



INTERNATIONAL
EPILEPSY NEWS

ISSUE 1 - 2021

IBE Elections 2021-2025

EPILEPSY & PREGNANCY SURVEY

Congress Awards



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FROM THE EDITOR

The cover of this issue shows a portrait photo of Francesca Sofia, who has been elected as IBE President 2021-2025. She becomes President-elect until the start of her term in late August.

This is the first issue of 2021 and, while most of us still struggle with Covid-19 restrictions that affect our day to day lives and under which we have been living in one guise or another for the last year, work at IBE continues apace.

In this issue of the magazine we feature news on an important new campaign on Epilepsy & Pregnancy and the urgent need to address the information gap that still exists in this area. The importance of making sure that all women of childbearing age are to be fully informed on the issues around epilepsy and pregnancy cannot be overstated.

On different note, we congratulate the seven young people who have been selected to receive a Golden Light Award at the Latin American Epilepsy congress in late February. We also call for nominations for the International Golden Light awards, open to all IBE chapters.

Also on the topic of awards, we share with you the names of those who have been selected to receive the Lifetime Achievement, Social Accomplishment and Ambassador for Epilepsy awards at the 34th International Epilepsy Congress in August. And we bring you a very interesting report on an epilepsy survey carried out in South Africa.

Happy reading!

Ann Little
Editor



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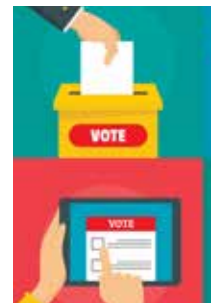
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PRESIDENT'S MESSAGE

DEAR FRIENDS

With the new year now afoot, IBE is busy with activities for 2021. Covid-19 is still with us, a situation that we could never ever have envisaged 12 months ago. We are learning to live with the restrictions that this brings to our work and lives but are optimistic that, by the end of this year, the new vaccines will have established the upper-hand on all versions of the virus.

IBE began 2021 with the launch of the 50 Million Steps for Epilepsy campaign, an initiative that a large number of our chapters took on board as part of their fundraising and awareness activities around International Epilepsy Day. I was delighted to see how many people from all regions took up the challenge and helped us to reach not just 50 Million Steps walked for epilepsy, but almost three times that figure. This is a clear indication of what we can achieve when we combine our efforts with the one common goal of improving the quality of life of people with epilepsy and those who care for them around the world. Already we are planning an even bigger event for 2022!

Just before the end of 2020, in November, the WHA approved Resolution 73.10 on a Global Plan for Epilepsy and Other Neurological Disorders. This marked another milestone in the recognition by WHO of the need for improved services and, more importantly, national plans for epilepsy at a global level. One of the requirements of the resolution is drafting an Intersectoral Global Action Plan. A working group drawn from IBE, ILAE and other collaborative organisations, including the World Federation of Neurology, are involved in this important initiative.

On International Epilepsy Day we launched our European Epilepsy and Pregnancy campaign, the first step of which is a Europe-wide survey to obtain a picture of the current information gap in young women with epilepsy. This is a very important area of their lives and we want to better understand the situation in order to ensure that everyone is fully informed of the risks for both mother and unborn child.

This survey represents the first part of the project and the results will inform on the design and delivery of future interventions via the development of a multi-faceted toolkit that we plan to launch at the time of the 34th International Epilepsy Congress at the end of August of this year. I would appeal to everyone to spread the news regarding the survey, which is available in 9 languages, as widely as possible. The more women completing the first part of the project the better.

The roll out of our Global Teams programme is underway and I would ask those who have indicated their interest to bear with us as we put plans in place. We have had very informative and successful



Open House calls and we are currently fine tuning the objectives of some of the Teams.

Finally, in recent days, it was announced that the 34th International Epilepsy Congress, which was scheduled to take place in Paris at the end of August will be a fully virtual experience. This is a disappointment to many, but the health and safety of all concerned must come first. While the meeting will be virtual, IBE will be very much present with a range of events for our chapters and their members. Once plans for these activities are further advanced, you will be hearing about them from the IBE. Of course, the congress is also the time when we hold our biennial General Assembly and the good news, on which I end my letter, is that these new arrangements should allow many more chapters and IBE members to attend, who would otherwise have been prevented from taking an active role due to travel costs.

Let us keep positive into the new post-COVID era!

Martin Brodie

President

A string of glowing Edison-style light bulbs hanging against a dark background. The bulbs are of various shapes and sizes, some round and some teardrop-shaped, all emitting a warm, golden light. The background is dark and slightly blurred, making the glowing bulbs stand out prominently.

INTERNATIONAL AND REGIONAL GOLDEN LIGHT AWARDS

A Golden Opportunity
to recognise
and award
young persons
affected by
epilepsy who
have been
"shining lights"
for others

Golden Lights at the 11th Latin American Epilepsy Congress 27 February - 1 March 2021



Matías Nicolás Páez, Argentina

Matías, who is 25 years old, was diagnosed with refractory epilepsy at the age of 13 years. As an adolescent he first played soccer but found team-work was difficult because of seizures. He then found his niche in athletics and excelled at 100 metres, winning many races both locally and at national level despite the fact that he sometime had a seizure right before a race. In recent years, the need to consider his economic future has reduced the time he has available for his sport. He is studying music and is teaching. Despite treatment, including surgery, his seizures remain - but so too does his determination to live as normal a life as possible, thanks to his parents who have always recognised the need for his independence.

Fernanda Bittencourt Hahl, Brazil

What do you think when someone says they have epilepsy? And if you were a boss, would you hire that person to work for your company? And if your child had a teacher with epilepsy, how would you react?

It is because of these issues that Fernanda says she fights for the cause! A graduated in Pedagogy, post graduated in Special Education a, since graduation she has not been able to get a job in the private network.

Despite medication, she continues to have seizures and the deprivation of driving a car, the lack of opportunity in the labour market, the ignorance of people about epilepsy, veiled discrimination and the absence of legal protection endures. And that is why she speaks openly about epilepsy. 'After all, most people cannot imagine how many obstacles we go through daily,' she says.



Noemi Canales, Chile

Noemi, who is 27, had her first seizure at the age of 15 years. Her advocacy work began in 2019 following status epilepticus which caused right hemiparesis and aphasia, resulting in refractory epilepsy. This experience motivated her to talk about epilepsy, recognize it, accept it, share it and show it. !

This led her to create the ASHOKA Foundation, as an agent for change, evaluating the importance of mental health and inclusion, accepting differences and encouraging people with epilepsy to support each person. She is a member of the Young People Roundtable at Liche with the purpose of creating inclusive spaces the allow integral well-being of young people with epilepsy, teaching and sharing experiences to recognize the importance of being different, accepting their condition with support, empathy and social conscience.

Katherin Yuliety Gonzalez Cardozo, Colombia

Katherin, who is 29 years old, has had difficult epilepsy but, thanks to two surgeries, her seizures are now finally controlled. She is now committed to helping people with epilepsy who have presented or present the same condition as hers, in order to improve their quality of life. Epilepsy has changed her life and the treatment she received has allowed her to meet people with epilepsy with whom she shares her personal experience in order to help them learn more. In this advocacy work, she has travelled to difficult to access communities, townships and very poor municipalities with very limited financial resources to talk about epilepsy, about her life history and encourage them to seek medical help. Also important to her work are efforts to reduce stigma and discrimination faced by people who have epilepsy, and to support them to accept themselves - their strengths and weaknesses - and to seek equality.



Debbie Salazar Zumbado, Costa Rica

Debbie's childhood and educational experiences have been very difficult due to her epilepsy. She has also faced discrimination in the workplace. However, being a nurse has broadened her epilepsy knowledge: she has had contact with patients who have seizures and others who are poorly diagnosed; has seen families collapse because they think their relatives will not be able to lead an ordinary life. She spends time with them, providing emotional support, answering all the doubts they may have, explaining the pathology, the importance of taking medications and attending appointments.

As a part of IBE, she no longer feels alone, there is a whole network of support for patients and their families. 'I may have epilepsy', she says, 'but it does not have me'.



Sonia María Sánchez Romero, El Salvador

For 27 year old Sonia María, life has not been so easy. She was two years old when she had her first seizure. Most of her classmates were scared of her seizures and some laughed at her, there were some teachers who treated her 'like an alien or someone from a different planet'. In recent years she had attended different talks on epilepsy, and this has motivated her to keep going in life, as well to keep in touch with people who share the same condition as her. This led her to create a blog on Instagram, which she did to inform people about this neurological condition and to let people know that we were not alone. She is thankful for who she is, even though she has epilepsy. She is an English teacher and soon will be graduating in her second career as an interpreter.



Beatriz Clavel Helena Calvario Reyes, Mexico

Despite neurodevelopmental delay due to a difficult birth and developing epilepsy at the age of 7 years, Helena has lived life to the full. An active sporting life in running and swimming, she won first prize in the Special Olympics marathon at the age of 11 years.

Difficult years followed with up to 90 seizures daily and mental health problems. But in 2015 life began to improve. Helena has become a tireless fighter always ready to do her best to achieve the goals of her association. Due to her strength to overcome adverse situations, her dedication to the inclusion of people with epilepsy and disabilities and her tireless defence of Human Rights, she was named "Ambassador of Epilepsy in the state of Yucatan". She continues to work to improve the quality of life of many people with epilepsy.





International Golden Light Awards 2021

A Golden Opportunity to recognise and award a young person affected by epilepsy in your chapter.

Is there a young member of your association who is affected by epilepsy or cares for someone with epilepsy, who has been a “shining light” for others and is deserving of recognition? We are calling on IBE chapters to submit nominations for the International Golden Light Award, to be presented during the 34th International Epilepsy Congress 2021.

To be considered for an award, candidates must be between 18 and 35 years of age on 1st January 2021. The candidate must be nominated by the IBE chapter in which they are involved and each IBE chapter is invited to nominate one person to be considered for the award. All candidates are asked to submit a written article, between 500 and 800 words in length, telling the story of their life with epilepsy.

Selection of candidates to receive an award will be made on a regional basis. Nominations will be judged by members of the local Regional Executive Committee. One candidate from each region will be chosen to

receive an award, based on a written article provided by the nominee and a supporting message from their chapter. At the discretion of the IBE Management, further candidates may be selected if appropriate.

Everyone selected for an International Golden Light Award will be presented with a trophy during the Congress Awards Ceremony at the end of August 2021. A lapel pin will also be presented, which we hope awardees will wear with pride. Successful candidates may also be invited to present their stories at a special forum as part of the official programme of the congress and will be introduced at the IBE General Assembly (held virtually).

Nominations must be submitted by an IBE chapter; those received from individuals will not be accepted.

Nomination forms have been circulated to chapters and may also be requested by contacting the office at annlittle@ibe-epilepsy.org.

**The closing date for the submission of entries is Friday 2nd April 2021.
No entries received after that date will be accepted.**

50 MILLION STEPS FOR EPILEPSY *WHAT A RESULT!*



#50MILLIONSTEPS

Complete your steps between Monday, January 4th and Monday, 8th February 2021

Please make a **donation** to the campaign.

Your donation help us to improve the quality of life of people living with epilepsy around the world.

164,817,721 steps achieved!

Following a tremendous effort by advocates for epilepsy worldwide, we have achieved more than triple our target!
Thank you to everyone who has participated in the campaign in 2021.

"When we walk in step together, nothing is impossible."

A big **Thank You** to everyone who helped make **50 Million Steps for Epilepsy** a huge awareness raising success. Setting out with trepidation on 4th January, who could have imagined that we would crash through the finish line in less than 3 weeks and almost complete two laps of honour before the campaign ended!

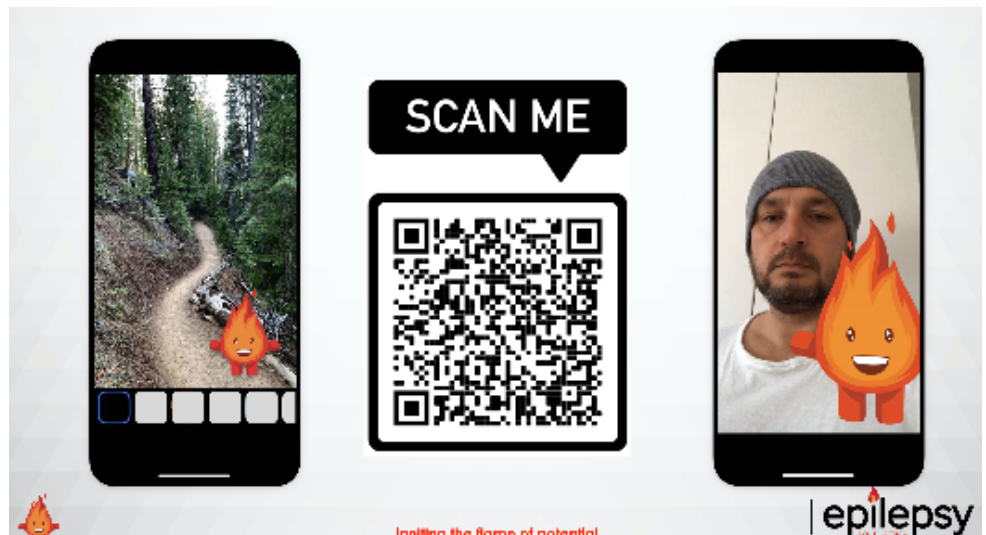
We are now gathering together stories, photos and statistics

from the campaign and from International Epilepsy Day itself, which will form our International Epilepsy Day Report 2021, due to be circulated in the next few weeks. Was a building lit up in your city or country? If so, do let us know.

In the meantime, already we are starting to plan for the 50 Million Steps challenge 2022, with ideas for new additions to make the campaign even bigger and better next year!

MEET FLAME

the mascot of
Epilepsy South
Africa



Flame, the mascot of Epilepsy South Africa is ablaze with ideas that the association puts into practice. The mascot provides the association's slogan 'igniting the flame of potential' and for the 50 Million Steps campaign it showed up in the most unexpected places.

Using a special 'augmented reality' phone app developed by the association, it was simply a case of downloading the latest version of Facebook, scanning the QR code and, hey presto, whenever you chose to use the app, Flame followed you on your quest to help us reach the 50 Million Steps for Epilepsy goal.

Hearing about the escapades of Flame, and with the IBE Campi logo that we have used in previous International Epilepsy Day
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campaigns and in our animated educational videos, we wondered whether more epilepsy associations might have a mascot that they use in their work.

Does your association have a mascot? If so, we would love to see how it looks and to learn about how you use it in your efforts to raise awareness or fundraise. How long have you had the mascot? How did it come about and what does it represent? And, most importantly, has it been successful in supporting your organisation in your work.

Let's see how many we can gather together and, who knows, we may identify a new campaign for the future.

Celebrating 60 Years of Service



This year IBE will celebrate 60 years of service to people with epilepsy and those who care for them.

IBE's beginnings go back to September 1961 and the 9th Meeting of the ILAE in Rome. Following a side conference on the *Role of the Lay Organisation in the Treatment of Epilepsy*, organised by the British Epilepsy Association (now called Epilepsy Action) at meeting, Dr Mosovich from Argentina proposed that an international bureau be set up and the rest, as they say, is history.

The next issue of IE News will include an article on the early days of IBE, which has now grown since then to have chapters in more than 100 countries world-wide.

ANNUAL DUES 2021

CALL FOR PAYMENT

Dues payments are important in funding IBE activities and in helping us support members in disadvantaged regions. We are now asking you to settle your dues payment for 2021 as soon as possible and before 1st April 2021.

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

The dues levels are:

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

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

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

Call for Proposals 2020 is open

INTERNATIONAL OPEN CALL AIMED TO FUND SELECTED RESEARCH ON DRAVET SYNDROME

GFD IN PARTNERSHIP



dravetsuisse



#StrongerTogether



Gruppo Famiglie Dravet ONLUS, Italy and its partners are making funds available for a 2-year research project that aims at a better understanding of Dravet syndrome pathogenesis and paving the way for new treatments.

Closing date for Letters of Intent is 1st March 2021.

Find out more at:

<http://bit.ly/3hMFwIE>.



European Epilepsy & Pregnancy Campaign

Getting the right
message, to the
correct audience,
in the appropriate
format, is vital

THE PROBLEM

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 antiseizure medications (ASMs) 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 ASMs 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, ASMs can also cause issues to pregnant women with epilepsy with levels falling during pregnancy and then rising post-partum so that it is very important for continuous monitoring of levels at this time.

Given that up to 50% of pregnancies are unplanned, it is very important, therefore, 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 very important for both mother and her unborn child. Getting the right message, to the correct audience, in the most appropriate format, is vital.

Despite the development of a number of information resources in the last decade, the information is still not reaching the right people at the right time.

OUR PROPOSED SOLUTION

IBE is addressing the knowledge gap around epilepsy and pregnancy in a recently launched campaign. The campaign, involving young adults and key professionals, including medical professionals will:

- establish why the message is not reaching young adults at the time of their lives where information on epilepsy and pregnancy is most urgent;

- identify the type of information and the format in which this is delivered that would be effective in closing the gap;
- create and deliver key messages in those formats to the widest possible audience.

Vital to delivering the message will be the young adults themselves. While stigma and medical paternalism have been barriers in the past in involving the most important stakeholder in raising awareness about epilepsy - the person 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.

SURVEY

The project is running as a pilot in Europe with, the first step a survey across the region to get a clear picture of the landscape in each country. A key partner will be the 58 IBE chapters in Europe.

The survey is now live, with translations to a number of European languages, and it is hoped to gather around 1,000 responses before 1st March in order to have a clear picture of the current gaps in knowledge. Of particular interest is establishing 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 specialists and 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?;
- at what point do they look for information – before considering pregnancy, when considering pregnancy, when they become pregnant?;
- how does the information received impact on their decisions?;

There is also the opportunity to ask respondents how they would best like to be informed. This could help in identifying the appropriate format for future roll out and in developing the best interventions.

SURVEY LINKS

Take the survey! If you are a woman of childbearing age and living in Europe, please take the survey and pass the information to others. We need your help to get the big picture!

English:

<https://www.surveymonkey.com/r/X7G3QG7>

Spanish:

<https://es.surveymonkey.com/r/76CKF3P>

German:

<https://de.surveymonkey.com/r/5X95LZD>

Georgian:

<https://www.surveymonkey.com/r/2D6PSZP>

Polish:

<https://www.surveymonkey.com/r/RS3ZPZQ>

Russian:

<https://ru.surveymonkey.com/r/9L96MQT>

Greek:

<https://www.surveymonkey.com/r/HCWYG9P>

French:

<https://fr.surveymonkey.com/r/DBXFNJ9>

Italian:

<https://www.surveymonkey.com/r/QJL8ZZX>

Czech:

<https://www.surveymonkey.com/r/6RSFBN2>



TOOLKIT

The findings of the survey will help us to:

- consider how best to empower young people to discuss issues around epilepsy and pregnancy with their healthcare providers;
- discuss the type of campaign that would be attractive to young people using social media, online documents, congress/webinar sessions, and other activities.

A multi-faceted 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 based on the criteria to be user-friendly, culturally relevant and visually engaging. It will be produced in a number of European languages with print, web and social media in mind and with any medical information validated by the medical members of the project team.

The project group will identify key messages to be incorporated in the campaign toolkit materials highlighting the importance of reminding healthcare providers of the importance of ensuring that all women of child bearing age are fully aware of the risks of anti-seizure treatments, poor seizure control while pregnant or contemplating motherhood and the need for careful and informed decision taking in advance of becoming pregnant. The toolkit materials will include:

- digital brochures and information on a dedicated page on the IBE website;
- social media icons, Twitter and Facebook graphic headers, badges and posters;
- FAQs document for people with epilepsy;

- educational video/conversation guide to support the patient in self-empowerment to have the conversation with their doctor on their safety and that of their child in understanding the risks associated with pregnancy for people with epilepsy;
- personal video testimonies for use, in particular, on social media. These can be extremely successful when well delivered. Supporting the young adult members of the project in developing short videos through communications training, could result in impactful social media messaging in a number of languages.

CAMPAIGN LAUNCH

The anticipated lead up to a full launch of the campaign toolkit, from the start of the survey, is likely to be six to seven months, allowing a launch at the time of the 34th International Epilepsy Congress in late August 2021. The launch will incorporate a well-coordinated digital campaign using all available platforms with common messaging across national chapters in Europe, with specific launch materials in the form of a launch toolkit in a number of European languages.

Six months after the launch of the campaign, we will carry out a second survey, using the same methodology as the pre-campaign survey, to establish how successful the campaign has been. Using much of the content of the original survey questions, will allow for 'before and after' comparison. Further questions will be added to establish take up of the campaign and its success.

The results of the survey will be important also in identifying if some elements of the toolkit require amendment or adaptation for future use both in Europe and for its roll out in other regions of the world.

This project is supported by a grant from Sanofi Aventis Group



CONGRESS AWARDS



34th International Epilepsy Congress 2021

The IBE/ILAE congress awards are presented biennially at the time of the International Epilepsy Congress, to honour individuals who have made significant contributions, over a long period of time and at international level, in the field of epilepsy. There are three categories: Ambassador for Epilepsy - presented to a maximum of selected 12 recipients; Social Accomplishment, presented to one individual; and the highest honour, Lifetime Achievement Award which, as its name implies, recognises a lifetime of achievement of an individual.



Lifetime Achievement Award

This is the highest award bestowed by IBE/ILAE and is given to an individual to recognise his or her exceptional and outstanding personal contribution over a long period of time to activities to advance the cause of epilepsy.

Presented to: Shichuo Li, China

Professor Li is founder of China Association Against Epilepsy (CAAE), establishing both the ILAE and IBE chapters in China. Internationally, Professor Li served as the Assistant Director-General of the World Health Organization (WHO), and WHO Representative in South Pacific (1998-2003). He is currently a member of the ILAE Global Advocacy Council. In 1996, representing the WHO Executive Board, he worked with IBE and

ILAE to initiate the ILAE/IBE/WHO “Global Campaign against Epilepsy” (GCAE). The Campaign was formally launched in Geneva on June 19th 1997. He introduced the very successful GCAE Demonstration Project in China. In recent years, his role was pivotal in the successful approval of the World Health Assembly Resolution 68:20 on epilepsy and the recent Resolution 73:10 on epilepsy and other neurological diseases.



Social Accomplishment Award

Every two years, one person who has carried out outstanding activities aimed at improving the social circumstances of people with epilepsy and those who care for them, over a long period of time, is recognised.

Presented to: Arlette Honein, Lebanon

In the early '90's, Mrs. Honein set up a first school for children with severe epilepsy and developmental impairments who were being rejected from regular schools. The services provided include speech and occupational therapy, physical therapy, special education and psychology. She established Avance association, a role model for the Middle East in advocating for epilepsy and educating the public. For 25 years she has provided pro bono services and financial assistance for those in most need. She has advocated tirelessly

with government agencies, resulting in more funds allocated for free medicines and appropriate educational and rehabilitative services for children with epilepsy. This exemplary work is recognized in Lebanon and the region as a model to emulate. During the financial crisis and the huge explosion that destroyed much of Beirut including the school that Mrs. Honein runs and Covid-19 restrictions, she has not wavered from her mission and dedication. Her work continues unabated and undeterred by these obstacles.

Ambassador for Epilepsy Award

The Ambassador for Epilepsy Award is the oldest IBE/ILAE award, having been introduced in 1968. To date, a total of 325 worthy recipients have received an Ambassador pin to reflect international peer recognition and which is given for the lifetime of the recipient. Twelve Ambassadors will be presented with their awards at the congress in Bangkok in June 2019.



Michael Alexa, Austria

A person living with epilepsy, Michael has been involved in the epilepsy world for more than 20 years and is well known in the epilepsy professional and lay communities worldwide. He has attended the majority of the IBE/ILAE international and regional epilepsy conferences over the last 20 years, at his own expense. His interventions and enthusiastic networking at congress have always made their mark and he is truly an ambassador for epilepsy.



Milan Brázdil, Czech Republic

At Brno Epilepsy Center since 1992, Milan Brázdil organises annual European Courses on Epilepsy Surgery (EPODES) for students from around the world. In 2016 he co-chaired the 12th European Congress on Epileptology (ECE) in Prague. Under his supervision, Brno Epilepsy Center became a full member of the European Reference Network (ERN) EpiCARE in 2016. He participates in IFCN-ILAE guidelines on automated seizure detection devices development.



Amy Brooks-Kayal, USA

Amy Brooks-Kayal has an outstanding record of impactful research productivity, scholarship, mentorship, and service to the epilepsy community. She is dedicated to training the next generation of clinical investigators and to promoting epilepsy research. She was instrumental in radical improvements at AES during her Presidency in 2015. She has permanent membership to NIH study sections and serves in the NINDS Advisor Council.



Jorge Burneo, Canada

Jorge Burneo was instrumental in improving epilepsy surgery services in Peru and now trains a Latin American neurologist each year in his Epilepsy Program. Former President of the Canadian League Against Epilepsy, he sits on the Executive Board of ILAE-North America. He led a task force to assess Disparities in Epilepsy Care in Canada, USA and the English Caribbean. He has trained 50 fellows from 12 countries at the Epilepsy Program in London, Ontario.



Dave F Clarke, USA

From Antigua and now based in Texas, Dave Clarke's goal is for unity and collaboration between Texan and building capacity in Caribbean Island-countries. He believes that outreach and engagement is the way to reach and care for all children with epilepsy. He provides epilepsy clinics in St. Lucia, Antigua and Tobago, 2-3 times per year and has improved care with shared lectures with colleagues in Martinique, Ghana, Cuba and 6 Caribbean Islands.



Edouard Hirsch, France

Edouard Hirsch is Professor of Neurology, at University Hospital in Strasbourg. He has undertaken clinical and research activities in Strasbourg with the support of two INSERM Units. He has worked with ILAE colleagues in Europe, America, Africa, Asia and Australia on several research topics on: Pharmacology, Epilepsy Surgery, Childhood epileptology, Neurophysiology, Neuro-psychology, Neuro-imaging, and Genetics and published more than 200 peer reviewed articles.



In addition to the 12 selected Ambassadors for Epilepsy below, Arlette Honein (as the Social Accomplishment awardee) and Francesca Sofia (as IBE President-elect), neither of whom have previously received the award, automatically qualify to be presented with an Ambassador for Epilepsy award at the congress.



Zhen Hong, China

Zhen Hong is president of China Association Against Epilepsy, professor, Depart.of Neurology; director, Institute of Neurology; chief, Epilepsy Diagnosis & Treatment Centre at Fudan University; and committee member, National Health & Family Planning Commission and Food & Drug Administration, China. An outstanding expert on epileptology, neuroepidemiology and clinical pharmacology, he received the Asian & Oceanian Outstanding Achievement Epilepsy Award in 2018.



Yushi Inoue, Japan

Yushi Inoue is an outstanding epileptologist and has made exemplary contributions to epilepsy care over a long period. He translated the “MOSES” and “famoses” educational programs for people with epilepsy to Japanese. After the 2011 earthquake, he set up an “epilepsy hotline” to support persons with epilepsy, receiving >1000 consultations from all over Japan in its first year. He received the Asian & Oceanian Outstanding Achievement Epilepsy Award in 2012.



Shirley Maxwell, Scotland

Based at Epilepsy Connections, Scotland since 1998, Shirley Maxwell is a member of the IBE European Regional Executive Committee since 2013, helping develop International Epilepsy Day, Chapter engagement, lobbying and awareness-raising activities, and the development of IBE’s Strategic Plan. In 2016, she contributed to the EU funded EPIPICTO project, an epilepsy information resource designed for adults with low levels literacy or recent immigrants to Europe.



Markus Reuber, UK

As its Editor-in-Chief, Seizure has become a global journal under Markus Reuber. He is a member of ILAE’s Psychiatry Commission and Psychological Treatment Task Force and Chair, PNES Task Force. He has held a Visiting Professorship at University of Shandong, China and lectured in 26 countries. His teaching activities have advanced the role of psychotherapy for individuals with epilepsy and the improvement of diagnostic and treatment services for those with PNES.



Nicola Specchio, Italy

Nicola Specchio has advanced understanding of epilepsy diseases for over a decade at Bambino Gesù Children’s Hospital, Rome. He has championed global awareness of epileptic syndromes, genetic of epilepsies, and peculiar conditions associated with epilepsies. He has authored 156 peer-reviewed articles in international journals. Recent papers help summarize epileptic syndromes and their possible etiologies, through which he has built networks with European collaborators.



Michael Sperling, USA

Michael Sperling is Editor-in-Chief of Epilepsia. He serves on the ILAE Finance Committee and on its Surgical and Driving Task Forces. He has delivered lectures at more than 70 international conferences. He has participated in several international research projects including the ILAE affiliated genetics project, international surgical collaborations; assisted with development of new epilepsy programs in Russia, Israel, Georgia, China; and trained international fellows.

FINDINGS OF A SURVEY OF SOUTH AFRICANS WITH EPILEPSY 2020

Marina Clarke, CEO of Epilepsy South Africa reports

The surveys were conducted in support of the World Health Assembly (WHA) Project to poll the views of persons with epilepsy to serve as the basis for the National Epilepsy Plan and to guide the work of Epilepsy South Africa.

METHODOLOGY

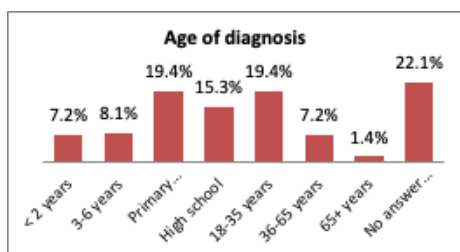
Given the target audience, the surveys were divided into three areas - social, health and economic - to enable respondents to select the information they wished to share rather than forcing them to complete all questions.

CHALLENGES

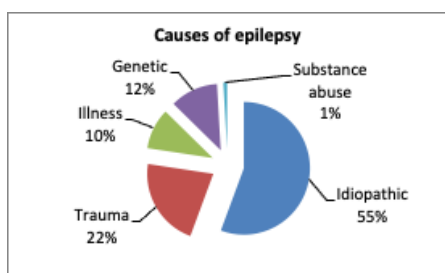
As surveys were conducted online and through Branch structures, the responses should be viewed in terms of a likely relationship between respondents and Epilepsy South Africa. In addition, the lack of respondents in some provinces influenced results while the Covid-19 pandemic and accompanying lockdown resulted in delays. The sample size was small with 636 surveys (264 on social issues, 222 on health issues and 152 on economic issues. However, we view these surveys as baseline information.

KEY FINDINGS - Health survey

These findings were drawn from participants from various ethnic groups (mainly females) from both middle to low income areas. 60% of participants were between 36 and 65 years of age with a further 25% in the 20 to 35 year age group. The majority of participants were from the Western Cape (40%) and Gauteng (40%). Sadly, almost 50% of participants never completed high school, 30% were unemployed and nearly 25% relying on social grants. Nearly 50% were diagnosed through medical tests with 40% of diagnoses were confirmed by a medical practitioner. It was interesting to note that nearly a quarter of respondents could not define when they were first diagnosed with epilepsy. However, there is a clear trend of diagnoses being made at a fairly young age which directs attention to key target audiences of awareness and education initiatives.



More than 55% of cases were idiopathic with trauma also being a significant cause:



A staggering 95% of respondents relied on daily medication of which 30% were not sure whether their treatment was actually effective. While there could be many reasons for this view (e.g. possible misdiagnoses and inappropriate treatment) the results remain the same - continued seizures and a poor quality of life.

75% of respondents received treatment from public healthcare facilities with 30% reporting no access to a neurologist. 35% reported using drug therapy for more than 10 years and 40% experienced negative impact of medication on their daily lives. However, 60% found that adherence to drug therapy improved their quality of life. This is a clear indication of the value of accessible and appropriate treatment and focuses attention on the treatment gap.

Challenges ranged from poor service delivery at clinics, medication shortages, the lack of effective neurological services and even concerns about the level of training of medical personnel. A major concern is the lack of trust in medical services (particularly in the public healthcare sector) and especially the attitudinal barriers with extensive reports about uncaring and negative attitudes displayed by personnel in primary health care clinics and hospitals.

Key findings from the health survey were:

1. Diagnoses largely made between the ages of 7 and 35 years.
2. Idiopathic epilepsy the most common followed by trauma as a cause of epilepsy.
3. Almost all respondents received drug therapy, generally over extended periods of time with good adherence to treatment.
4. Monitoring of treatment efficacy seemed insufficient.
5. Epilepsy SA viewed as a key resource (although this may be due to the demographics of the sample population).
6. Three quarters of respondents receive treatment in the public healthcare sector.
7. There is general satisfaction with treatment despite problems areas highlighted.

These findings require responses, most notably:

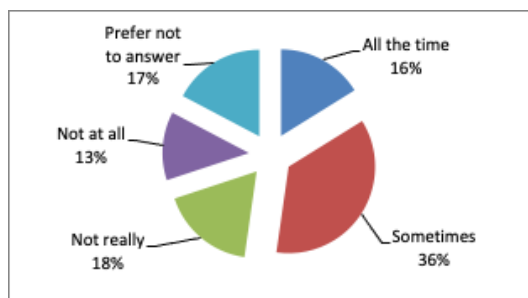
1. Implementation of WHA Resolution 68.20.
2. Making epilepsy a health priority through development of a National Epilepsy Plan focused on addressing the treatment gap.
3. Addressing treatment challenges, especially access to medical professionals; addressing medication shortages; sensitisation of medical personnel about epilepsy and improved interaction between persons with epilepsy and healthcare providers.
4. Enhanced focus on children and youth given the high levels of diagnoses in this age group.

KEY FINDINGS- Social survey

The profiles of respondents were very similar to the health survey, as many respondents opted to complete both.

Unsurprisingly the stigma and attitudinal barriers experience by persons with epilepsy remain a key area of concern with three quarters of respondents either choosing not to provide an answer or indicating some level of discrimination:

Examples of myths and misconceptions included accusations of

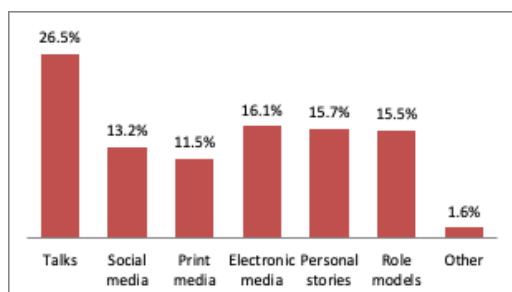


being possessed by an evil spirit, having a “snake in your stomach” and beliefs about epilepsy resulting from witchcraft or curses. This meant that people were scared of interacting with persons with epilepsy and even their family members. These perceptions also had a major impact when seeking employment.

Nearly 40% of respondents reported a lack of support for persons with, and affected by, epilepsy while many feared being in public. Their fears were largely ascribed to the risk of an unexpected seizure with nobody able to assist them or even with people taking advantage of them (e.g. robbery, assault and rape). This is particularly important given the reliance of persons with epilepsy on public transport given regulations relating to driving.

Relationships and interaction with others suffered due to misconceptions and negative attitudes. As a result, persons with epilepsy (and even their families) experienced isolation with many reporting that disclosure of their condition tended to end relationships.

There is little doubt that epilepsy awareness and education could effectively counteract the misconceptions and reduce stigma and discrimination. Respondents suggested several ways to raise awareness about epilepsy:



Only 30% of respondents regularly attended a support group. Responses varied from lack of interest (6%) to lack of knowledge about support and absence of a suitable group. There is clear need to counteract the isolation experienced by most people with epilepsy. More than 70% of respondents voted in the previous national elections in the hope that their human rights to a better quality of life would be addressed.

Shockingly, half of respondents believed that their epilepsy affected their learning ability, thereby resulting in their inability to complete school or further their education. Contributing factors included anxiety, stress, side effects of medication, short term memory loss, difficulty concentrating and co morbidities (e.g. ADHD and cognitive disabilities). These factors contribute to poor employability of many people with epilepsy and lack of economic independence.

Nearly 30% of participants only use public transport given their inability to drive due to seizure risk. Less than 15% were given clearance to drive in light of their seizure control.

Key findings from the social survey were:

1. Disclosure remains a key factor to wellbeing and personal development.
2. Lack of awareness and knowledge about epilepsy results in fear manifesting through discrimination and stigma.
3. Cultural/religious beliefs (myths and misconceptions) continue to impact negatively on the lives of persons with epilepsy.
4. Persons with epilepsy experience a lack of support.
5. Fundamental fears include unexpected seizures, lack of support (first aid), vulnerability and public humiliation.
6. Persons with epilepsy reported feelings of isolation and a belief that others do not understand their “lived experiences”.

These findings require responses, most notably:

1. Public awareness and education.
2. Social development services focused on the development of a positive self-image and self-confidence.
3. Support for persons with epilepsy in the workplace.
4. A holistic approach combining medical and psychosocial aspects.
5. Equitable access to social protection (especially disability grants).
6. Support services in communities.
7. Development of support groups that meet the needs of persons with, and affected by, epilepsy.

KEY FINDINGS - Economic survey

The quality of the economic survey information was disappointing with many respondents failing to provide adequate information. However, the survey indicated that epilepsy continues to negatively impact on job-seeking with little advantage being drawn from Employment Equity and BBBEE legislation. Only 7,6% of respondents believed epilepsy could assist them in finding employment. The high levels of disclosure in the workplace can be ascribed to the demographics of the sample population which drew heavily on protective workshop workers. This is also true in terms of the level of support noted.

Learnerships, don't seem to provide a solution; only 7,3% of respondents reporting that their participation in a learnership resulted in employment. 62,5% of respondents were unable to find learnership opportunities and 18,8% had no knowledge about learnerships. Fair and appropriate remuneration remained problematic for most persons with epilepsy. Interestingly, the concept of self-employment was viewed with enthusiasm despite the challenges identified, including limited training/skills, the lack of partners and start-up capital and poor family support. Respondents generally viewed these as a result of stigma and discrimination linked to their condition.

Despite the disappointing results of this survey, three focal areas were identified:

1. Expanded awareness and education about epilepsy in the workplace to address attitudinal barriers and the lack of market-related skills resulting from poor education.
2. Addressing root causes of high unemployment amongst persons with epilepsy, most notably appropriate skills development initiatives and safety concerns.
3. Expanded self-employment opportunities through organisational capacity building.



IBE ELECTIONS FOR THE TERM 2021-2025

The schedule to elect the IBE International Executive Committee (Board) for the term 2021-2025 began last year. Following the change to the Bylaws in 2019, the election of the President now takes place first and is held separate to elections for the other board positions. Following the close of the election, in early December, Francesca Sofia, Italy, was declared elected. Francesca becomes President-elect and will begin her term of office in late August this year.

Francesca Sofia's photo forms the cover of this issue of the International Epilepsy News and in a future issue we will feature an in depth interview with her on her plans for IBE during her four year term of office.

Since mid-January, chapters have been balloting on the positions of Secretary General and Treasurer and the closing date to submit votes is Monday 8th March.

On the page facing you can see the candidates standing for these two positions with very brief details of their plans for IBE. The full election statements of each of the candidates was circulated to chapters with other election papers but are also available on request from the IBE Office by emailing annlittle@ibe-epilepsy.org.

The final element of the current election process will be elections to fill the positions of Vice-chair and Secretary on the seven Regional Executive Committees. In Europe, two Members will also be elected. These elections will begin in mid-March with the call for nominations.

All elections will be completed well ahead of the IBE General Assembly, which will take place in late August 2021 and which will mark the start of the term of the new board.

The Regional Vice Presidents are now reaching the mid-term point of their terms of office and will remain in position until 2023. The exception to this is the position of Vice President North America. This position is currently vacant following the resignation of Susan Pietsch-Escueta at the end of 2020 and an election to fill this vacancy will run in tandem with the Regional Executive Committee elections.

All full (voting) chapters are earnestly requested to play an active role in all IBE elections. If you have not already done so, please make sure to cast the ballots of your chapter in the current elections before Monday 8th March. Your voice counts!

NOMINATIONS FOR SECRETARY GENERAL



GUS BAKER
UNITED KINGDOM

My ambition is for IBE is to be a global organisation that is capable of reaching out to any individual and family with epilepsy and asking “**how can we help you?**”. That help has to be practical, informed, compassionate and appropriate, and may range from simple advice and information, through enrolment on a self-help management programme, or understanding the latest developments in treatment, to stigma reduction campaigns or training as an advocate.



MAN MOHAN MEHNDIRATTA
INDIA

I have felt the need of education, the pain and difficulties of PWE especially in resource limited countries and am committed to educate and alleviate the sufferings of PWE and reduce the treatment gap world over. Similarly will work hard to provide Guidelines on Epilepsy Management to the Resource Limited Countries for better management of Epilepsy and bring countries who are not members of IBE especially in Asia and Africa into the main fold of IBE.



YOUSOUF NOORMAMODE
MAURITIUS

As a person with epilepsy, the opportunity to serve as IBE Secretary General is a RIGHT firmly grounded in international law, enshrined in the UN Convention on the Rights of Persons with disabilities and the African Disability Protocol. In doing so, people with epilepsy will be seen as catalyst of change and in new leadership position to speak of their rights, challenges and needs. This is essential in creating a more equitable and inclusive international organization.

NOMINATIONS FOR TREASURER



NAJIB KISSANI
MOROCCO

If elected, my plans would be:

1. Creating more chapters
2. Assist chapters develop fund raising
3. Involving pharmaceutical companies more efficiently
4. Avoid any losses in future congresses
5. Involve foundations in financing IBE projects
6. Improve financial resources by developing collaboration
7. Share good initiatives collected from other chapters and regions.

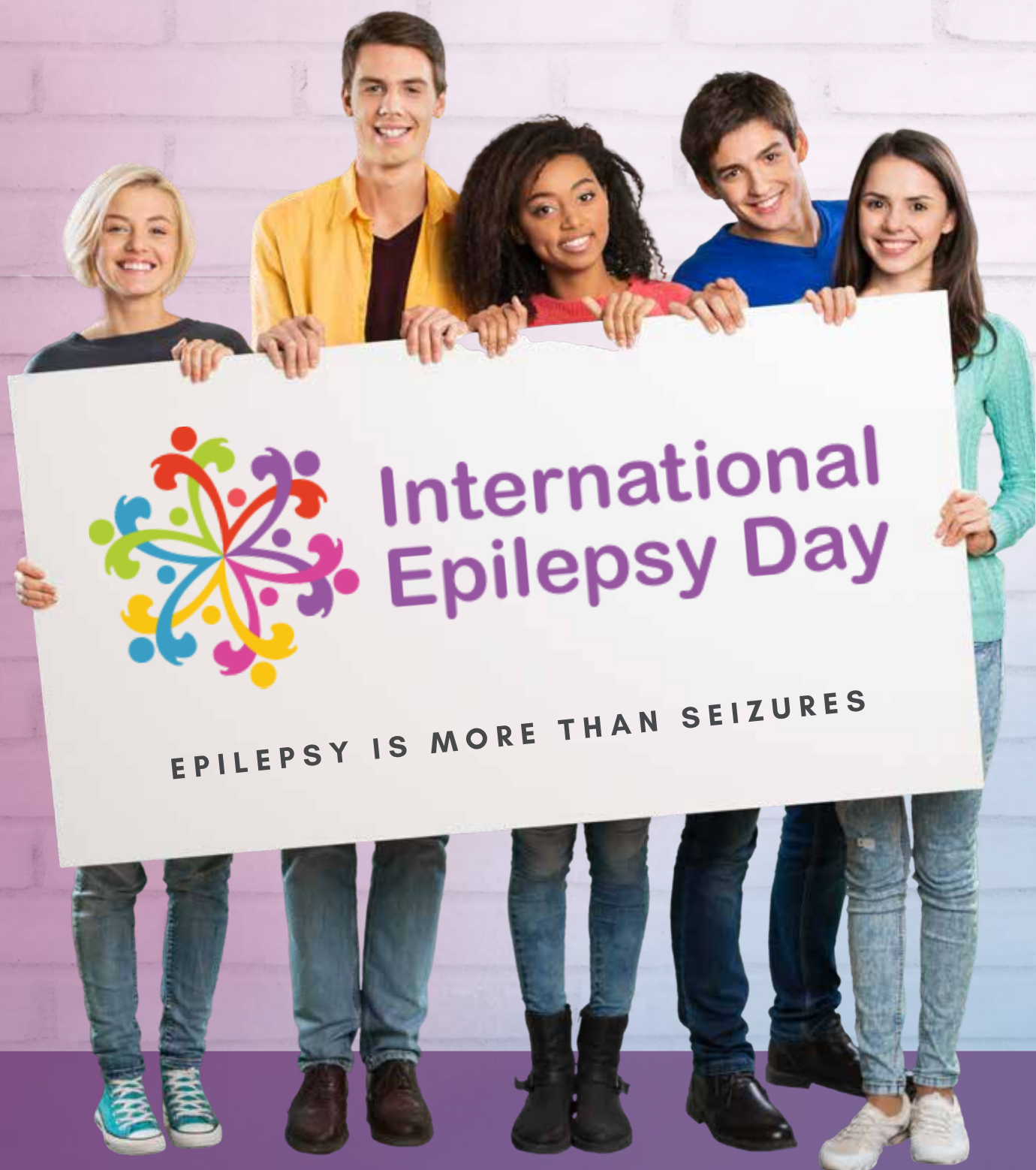


GRAEME SHEARS
AUSTRALIA

IBE is in a unique position to improve the lives of people living with epilepsy no matter where they live. However, for IBE to be successful it must be financially sustainable. Heavy reliance on falling revenues from congresses has seen the IBE record losses over recent years. We can and must find new revenue streams and continue to adapt to the new environment. I believe my experience and qualifications will be of great benefit in creating a financially sustainable IBE.

SAVE THE DATE!

MONDAY, 7 FEBRUARY 2022



www.internationalepilepsyday.org