

INTERNATIONAL EPILEPSY NEWS

ISSUE 3 - 2020



**Remembering
Anthony Mulenga Zimba
1954-2020**

Photo: Eszter Papp

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FROM THE EDITOR

The cover of this issue features a wonderful portrait photo of the late Anthony Zimba, IBE's Treasurer, who sadly died from Covid-19 in early August. His obituary and an extract from an interview he did with Fraser Morton are published in this issue. The photo was taken by Eszter Papp in Bali in 2018. We were also saddened to hear that a former IBE Vice President, Vinod Saxena, had died from Covid-19 in July. His obituary is included in this issue.

While we mourn these losses, it has been a busy time for IBE as you will see from the contents of this issue. The procedure to elect the President, Treasurer and Secretary General for the term 2021-2025 is now underway. The first election will be for the President position, which will end in early December. The other two elections will then follow.

Two exciting new initiatives have been announced recently and you will find information on these in the pages of this issue. The IBE Teams programme will see the development of five Teams over the coming months, while the 50 Million Steps for Epilepsy initiative, for International Epilepsy Day 2021, will provide the opportunity for IBE chapters and all stakeholders to raise both funds and epilepsy awareness.

Elsewhere in the magazine you will find details on the latest Promising Strategies projects, Anitas' Covid-19 story and very interesting articles on RARE and ePAG EpiCARE.

Happy reading!

Ann Little
Editor



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PRESIDENT'S MESSAGE

DEAR FRIENDS

Dear friends

Covid-19 struck close to home when we heard from our Treasurer, Anthony Zimba, at the end of July, that he had caught the infection and was in hospital. Unfortunately, as a person with underlying health issues, he failed to recover and, sadly, passed away on 9th August. Anthony had been involved with the work of IBE for 15 years and he will be sorely missed by many. To mark his passing, we opened a Book of Condolence, to which many chapters and colleagues contributed. This has been sent to his family and posted on our website.

It seems only last week that I began my term as IBE President, although, looking back, I can now see how much has happened and how much has been achieved, since I was elected in 2017. As I start out on the last leg of my four-year term, the election process to find my successor is getting underway. I would encourage active participation by all interested parties in this important process.

In the last issue of IE News, I mentioned our plans to introduce a new global "Teams" initiative. This project, which is now underway, reflects the IBE strategy that recognises the necessity of engaging people with epilepsy and their care providers in our programmes and decision making initiatives. The objective is to see an expanded range of IBE working groups emerge over the next decade, whose membership consists of people with a wide range of knowledge, experience, expertise, and skills. We are offering a great opportunity for people with epilepsy, their care providers, and other stakeholders to work closely with IBE. Paperwork has already been circulated to our chapters and others and this initiative has been widely advertised through eZines, social media and on the IBE website.

In October, we will host a series of Webinars to provide you with the opportunity of discussing the details of this initiative before applying to be part of any of the global "Teams". You can find out more in this newsletter, on the IBE website or directly from the IBE office via annlittle@ibe-epilepsy.org.

With less than five months to go, we are also getting ready for International Epilepsy Day 2021 with the creation of our 50 Million Steps for Epilepsy project. The title reflects the WHO figure for the number of people diagnosed with epilepsy globally. We see this project as something that can be used by chapters, epilepsy groups, and other stakeholders, to raise awareness about epilepsy around the world. The project can also be used as a fundraising campaign, which in these Covid-19 times becomes more essential than ever. A special website is being created and I will bring you details of this initiative as soon as it is launched.



Elsewhere, the Utetezi project in Africa, funded by the BAND Foundation, has now started on Phase 2 with work on developing a toolkit for chapters that can later be adapted for use in other IBE regions. Phase 2 also includes a funding programme for chapter projects. The successful applicants will shortly be revealed. The IBE Africa website, epilepsyafrika.org, will carry all the details of this and other initiatives in Africa, including the recently awarded Promising Strategies funding.

Our busy programme of global activities in support of people with epilepsy around the world continues despite the many challenges posed by COVID19!

Martin Brodie
President



ANTHONY MULENGA ZIMBA
17 March 1954 - 9 August 2020

It is with great sadness that IBE learned of the death of its much loved and esteemed Treasurer, Anthony Mulenga Zimba. A victim of Covid-19, and with underlying medical issues that made his ability to recover much more difficult, Anthony passed away in hospital in Lusaka, Zambia, on the morning of Sunday 9th August 2020 after a hard fought battle.

Anthony had a long history of service to IBE. He was a member of the African Regional Committee from 2005 to 2009 and then stood for, and was successfully elected to, the position of Vice President Africa on the International Executive Committee for the term 2009-2013. He was re-elected to this position to serve for a second term, 2013-2017. His third term on the board was as IBE Treasurer, a position he was elected to in 2017 and which he still held at the time of his death.

During his four years as a member of the African Regional Committee and the 11 years he spent on the IBE International Executive Committee, Anthony worked tirelessly on behalf of people with epilepsy and those who care for them. His particular focus was on his beloved Africa and, as a result of his efforts, many IBE chapters in the region were supported through the IBE Promising Strategies Program in a range of projects aimed at improving their quality of life through training, advocacy and employment opportunities. He travelled to several countries in the region and supported the development of new associations that would become IBE chapters.

He was also a member of the organising committee of the African Regional Epilepsy Congresses that took place in Nairobi, Cape Town, Dakar and Entebbe.

He was a member of the Steering Committee of the IBE Utetezi Project at the time of his death. This BAND Foundation funded project is supporting chapters in Africa to encourage the implementation of the World Health Assembly Resolution on Epilepsy through the development of national plans for epilepsy.

Anthony was the founder of the Epilepsy Association of Zambia in 2001, which became a chapter of IBE soon thereafter. To improve his knowledge and skills in the epilepsy and allied fields, he undertook a number of professional courses including the Professional Diploma in Epilepsy Care from Leeds Metropolitan University, UK; the Certificate in Clinical Epilepsy from the Foundation for Professional Development, South Africa; and the Certificate in Project Management at the University of Zambia. Previously, in 1982, he had studied for a Diploma in Clinical Medical Sciences at the College of Health Sciences in Lusaka.

He worked as an Epilepsy Specialist at Levy Mwanawasa Hospital in Lusaka and established epilepsy clinics at government health institutions in collaboration with the Ministry of Health. He also had a private practice - the Country Travellers' Health Care Clinic - which specialises in psychiatry and epilepsy. To his colleagues and patients, his death will be a tremendous loss.

Anthony leaves behind his wife, Dr Meaumui Mumbela, and four adult children from his first marriage - Alex, Anthony, James and Cindy.

In response to the many messages received by IBE from Anthony's former colleagues and from those with whom he came in contact in the wider epilepsy and healthcare fields, IBE has arranged a Book of Condolences, which will be presented to Anthony's family.

The Politics of Epilepsy in Zambia

Fraser Morton, of Far Features, who was working on a project about epilepsy called *A Life Electric*, had an interview with Anthony in 2018, at the Asian & Oceanian Epilepsy Congress in Bali, about issues facing Zambia's epilepsy community. The interview in full can be found on the project website: alifeelectric.org.

Far Features' Eszter Papp also took his portrait, which we have used as our cover for this issue.

The words of Anthony Zimba:

In my country, there is a lot of stigma attached to epilepsy. People think it's bewitchment, or that it's a curse from God. We try our best to demystify epilepsy, and teach people that this is a treatable condition, which about 70 to 80 per cent of people, when diagnosed and treated correctly, can live good lives.

For some people, we can completely remove drugs from their lives, while others continue on taking medication, and experience improvement in their quality of life. We focus on positive reinforcement, and educate people that they can still go to school and get married.

A lot of employers in Zambia think that people with epilepsy cannot perform certain jobs or do things independently, but they definitely can. Recently, there was a case of a young man who was staying with his mother, sister and brother in a rural village in Zambia. He had focal seizures and the family didn't understand what was happening to him. This led to an argument between the man and his mother. Then the brother joined in, and then an argument escalated. Soon other villagers joined in, too, and descended upon the man, beating him very badly. Luckily, in the neighbourhood there was someone who knew our epilepsy association. She called me in distress, and I drove there to rescue this young man from the mob before things got even worse. This is simply because of a misunderstanding of his epilepsy.

Epilepsy is almost always put at the bottom of the list of health issues in African countries. We are working to change this. Some good news recently, because of the intervention of the World Health Organization on non-communicable diseases, epilepsy has been elevated in priority.

You must come to Zambia to film your documentary. I will take you to the hospitals around our country. You will find out about the availability of drugs. I would also like to take you to visit some of the traditional healers to show you how they conduct their practices. For most people in Zambia, the first point of entry to health-care, is actually these traditional healers. It is good you understand and see this first-hand.

Also, I will take you to interview our policymakers in Zambia. The Permanent Secretary and the Minister of Health, so that you can ask them questions about their plans are for the future of people with epilepsy in our country.



Anthony with, from left, Thanos Covanis (Immediate Past President), Janet Mifsud (Congress Organising Committee) and Martin Brodie (President), taken at the 4th African Epilepsy Congress in Dakar, Senegal, 2017. Photo provided by Janet Mifsud.



London, January 2020: Anthony with (left) Natela Okujava and Ding Ding, at the meeting of the International Executive Committee. Photos above and below provided by Ding Ding.



Attending the Opening Ceremony of the 32nd International Epilepsy Congress, Bangkok 2019.



Dinner held in London, January 2019, following the Strategic Planning Meeting. Anthony's wife is seated to his left. Photo provided by Phil Gattone

IBE ELECTIONS

for the term 2021-2025



Elections to fill the positions of President, Secretary General and Treasurer on the IBE International Executive Committee got underway on Friday 4 September with the call for nominations for the position of President.

Members, staff and board members of voting chapters are eligible to be nominated and all are encouraged to allow their names to go forward.

Candidates must be nominated by one voting chapter and seconded by another voting chapter.

The closing date for nominations is Sunday 4 October.

For election papers and further information: ibe-epilepsy.org

IBE Global Teams

An invitation to find out more!

IBE's Strategic Plan recognises the importance of engaging people with epilepsy and their care providers in all our decision making. Involving these stakeholders in all our activities is vital if they are to become the motivators of tomorrow. The 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. As a first step, a new series of working 'Teams' is being created, each one focusing on a specific issue related to epilepsy and we would like you to consider membership.

A **Global Academy Team** will work on an important new initiative to train people with epilepsy to become international advocates and spokespersons. They will need to develop the necessary knowledge to be confident in interacting with public institutions, the scientific community and industry. Members of the Team will provide:

- input of people affected by epilepsy on module content; support with translation as necessary;
- promotion of the academy at local, national and international levels.

A **Global Action Team** will work on encouraging the implementation of the World Health Assembly Resolution on Epilepsy at national and regional levels around the world allowing them to develop local initiatives. Implementation of the resolution will help to:

- reduce stigma and improve inclusion;
- increase awareness of epilepsy;
- educate people about epilepsy;
- bring epilepsy into public and political focus.

A **Global Research Team** will know about scientific, medical and psychosocial research occurring in all regions and areas of IBE activity. The goal is for our members to take an active role in developing research programmes;

- to promote opportunities to participate in research and learn to be part of the leadership team;

- to promote opportunities to participate in research and help bring research advances back to the community.

A **Global Youth Team** will recruit young people from around the world interested in being involved in a range of epilepsy initiatives and, potentially, training them to be the next leaders of IBE. The aim is to:

- increase participation of young people affected by epilepsy in decision-making processes within IBE;
- seek out advocacy opportunities so that young people can be actively involved in our global remit;
- support capacity building in young people to help them make a difference in society.

A **Global Congress Team** will develop the potential, and harness the significant opportunities, that virtual congresses can bring for people with epilepsy and their care providers. The Team will assist in:

- creating IBE-centred programmes for virtual regional and international congresses;
- encouraging the active participation of IBE chapters and their members in virtual congresses;
- identifying other opportunities to increase the visibility of IBE members at virtual congresses.

OPEN HOUSE MEETINGS

We are organising a series of Open House online meetings to tell you more about these new Teams and to allow those interested to meet other potential members. If you'd like to attend, please let us know, no later than Monday 21st September. We will also need to know the city and country in which you live so that we can match you with the appropriate time slot. Only those responding will be provided with a link to join an Open House webinar, so be sure to send us your response before the deadline.

After the Open House webinars, if you are still interested in getting involved, you will be apply to formally apply to join a Team.



RARE Epilepsy Landscape Analysis (RELA)

Reimagining the Rares and their future

Report by Ilene Penn Miller

Ten years in the trenches as the co-founder and President of a rare epilepsy organization set me on a personal mission. I watched as, each year, more and more rare epilepsy organizations (Rares) were founded, fueled by the passion of caregivers and patients touched by each disease. Like the organization I helped found a decade earlier, after my toddler son was diagnosed with a rare epilepsy, many of these organizations were born by necessity to address the information, support, treatment, and research needs of patients struggling with the most severe forms of epilepsy and their comorbidities. The explosion of rare epilepsy diagnoses and corresponding organizations was spurred by advances in genetics, imaging and mechanistic understanding, which accelerated the discovery of epilepsy genes, abnormalities and complex chromosomal anomalies. The trend continues with even more diagnoses on the horizon.

Moreover, technology and the Internet have similarly accelerated the capacity for disparate individuals to find one another online, irrespective of geographic boundaries, and create community and organize informal support groups into more formal nonprofits. The story was then and is often the same now - small numbers of geographically dispersed patients organically find each other. They have experienced long and winding diagnosis odysseys including delays, misses, and misdiagnoses. Their access to multi-disciplinary cohesive care is sparse at best. Many experience developmental epileptic encephalopathies. Oftentimes, the comorbidities more profoundly impact the patients and their families than the seizures. There is a scarcity of research and funding. The public health burden is unknown and likely underestimated. Health professionals are working in isolation and missing opportunities to exchange knowledge and best practices. Guidelines for diagnosing, treating and managing these diseases don't exist.

After years of fielding courtesy calls from desperate parents, with newly discovered genes, who were founding patient advocacy organizations, I approached the Epilepsy Foundation (EF) and pitched the idea of underwriting a rare epilepsy landscape analysis. EF had taken an early interest in the rare epilepsy ecosystem having served as one of three Principle Investigators (PIs) on a multi-year \$2.9M PCORI grant to create the first rare epilepsy registry – the Rare Epilepsy Network (REN)¹. My proposal was simple: to undertake a thorough scan of the landscape to better understand the individual and collective goals and needs of the disease focused epilepsy organizations to inform future strategies and collaborations.

The contract was approved and I was given autonomy to develop a qualitative study of the Rares' landscape. From the get-go, this project was to be by, and for, the Rares – to identify partners for collaboration; raise the Rares awareness and profile among profes-

sionals, policymakers and the public; to pinpoint resources; benchmark organizations against other comparables; inspire new ideas for programs and services; save time and money to avoid reinventing the wheel; and to find mentors and mentor others following on the same pathway. The project began with in-depth interviews with leaders from key stakeholders². Collectively, we identified 75 Rare organizations – more than double the number I had started with. A 10-part 111-question survey covering background, founding, disease impact, patient/caregiver information, research, professional education, advocacy and awareness, management and operations, resources, financials and fundraising was developed and tested in collaboration with a volunteer advisory committee³. The survey was built in Qualtrics, launched in September 2019 and closed after three extensions, to maximize participation, in November 2019. Forty-four (44) complete responses were received and comprise the basis of the Rare Epilepsy Landscape Analysis (RELA).

Most striking about the RELA were the similarities in priorities, challenges and collaborative opportunities across the rare epilepsy organizations. The Analysis (and Appendix) are available in full text and include many findings relevant to patients, clinicians, researchers, industry and government. Insights from three of the areas are illuminated here:

- **Information & Support:** The Rares shared their highest priorities as being accurately and expeditiously diagnosing patients, followed by connecting patients to specialists for high quality care and patients to other patients for community and support. Challenges included accessing services for disparate patient populations as well as providing specialized support when the spectrum of patients and their needs within each disease was broad. Moreover, some Rares expressed concern over the general lack of professional collaboration among doctors and institutes. The Rares are united in their advocacy for rare multi-disciplinary clinics and on-line video libraries to recognize seizures as key cross-rare collaborations.
- **Research:** In research, the Rares prioritized understanding the mechanism of their disease, developing natural history studies, and funding translational science. Roadblocks to realizing these goals included the lack of infrastructure to connect researchers to seed collaborations, access to funding, and the challenge of acquiring sufficient patient data for clinical trials. The Rares seek collaborative opportunities to build shared biorepositories and natural history studies; collectively develop clinical quality care scales; and promote rare epilepsy centers of excellence to advance clinical trials for improved therapeutics and care.



- **Professional Education:** Improving professional education to detect and diagnose diseases, and developing and disseminating best clinical practices, were among the highest priorities irrespective of rare diagnoses. Moreover, updating researcher thinking on Rare conditions was called out by many of the Rares. Common challenges included educating disparate professionals, treating small numbers of patients, and a perceived cultural unwillingness among some professionals to learn beyond the scope of their practice focus. The Rares are aligned in their shared objectives to reach out to medical schools and other professionals in training as well as in other key fields including genetics, psychiatry, and neuropsychology. Moreover, working to develop and disseminate clinical treatment, evaluation, and diagnostic guidelines was a high shared initiative.

The RELA provided a first-of-its-kind snapshot from a moment in time of the United States rare epilepsy ecosystem for 44 organizations. Months later and in the middle of a global corona virus pandemic, so much has already changed – families are more isolated, services and supports are inaccessible, labs are shutting down, research funding is being diverted to COVID19 efforts, and there is genuine fear among many rare organizations about their long-term financial sustainability. What is constant is the fierce determination and perseverance of the Rares to push for change. It's evident not just in the US through consortium like Rare Epilepsy Network (REN) but in international initiatives like EpiCARE⁴ across Europe and EPILEPSY-PM⁵ in Australia where clinicians and advocates are teaming up to effectuate systemic change for patients living with rare epilepsy. The Rare voices are strong, they are gaining momentum, and the time is ripe to reimagine the Rares and their future.

1. Began in 2013 with just 10 organizations, by 2019 the REN registry had grown to include 32 partner organizations across 41 diagnoses and data for 1,500 patients and caregivers. Registry data on seizure medications, side effects, comorbidities and more, is available for request and use by academia, clinicians, researchers, industry, patient advocacy groups, government and others. <https://efa.rexdb.net/anon/site/anon/home> Today, the Rare Epilepsy Network (REN) includes 50 members and partners working with urgency to collaboratively improve outcomes of rare epilepsy patients and families through patient focused research and advocacy.
2. Interviews included the Epilepsy Foundation (EF), Rare Epilepsy Network (REN), Leadership Council (ELC), American Epilepsy Society (AES), National Institute for Neurological Disorders & Stroke (NINDS), National Organization for Rare Diseases (NORD), Global Genes, Citizens United for Research in Epilepsy (CURE), Child Neurology Foundation (CNF); Centers for Disease Control (CDC), Rare & Catastrophic Seizures of Childhood (RCSC) and individual rare epilepsy organization leaders.
3. RELA advisory committee included: Brittany McLarney (PMSF), Jo Anne Nakagawa (TS Alliance); Mary Anne Meskis (Dravet Foundation), Geraldine Bliss (Cure SHANK), Shelley Frappier (The Cute Syndrome), Amber Freed (slc6a1 Connect), Heidi Grabenstatter (Cdk15), and Jay Etta Hecker & Gabi Conecker (Wishes for Elliott).
4. EpiCARE: a European Reference Network for Rare and complex epilepsies across 24 European countries with funding from the European Commission that is advocating for many of the same aims – seizure control, early and correct diagnosis, increased awareness of syndromic and comorbidities etc.
5. EPILEPSY-PM is a project led by Professor Ingrid Scheffer at Melbourne Brain Centre, University of Melbourne, to develop an Australian-wide genetic epilepsy network, bringing together clinicians, researchers and families of children with DEEs to build a database of all patients with genetic DEEs in Australia; develop fine-grained tools to determine whether Precision Medicine therapies produce changes in development, motor skills and comorbidities; and to understand families' and clinicians' attitudes to Precision Medicine for DEEs and their impact.

rare epilepsy landscape analysis



ABOUT THE AUTHOR

Ilene Penn Miller serves as the volunteer director for the Rare Epilepsy Network (REN) and Advocacy Co-Chair on the 2020 NINDS Curing the Epilepsies Conference. She has recently published the Rare Epilepsy Landscape Analysis (RELA) and an editorial in October 2020 journal *Epilepsy & Behavior - Raring For Change*. She is also an active participant on the Epilepsy Leadership Council (ELC), the Epilepsy Learning Health System (ELHS) and a former Advisor on the NIH National Institute for Neurological Disorders and Stroke (NINDS) Advisory Council (2013-2017). Previously, Ilene co-founded and is past President of Hope for Hypothalamic Hamartomas (hopeforhh.org) (2009-2019). Ilene earned a BS in communications from Boston University; a JD from the Columbus School of Law at Catholic University of America (Washington, DC); an LL.M. in advocacy from Georgetown University Law Center (Washington, D.C) and a Nonprofit Management Certificate from Georgetown University (Washington, DC).



LIFE IN THE TIME OF COVID

Anita Mago, Uganda, shares her story with us

We would love to hear from you if you would like to tell us about your experience of living through the pandemic.

It started like something unreal when I first heard about Covid-19. It was so far away in China and it had killed a lot of people. As we monitored the news, Covid had spread to other parts of the globe and countries had started to lockdown their social lives. My first thoughts and worry were about for my daughter. Not that she was in any of the countries where cases had been reported: she was here in Uganda with me; but she has epilepsy. My heart was racing because of the urgency to get a store of medications which are always hard to afford and rare to find. My daughter was equally worried and this raised her anxiety. Those who are caregivers like me will appreciate what I was going through and for those who have never experienced a near to no supply of life long medication, it would be hard for me to explain.

I walked from pharmacy to pharmacy and could not find any supplies, each one promising to be stocked the following week. I wondered where they would get more drugs into their stores since we were already under lockdown. The game was simple: they need just a few days to triple the cost of the medications. Every single medication was tripled in price and this was very frustrating. But life has to go on. There are many things I was taking for granted before this endemic - like access to drug stores and a regular visit to a health specialist. Support groups can no longer come together. The hours of the day have 'shortened' because of the lockdown and curfew. My active hours each day are ten, including travel to and from my home. Covid -19 has positively improved my prioritising skills and I am now appreciative of all the little things.

When schools closed in March, that added insult to injury. However, life became even more challenging when it dawned on me that I could not visit my friends; I was conditioned to wearing a mask all the time outside the home; and there was this paranoia of washing hands wherever one went, even when you had a hand sanitizer evidently hooked on the strap of your handbag.

Covid 19 turned around lives in the family. With lockdown and most facilities closed, I needed to go out of my way to look for items I would normally find within the locality where we live. Public transport was not available and the favour we had enjoyed for a few days to drive private cars was withdrawn because this means of transport was said to be spreading the virus.

Some distances were not easy to walk since one had to be indoors by curfew time. This is the time when my sports bike, that I had not used in years, came in handy. I took it to a makeshift repair shop

and had it fixed, but for a fee that was more than it had cost brand new. The few of us who had bikes were the envy of many. Those who had a stall selling secondhand bikes made a killing as bikes were going for US\$300 or more. Nevertheless, most of us have put on weight. We hardly miss a meal of the day but the exercise does not match what we eat to shed off weight. Besides it was not safe to ride into the city since the few vehicles that were granted permission to be on the roads had reckless drivers.

I had to walk to town a few times to get garden tools and packets of seeds for my urban farming activities. This is about a six kilometer return journey. Apart from input on a few projects for the organization I work for, I planted tomatoes, spinach, lettuce and kale in addition to improving my indoor plants. My chickens were laying eggs so I decided to take some eggs and put them in an incubator I had not used in a while. In May I got forty-five brand new chicks and as we talk now, I should expect some more eggs come August or September.

The Covid lockdown opened my eyes to making plants a business. My friends are asking for a little potted plant to put on the window sill or at their reading table or desk; some came to appreciate the fresher environment during lockdown so now my indoor plants are on demand and there is scramble for the organic eggs from my chickens.

For the three months that we had few vehicles on the roads the air was fresh and it was noticeable. My car that was parked outside for that period never gathered dust at all and pollution levels were down.

So far, there are no reported cases related to Covid in Uganda. This is a puzzle that I am not yet about to solve. What confuses me is that here in Africa in general we cannot social distance because of poverty: we share the same clothes, utensils and facilities whatsoever. We dearly love shaking hands; hugging and close physical contact is in our nature; and we can hardly stay at home.

At first some sources whispered that we didn't have efficient facilities to test for Covid and others said that we were underreporting our cases. As I write my story, while some facilities still remain closed, some areas of the city are crowded and it's business as usual. Some people have abandoned wearing masks and there is hardly any concern about washing hands.

Everyone for themselves and God for us all.

PROMISING STRATEGIES 2020

Fourteen years after the first launch of the Promising Strategies Program in 2005, we took time out to reflect on the many successful outcomes: those projects that had continued to run successfully when funding support ended or which had grown and adapted into other initiatives. We also considered those projects that disappointed, by falling short of expectations.

One of the biggest issues was the level of funding provided to each project. In our efforts to support as many as possible, the thin spread of funds prevented us from adequately evaluating why some projects were so successful and why others failed to deliver fully on their promise. We decided to address this by selecting a lower number of projects, with a narrower focus in terms of the issues to be addressed, thus allowing an increase in funding for those chosen for support. We were delighted, also, to receive a grant from the BAND Foundation

We realised also that, for the future, we needed to take on board the new technologies that have revolutionised communications. These technologies provide cost-effective means of equipping both young and old with the training, information and self-confidence to play active roles in their society.

Equally important is the changing role of the patient in decisions made on their care and treatment. The call of the World Health

Organization, the European Union, and social and political scientists, for a redistribution of power between patients, experts and specialists in policy and decision-making that concerns them, is also a huge step in the right direction.

The latest round of the Promising Strategy Program, which focuses on the African continent, is funding projects aimed at equipping people affected by epilepsy with the expertise needed to be an equal partners in all aspects of their healthcare, education, employment opportunities, legal rights and, in particular, in issues related to stigma reduction. Many African patient organisations are motivated to change epilepsy understanding on their continent. Unfortunately, the capacity of such chapters in Africa is limited, yet there is a strong desire by these member chapters to build their infrastructure in order to narrow the knowledge gap and to reduce the stigma and discrimination that people with epilepsy face in Africa and which often leads to inhumane treatment by society and even by their families.

Five projects have been selected and their projects are now underway, albeit with some delay due to COVID-19 restrictions. While the latest Promising Strategies projects are based in Africa, they have been chosen also on their suitability to become a template for roll out in other regions of the world.

MALAWI

Fighting Epilepsy Silence in Rural Malawi using Technology



Persons with epilepsy face many forms of stigma and discrimination in Malawi, as well as barriers to access health services ranging from inaccessible health systems to non-existent services in some remote areas. Non-commitment by the government to address these barriers creates a serious treatment gap. Persons with epilepsy now have a high risk of non-adherence to medication, leading to recurrence of seizures which forces many not to participate or be included in society on an equal basis with others.

The project aims to improve the quality of service to persons with epilepsy by providing real-time evidence of gaps in service using a tracking system. Using mobile phones, persons with epilepsy will work as monitors capturing data that will be analysed and used to generate evidence of the treatment gap and social exclusion.

MAURITIUS

Training preschool teachers about epilepsy



In Mauritius, preschool teachers supervise children up to six years of age. Research undertaken by Edycs Epilepsy Group through direct conversation with 15 teachers from different preschools concluded they have no understanding or knowledge about epilepsy and seizures. Parents reported that their children were bullied while preschool teachers were frightened when witnessing seizures in class, not knowing what to do. It was also evident that preschool teachers did not have sufficient knowledge on how to manage and work with children with epilepsy in the preschool setting.

It is therefore essential to equip preschool teachers with adequate and relevant tools to help them identify children with epilepsy in early years, and at the same time to help those children in class, so that no child is left behind.

SOUTH AFRICA



Epilepsy South Africa has been provided with funding to continue the work it began during Phase 1 of the Utezezi advocacy program, focused on the World Health Assembly Resolution WHA 68:20, that finished earlier in 2020. The association will retain the Utezezi project objectives:

- Establishment of a National Epilepsy Task Force;
- Development and implementation of a National Epilepsy Plan;
- Epilepsy awareness and education; and
- Supporting international initiatives to ensure that the Resolution remains on the WHO agenda.

ZAMBIA



The Epilepsy Association of Zambia will carry out a survey to establish the number of children with epilepsy not attending school; to establish why high numbers of children are not attending school (it is believed this is due to the consequences of the disease, which include overprotection, stigma or lack of self-confidence); and help them and their parents or guardians, to make informed decisions regarding school attendance despite living with epilepsy.

Following the formulation of the 2015 national policy on disability, the vision of the Zambian government is to see that all people with disabilities enjoy equal rights, including the right to an education.

UGANDA



Epilepsy Smart Communities is a project of Purple Bench Initiatives in Masaka, Uganda, that will:

- Create understanding of epilepsy among government officials to support policies that favour people living with epilepsy
- Establish working relations with other NGOs to promote programs geared towards reduction of stigma and discrimination
- Train trainers to create continuity and to change the mindset of school communities to be epilepsy smart
- Empower caregivers to better manage people living with epilepsy
- Respond to the call to action for Sustainable Development Goals through the pledge to “Leave No One Behind” in efforts to ensure that all people enjoy peace and prosperity by 2030.

GOOD NEWS FROM AUSTRALIA

Epilepsy Foundation has received a government grant of 20 million Australian dollars over 4 years to develop the Epilepsy Smart Australia Program Pilot. The objectives are to:

- enhance epilepsy related services, avoiding duplication of current resources;
- deliver nationally consistent, evidence-based epilepsy related services and supports across all states and territories;
- ensure Australians living with epilepsy have access to support to assist them to be knowledgeable, healthy and active community participants;
- enhance understanding of epilepsy across all sectors and the broader community, for appropriate responses to the needs of people living with epilepsy;
- support the health sector workforce, and those living with epilepsy, through the development of digital epilepsy management tools;
- provide support for Australians living with epilepsy at all life stages, in particular for children and adolescents, and people over 60 years;
- ensure resources are culturally appropriate and address the needs of Aboriginal and Torres Strait Islander people and culturally and linguistically diverse groups.



Vinod Swaroop Saxena

July 17, 1942 - July 20, 2020

It was with great sadness that IBE learned of the death of Dr Vinod Saxena, who served as Vice President South East Asia on the IBE International Executive Committee for the term 2009 to 2013.

From the minute we are born to the moment we take our last breath, there is the period in between it all..... that we call life. A person who is born is destined to die. Death is a universal truth of life. Yet, the concept of losing someone near and dear forever, is something that's difficult to grasp. Soon after losing a person being as close as a family member, comes the grueling process of making that announcement in the form of an obituary!

Dr Vinod Saxena left a huge void in the epilepsy spectrum of India when he breathed his last. He was one of the most prominent and energetic leaders who have contributed towards the resurgence of interest in epilepsy in the Indian sub-continent. In his near 50-year-long professional career, he achieved milestones that one can only aspire in one's lifetime.

Vinod was born on July 17, 1942 in Lahore (now in Pakistan) the only brother of four siblings. He obtained the MBBS degree with distinction and a gold medal in Social and Preventative Medicine from the Maulana Azad Medical College, New Delhi in 1964. After graduation, he joined the Indian Army and saw action in the 1965 Indo-Pakistan war. He left the Army in 1969 to begin a long career in the pharmaceutical industry. While Medical Advisor at Reckitt and Coleman, he was the man behind the introduction of sodium valproate not only in India but also in the neighbouring South-East Asian countries. He left the industry in the late 1990's and dedicated the rest of his life to the cause of epilepsy.

I first met Dr Saxena in 1985-86 when we were preparing to host the 18th International Epilepsy Congress (IEC) in New Delhi. I was a young neurologist working in the AIIMS, while Vinod was already at the height of his professional career. Despite the difference in the scale of achievements and age between us, he always treated me like a professional colleague while we worked together and like a younger brother whenever we met socially.

After the successful congress, Vinod played a pivotal role in the formation and growth of the IEA-18th IEC Trust created with the congress surplus funds donated by IBE and ILAE. Under his stewardship the Trust has funded various epilepsy awareness programs, disseminated guidelines on the management of epilepsy in India through publications, supported members of Indian Epilepsy Association and Indian Epilepsy Society to attend international conferences and even funded research projects.

Dr Saxena served both the Indian Epilepsy Association (IEA) and the Indian Epilepsy Society (IES) with distinction. He was Treasurer, Secretary General and President of both the organizations during

his time as office bearer. He was also a founder member of the IES. Finally, there was Vinod Saxena the man. He rubbed shoulders with the Who's Who of the global epilepsy movement and came from an incredibly cultured and respected family. However, not once in the decades that I have known him, did any of this have the slightest bearing on the way in which he treated friends, acquaintances, colleagues and the numerous people who importuned him every now and then. He led an exceptionally disciplined and fit lifestyle - enjoyed listening to music, watching musical productions, discussing politics and reading voraciously! He travelled extensively across the world and shared anecdotes with friends and family members. He enjoyed his club life with family and friends, played golf and swam during the weekends. Those close to him would know of his being a connoisseur in food and drink.

Having enjoyed his company on so many occasions, I can vouch that he was also a wonderful host. There was no humbug about the man and he wore his vast knowledge lightly. Unfortunately, just 3 days after I last interacted with him on possible treatment options for COVID-19, he contracted the disease possibly while attending to migrant labourers at a construction site across from his home where he often donated supplies. He spent almost 40 days in the ICU before his heavenly departure just 3 days after his 78th birthday. He fought COVID like a warrior but failed to win the battle against sepsis during his prolonged stay in the ICU. Dr Saxena's time after retirement was committed to epilepsy related activities in India, Asian-Oceanian region and globally. He was dedicated and diplomatic in his approach to complex issues. What he achieved in the last 3-4 decades will be difficult to match. To me personally, he was like an elder brother. He was very close to my wife Menka, our children and even the grand-children. With Dr Saxena's death, an era of refined leadership defined by consensus, humour, charm, wit, vision, intelligence and humility comes to an end. His passing leaves me personally bereft but I want to say that the life he lived was one to be celebrated.

Our prayers and condolences go to his wife Shobana, children Saurabh (and his wife Vandana), Surabhi and Laltu, and the grand children who have been devastated by his untimely death. We in the Indian Epilepsy Association, Indian Epilepsy Society and the IEA-18th IEC Trust pray for the departed soul.

It's okay to miss you, It's okay to cry!

Just know we'll never forget you, This isn't a permanent goodbye!!

SATISH JAIN, MD;DM;FRCP, New Delhi, July, 31, 2020.

HARNESSING THE PATIENT VOICE

EpiCARE ePAG delivers its first live Webinar

Emma Nott, Secretary Hope for HH, Secretary ePAG EpiCARE, reports



Emma Nott

On 16 July this year representatives from the ERN EpiCARE ePAG (European Patient Advocacy Group) delivered its first live Webinar. The Webinar introduced the ePAG and explained our role within EpiCARE, with the dual aims of highlighting our work and attracting new members. Presenters included Isabella Brambilla from Dravet Italia, Allison Watson from Ring20 UK, Jose Aibar from Dravet Espana, and

Emma Nott from Hope for Hypothalamic Hamartomas UK. There were 80 registrants; the webinar was recorded and can be viewed [here](#).

The message was simple – through patient group participation we can help shape the present and future of epilepsy treatment and research. There are more than 130 rare and complex epilepsies spanning 27 member states of the EU, but only a handful are currently represented within the ePAG. By joining EpiCARE as a patient group you will receive our NEW! regular newsletter to stay informed and be invited to contribute to our work and have your voice heard.

Through participating in ePAG activities, a patient group gains access to resources and ideas designed to help the whole patient community. For example, through ePAG collaboration each representative has created a Patient Journey describing the needs, treatment path and life-long journey of the typical sufferer of that representative's patient group. Each Patient Journey is comprehensive but succinct – presented as an infographic on a single poster, it is designed to allow a busy clinician to take in the salient features at a glance. Similarly, each patient representative has created two summary information leaflets for their disease – one for the clinician and one for the patient/family. The leaflets conform to templates

agreed by ERN EpiCARE and set out the key features and treatment protocol of the rare and complex epilepsy described, as well as where to obtain support with links to patient group(s). These projects have created invaluable resources to benefit newly diagnosed families as well as help the non-specialist clinician both to recognise the symptoms of these rare and complex epilepsies, and to place the patient on the appropriate treatment path.

Any patient advocate interested in learning more about the ePAG's work with a view to help increase our resources and, hopefully, joining us, can find out more [here](#) or you can contact us directly at epag.epicare@gmail.com. We need YOUR HELP to ensure EpiCARE successfully delivers change for the patient benefit!

SAVE THE DATE! There will be a face-to-face opportunity to learn more: the Italian healthcare professionals of EpiCARE are hosting a three-day conference in Rome on 17-19 December 2020, pandemic permitting*. The theme is "In Search of Lost Time in Children and Adolescents with Epilepsy". Members of the ePAG will be there, presenting our Patient Journey posters and Information leaflets, and describing our work in more detail. The conference is open to all patient advocates as well as to the medical community – you are warmly invited to register. The planned programme is [here](#).

*The Rome meeting will be face-to-face. Therefore, if the pandemic is still prohibiting conferences in December 2020 it will be adjourned to a date in 2021.



50 MILLION STEPS

One step for every person living with epilepsy



An initiative to celebrate
INTERNATIONAL EPILEPSY DAY 2021
Monday 8th February 2021

BACKGROUND

According to World Health Organization figures, there are 50 million people living with epilepsy around the world.

The World Health Assembly Resolution on Epilepsy WHA68:20, approved in 2015, recognises the need “to ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, in order to help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions”.

International Epilepsy Day provides an ideal vehicle to address the need for improved awareness on epilepsy in all strata of society. A joint initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE), launched in 2015 and celebrated annually on the second Monday of February in more than 120 countries, it’s a powerful opportunity to highlight the problems faced by people with epilepsy, their families and care providers.

Echoing the recommendations of the WHA resolution, International Epilepsy Day was developed in line with a strategy to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life by highlighting that:

- epilepsy still remains a hidden disease due to the stigma attached;
- it is treatable, yet 40% of people living with epilepsy in wealthier countries do not receive appropriate treatment. Over 70% of those living in low income countries cannot even access epilepsy medication regularly;
- lack of treatment imposes a huge financial burden on national health systems;
- research and legislation remain key issues in improving the quality of life of persons with epilepsy.

50 MILLION STEPS FOR EPILEPSY

For International Epilepsy Day 2021, we are launching our 50 Million Steps for Epilepsy campaign. This is a campaign that is easy to get involved in and has a range of benefits for both sponsor and participant. Sponsored walks and runs have long been a popular means of raising awareness and funds. IBE chapters from around the world, from major organisations to small volunteer groups, have used sponsored walks in their programmes of activities for many years and to great success. In recent years, recognition of the benefits of exercise and the huge range of electronic equipment available to measure achievement, makes a steps campaign even more attractive. Exercise will:

- raise energy levels and improve sleep
- help with blood pressure and heart health
- help to maintain a healthy weight
- reduce stress levels and help with depression

HOW IT WILL WORK

The campaign will launch in September, allowing time for chapters and other groups to work on your own plans to embrace the challenge and to begin promoting it at a local level. Although International Epilepsy Day is organised by IBE, supported by ILAE, it is an opportunity for all stakeholders to embrace the day in whatever way you choose. Some of you may decide to organise a public walk to raise awareness about epilepsy while others will use the campaign as a fundraising opportunity. Many of you may do both. The 50 Million Steps for Epilepsy challenge itself will start on Monday 4 January 2021. This is perfect timing as it is just at that time when New Year’s Resolutions are set and people get active again to lose those extra kilos gained over the holiday period! It’s also the time when media focus shifts from holiday food and drink to weight loss and fitness, which will help in attracting media attention to your campaign at a local level. The campaign will end five weeks later on International Epilepsy Day. During this time, IBE will need at least 500 people to walk 20,000 steps each week.

Pictured right: a glimpse of the campaign website which is under construction

The screenshot shows a website layout for the '50 Million Steps for Epilepsy' campaign. At the top, there is a navigation bar with links for Home, About, Fundraising, Events, Map, and English, along with logos for IBE and a SPONSOR button. The main header features the text '50 million STEPS FOR EPILEPSY' and a silhouette of a person walking. Below this, a progress bar indicates '#50MILLIONSTEPS' and 'Complete your steps between Monday, January 4th and Monday, 8th February 2021'. A central message states '50 million people worldwide are affected by epilepsy. To raise awareness of this and to raise vital funds for epilepsy organisations across the world, we are asking you to help us walk 50,000,000 steps for epilepsy ahead of International Epilepsy Day 2021'. A form allows users to 'Add your latest steps' with a blue 'Add your steps' button. A counter shows '732,435 steps walked so far!'. The 'About the campaign' section explains the goal and provides a link to 'Add your steps to our grand total?'. It also states 'Between Monday, January 4th and Monday, February 8th (International Epilepsy Day) we'll need at least 500 people to walk 20,000 steps every week... ..are you up for the challenge?'. There are sections for 'How to count your steps' and 'Download resources'. A 'Fundraising and sponsorship' section includes a list of placeholder links. The 'Organising an event?' section has a 'Share event details' button. The footer displays logos for various partner organizations and the hashtag #50MillionSteps, with a note to use the hashtag on social media and a map showing global participation points.



Wheelchair users can convert distance covered into steps

It's not a huge ask and we are confident that we will more than surpass the challenge goal.

We will be promoting the campaign using the hashtag on our social media platforms, on the IBE and International Epilepsy Day websites, and through eZines and newsletters. Ideas for a campaign photo/video competition – cutest baby step, silliest step, weirdest walk, best pet step - are also in our plans. We will be asking people to upload their photos or videos to social media so that their cute, funny, weird and novel steps can be widely shared.

THE CHALLENGE

The 50 Million Steps for Epilepsy campaign will be attractive to all age groups, in all regions:

- Teachers can use the campaign to talk about epilepsy during sports class
- Companies can use the campaign as part of their social awareness activities
- Families can count steps while out together
- People can walk alone or as part of a group
- Age is not a barrier either. What about baby's first steps or the aided steps taken by an older person?
- Wheelchair users can convert the distance covered into steps using simple calculations that we will provide
- Steps up a mountain or the stairs, on a treadmill, across a dancefloor, high up on stilts – they all count!

SUPPORTING YOU, OUR CHAPTERS

Central to the campaign will be the 50 Million Steps for Epilepsy website. It will hold a wide range of resources available to view content in a number of languages:

- a step counter to allow steps to be logged
- an interactive map to show photos shared on Twitter, Instagram and Facebook using the campaign hashtag
- logos of our chapters and other participating associations
- promotion of events being organised by epilepsy associations as part of the campaign
- toolkit in a range of languages that will include information on organising an event, hints and tips for a successful campaign, how to fundraise through Facebook, campaign logos, etc.

We are still finalising details on the website but will let you know as soon as it is launched.

COVID-19

The Corona virus has had a devastating effect on the plans of many organisations and companies with thousands of events being cancelled due to lockdowns, travel restrictions and social distancing measures.

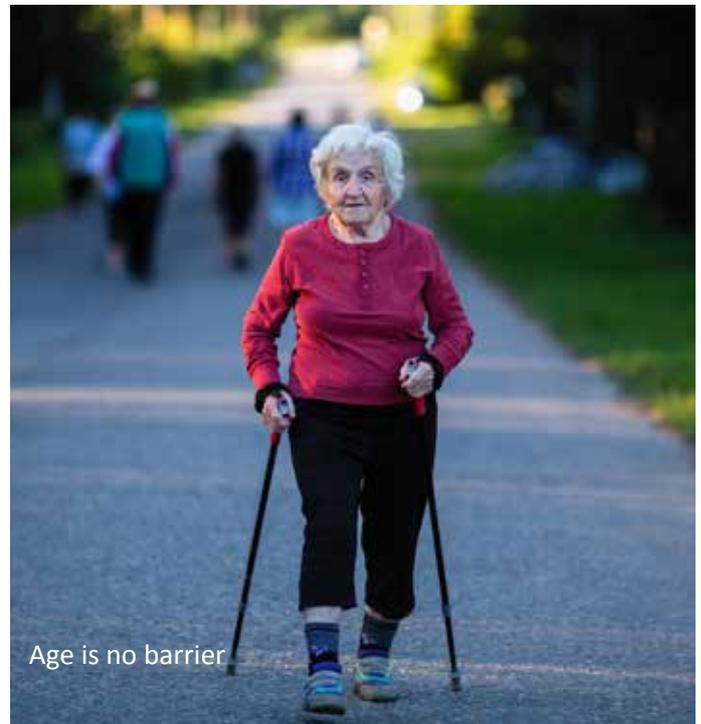
The 50 Million Steps for Epilepsy campaign can meet the challenge of social distancing. It's not difficult to social distance while walking; walking can be done indoors or outdoors; and gyms provide the option of the treadmill.

Let's get started!

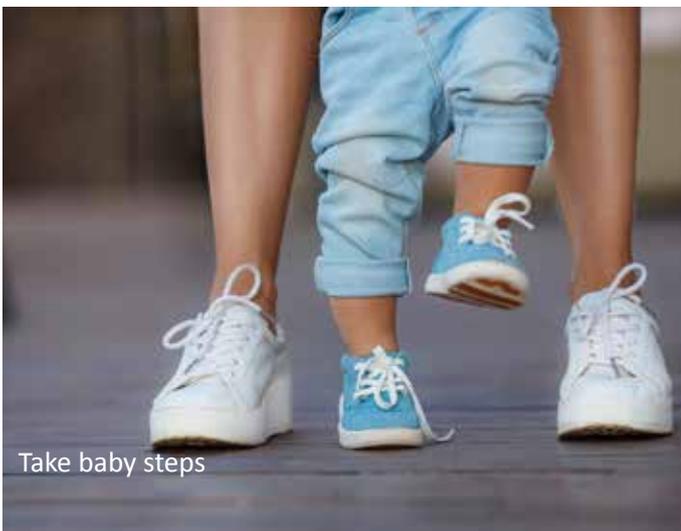


BENEFITS FOR CHAPTERS

- Recognition as a partner on the campaign website
- Involvement in a world wide campaign
- Raising public awareness at a local level
- Opportunity to fundraise
- Attracting media focus
- An opportunity to create competitions and challenges that have the potential to attract media attention as well as fundraise.
- Raising awareness of epilepsy as a health-care imperative
- Addressing the recommendations of WHA 68:20



Age is no barrier



Take baby steps



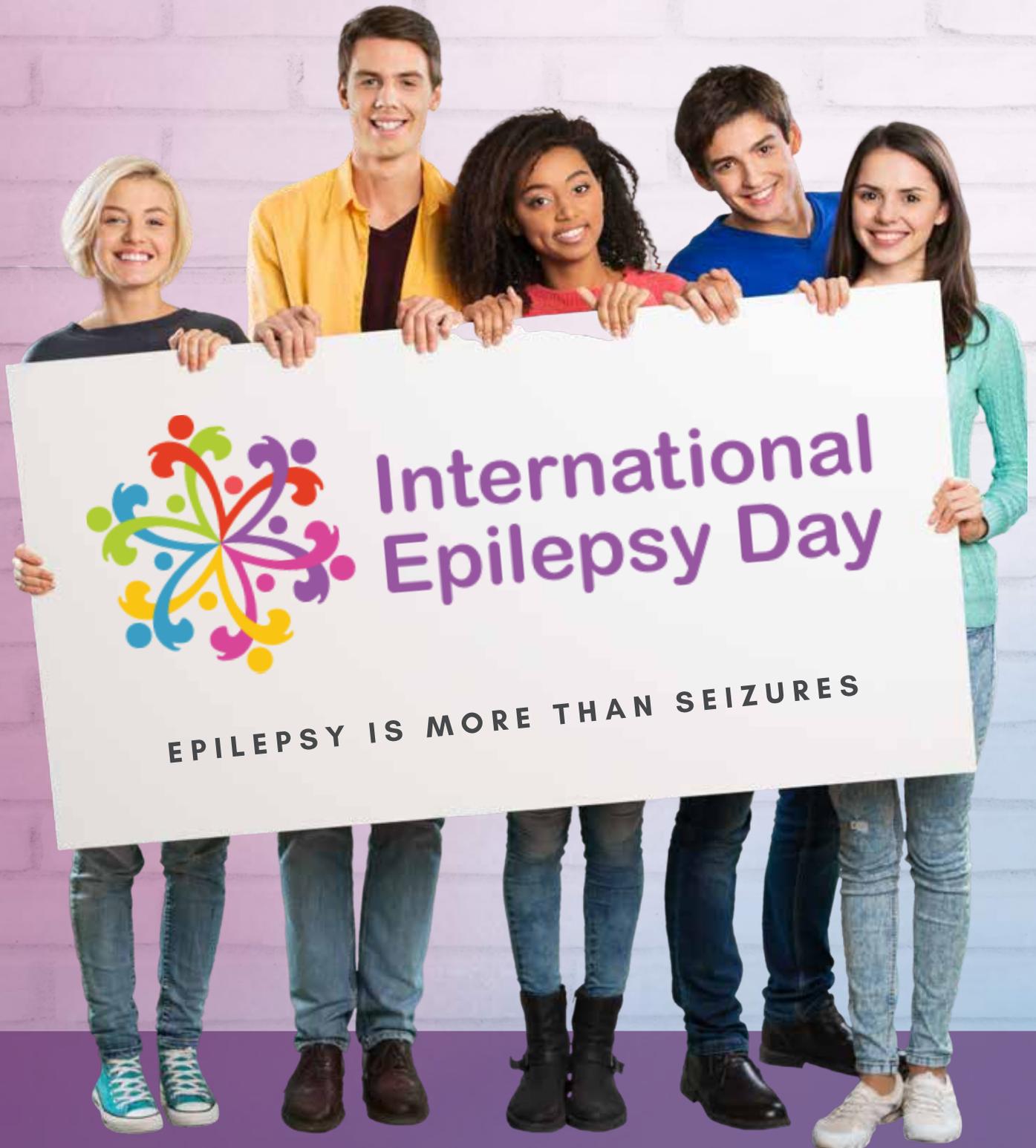
Test your balance with stilts



Arrange a public awareness walk

SAVE THE DATE!

MONDAY, 8 FEBRUARY 2021



www.internationalepilepsyday.org