was time to want to conceive. They gave me peace of mind knowing that always planning and controlling everything would be fine and that they (my doctors) were going to accompany me at all times. I feel calm when the moment comes, although I must admit that insecurity will always be in me." [Spain]

I have decided to never become pregnant due to the risks involved. I would like there to be more research done and a focus by neurologists etc. on menstruation and epilepsy. [UK]

I am lucky to have a good relationship with my neurologist and GP. Any life decisions I make I have always discussed with them to make sure I always am able to make an informed decision. [UK]

I know that there are medications that are toxic to the foetus, as well as these can be avoided during pregnancy, the first thing is to go to the neurologist and then to the gynaecologist, the most important thing is to take care of yourself. [Spain]

## DISCUSSION

1. This survey was conducted to understand the experiences of women with epilepsy of child-bearing age. The survey aimed specifically to gather information on their understanding of the risks of epilepsy and pregnancy; determining the degree to which women were informed of the risks and by whom; their perceptions of the adequacy of any information provided; and whether or not this informed their decisions in relation to having a child or not.
2. The survey set out to collect information from women with epilepsy across Europe. At the outset of the survey it was agreed to limit the duration of the survey to a period of eight weeks. The sampling frame was social media, mailing and IBE databases and website promotion. There were 890 valid responses from 11 countries

### Limitations of the Survey

3. There are a number of limitations to the study that include the following:
  - [1] There were only 9 countries involved in the study and membership was influenced by the ability to identify chapters willing to participate in the country. There was a lack of response from Scandinavian countries.
  - [2] The responses from a number of countries were so low as to necessitate excluding them from the analysis e.g. Greece [N=4], France [N=8] and Georgia [N=13].
  - [3] A significant proportion of the respondents were either college or university educated suggesting that the survey did not capture the views of individuals who were less educated.
  - [4] Given the limitation on resources it was not possible to conduct forward or backward translation of the questionnaire. However, native speakers with an excellent command of English were utilised in the forward translation process.
  - [5] As a result of the above some caution should be taken when generalising the results to all women with epilepsy of child-bearing age





## MAIN SURVEY FINDINGS

1. The main findings of the results of the survey can be summarised as follows:
  - The majority of respondents were educated to College or University level.
  - The majority of respondents had been diagnosed with epilepsy for more than 2 years
  - A significant proportion of the respondents were not members of an epilepsy organisation or support group
  - The majority of respondents were under the care of a neurologist independent of their country of origin.
  - Between 44% and 75% had reported having at least one pregnancy.
  - There was a significant variation by country as to whether respondents were on anti-seizure medication at the time of the pregnancy, with 96% of respondents from Spain on medication and 50% from Russia.
  - According to responses, the majority of pregnancies were planned with a mean of 66% and a range of 64-78%.
  - Between 51% and 79% of responders, depending on the country of origin, reported that they had accessed or been provided with information about becoming pregnant with epilepsy.
  - Many respondents reported that they did not receive information about the risks of pregnancy until after their first pregnancy
  - Respondents in the main reported that the information they received was easy to access, easy to understand and generally helpful.
  - Information was generally provided by neurologists or gynaecologists, followed by the Internet or finding the information for themselves.
  - Only a small percentage of responders accessed Epilepsy organisations or epilepsy support groups for information about epilepsy and pregnancy.
  - A third to two thirds of respondents reported that they did not receive information in respect of contraception.
  - Few respondents reported that they had been referred for additional social and medical support.
  - Between 60-90%, depending on country of origin, of respondents reported that they had been made aware of risks of taking antiseizure medication whilst pregnant.
  - Between 40% and 66% of respondents reported having ever been advised to plan their pregnancy by a medical specialist.
  - Any medical advice provided to women with epilepsy of childbearing age was likely to come from the treating neurologist or gynaecologist
  - The majority of respondents reported that they would take medical advice before stopping medication if they found themselves to be pregnant.
  - Respondents were asked about the availability of clear and concise information in their country in respect of epilepsy and pregnancy. There was significant variation in the responses with between 35% and 65% responding yes.
  - Between 16% and 53% of respondents reported that they would avoid becoming pregnant if they were on anti-seizure medication.
  - Between 17% and 50% reported that the information they had received had helped them making a decision whether to become pregnant.

## KEY POINTS

### Key Point 1. The Survey

2. The aims of the survey were clearly identified as documenting the following: an understanding of the experience of women with epilepsy; their information needs; the support received from professionals and the degree to which the information they received impacted upon their decision. The survey, administered through 'survey monkey', was constructed to address the afore mentioned aims. Forward translations was provided by the project group membership. The survey was administered through Social media and IBE distributions lists. The limitations of the study have been discussed above. Despite these limitations the general impression from the responses was that the survey was fit for purpose.

### Key Point 2. The Responses

3. There were 890 responses from 9 different countries subject to reporting. The majority of respondents were women with epilepsy between the age of 20 and 39 with 71% being married. Sixty-one percent of the respondents were educated to College or University level. The majority had been diagnosed with epilepsy more than two years ago. Between a half and two-third of the respondents had been pregnant. While the results are not perhaps surprising in terms of educational levels of the respondents, it does raise issues about ensuring that when a tool kit is rolled out it is tested on a range of women with varying educational levels to ensure that it is easily and fully understood.

### Key Point 3. Membership of an epilepsy organisation or epilepsy support group

4. The mean number of respondents who were member of an epilepsy support group or Organisation was extremely variable. In Russia only 10% of respondents were members while in Italy the figure was as high as 75%. This will have implications for rolling out of a tool kit and limiting the roll out to IBE Chapters only. It also highlights the need for the IBE to make greater strides in improving our communications with our chapters.

### Key Point 4. Who provides the care?

5. The majority of the respondents were under the care of a neurologist or a gynaecologist. It will be important when the kit is rolled out to ensure that that these two professional groups are made aware of its existence, and able to signpost potential benefactors to it. Further to include materials in the toolkit aimed at the professionals.

### Key Point 5. Experience of epilepsy

6. The majority of respondents were taking anti-seizure medication at the time of their pregnancy apart from respondents from Russia who were equally likely to be or not to be taking medication during their pregnancy. Most pregnancies were planned independent of the country of origin. Information was available to women with epilepsy but, quite worryingly, **many of the respondents did not receive that information until they were already pregnant.** The toolkit will have to be specifically targeted at women before their first pregnancy if it is to be of use.

## Key Point 6. Information

7. When women with epilepsy do receive information the general perception held that the information is easy to understand, relevant and helpful. These need to be essential characteristics for the development of the tool kit.

## Key Point 7.

8. There was a range of comments with a number of themes including: [1] the need to investigate all anti-seizure medication for their risk to those women who are pregnant or plan to become pregnant; [2] endorsement that information received was generally helpful; [3] comments that the information could be frightening and confusing; endorsement that information on the risks to the unborn child has influenced some to make the decision not to have children; [5] that some women would be fearful to undergo a pregnancy.

## Key Point 8. Who provided the information about the risks of epilepsy and pregnancy?

9. The main providers of information relating to the risks of epilepsy and pregnancy were neurologists and gynaecologists and women with epilepsy themselves. Epilepsy organisations did not appear to be an important source of information provision. The authors are cognisant that IBE chapters are seen as providers of advice on the social aspects of epilepsy while epilepsy & pregnancy is a medical issue? Further there may be a tendency for people whose epilepsy is controlled to not join (or to leave) an epilepsy association because of the stigma associated with epilepsy?

## Key Point 9. Information and advice on contraception

10. High level of respondents reported not receiving information in relation to contraception in the majority of those countries surveyed. There were significant numbers of respondents who reported that they were not given advice about planning their pregnancy by a medical specialist. However, many respondents reported that they would contact a medical professional about stop taking their medication if they were wanting to become pregnant.

## Key Point 10.

11. In the main between a third and a half of the respondents would avoid becoming pregnant if they were on anti-seizure medication. These results are in contradiction to the evidence from published trials that for the majority of women they can have a successful pregnancy whilst taking anti-seizure medication if well advised and supported by neurological and gynaecological staff.

## Key Point 11

12. There is clearly a significant number of respondents, between a fifth and a half, who were of the opinion that they were not provided with adequate information to make a decision about whether or not to become pregnant. This is not a finding that should be acceptable to the epilepsy community.

## Members of the Epilepsy and Pregnancy Group

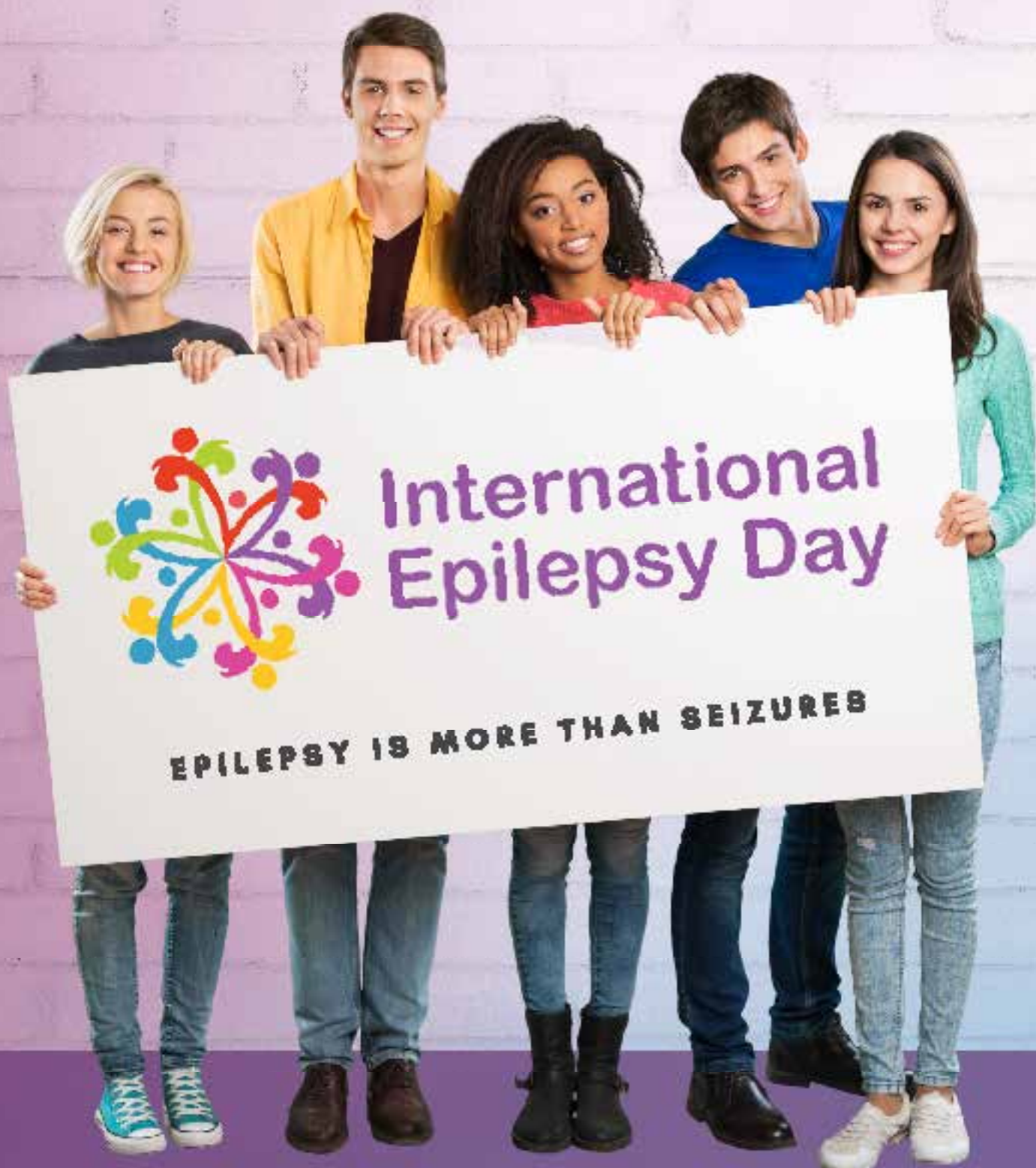
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# SAVE THE DATE!

MONDAY, 14 FEBRUARY 2022



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