

# INTERNATIONAL EPILEPSY NEWS

ISSUE 2 - 2020

**Covid-19: a psychological perspective**

*Utetezi Project in Africa*

**More news from round the world**

# INTERNATIONAL EPILEPSY NEWS

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## FROM THE EDITOR

You are probably wondering what the cover image signifies? I once had a screen saver that showed daylight hours slowly cross a map of the world. As the day progressed, I could see when it was bedtime in Asia while in America it was time to start the day. That image of daylight returning in Asia while the Americas are still facing hours of darkness, now transfers itself, in my mind, to the westward course that Covid-19 is travelling. The east is slowly returning to a new day, while further west darkness still holds the grip with continued high numbers of deaths. In addition, the latest news from China raises the fear that the screen saver is starting again on a neverending circuit. Let us hope that this does not turn out to be the case.

As the world continues to rotate, IBE chapters are still working despite the challenges now faced by most of us. So, this issue of IE News includes reports from chapters on initiatives that have been undertaken in response to Covid-19 or which have had to be adjusted to deal with lockdown restrictions. We also have a special report on the psychological perspectives of Covid-19 with excellent suggestions to address issues that might arise. From Africa comes the final report on Phase 1 of the Utetezi (advocacy) Project while, in Europe, Emma Nott tells us about her work with HOPE and her involvement in ePAG. There are reports on National Epilepsy Day in Spain and International Epilepsy Day in India and Martin Brodie marks Richard Holmes' retirement as IDM.

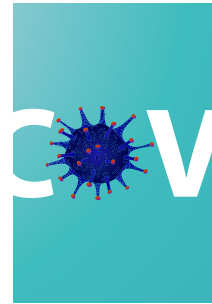
Happy reading!

Ann Little  
Editor



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EDITOR: Ann Little  
REGIONAL SUB-EDITORS:  
Action Amos, Hassan Hosny, Tomás Mesa,  
Natela Okujvava, Susan Pietsch-Escueta,  
Man Mohan Mehndiratta, Ding Ding  
ADVISORS: Martin Brodie, Mary  
Secco, Anthony Zimba



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# PRESIDENT'S MESSAGE

## DEAR FRIENDS

Dear friends

I'm sure you don't need me to remind you that we are now living in a very different world. Some of you will already be well adjusted to many of the major changes that we have had to make, both in our working conditions and in our personal lives, to safeguard ourselves, loved ones, friends and colleagues from the ravages of Covid-19. There have been and will be many changes too in IBE, as we have been considering how to continue to roll out our services amid national and international restrictions, many of which are likely to remain in place for some time into the future. However, also borrowing from the image that Ann has chosen for our magazine cover, there is the promise of daylight ahead. Covid-19 has forced us to sit back and consider what we have been doing to date and anticipate how IBE's initiatives might continue and, perhaps, become even more accessible to our chapters and their members.

Until earlier this year, when Covid-19 began its journey around the world, the personal journeys that many of us had planned to attend our regional congresses and other engagements were suddenly thrown into disarray. All of the ILAE/IBE meetings planned for 2020 have been postponed until 2021 and, when new arrangements are put in place, it is likely that these, to a large extent, will be held as virtual events. For IBE this may even be good news, because it will mean that many more of our members, who in the past have struggled with the costs of travel, accommodation and registration fees, will now be able to participate in congresses for a fraction of the price without the need to leave their own homes!

This was one of the issues that was discussed by the IBE International Executive Committee recently, as we held our first virtual board meeting since the COVID storm hit us. Central to our deliberations was consideration of how best to involve more people affected by epilepsy and those who care for them in IBE activities so that they can become the motivators of tomorrow. Our objective is to see an IBE board emerge over the next decade whose membership consists of people with a wide range of expertise and skills.

As a first step, I am creating a new series of working 'Teams', each one focusing on a specific issue related to epilepsy:

- An 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 the pharmaceutical industry.
- A Global Advocacy team will work on encouraging implementation of the World Health Assembly Resolution on Epilepsy at a national and regional level around the world and help to develop local initiatives.



- Our Research team will know about medical and psychosocial research occurring in all regions of IBE activity. The goal here is for our members to take an active role in research programmes and, indeed, possibly learning to be part of the leadership team in some of them.
- Our Youth team will recruit young people from around the world interested in being involved in a range of epilepsy initiatives and, potentially, training to be the next leaders of IBE.
- Virtual congresses have the potential to provide significant opportunities for IBE to capitalize on their benefits by ensuring that all of them have a programme that is IBE focussed and interactive. Planning the content and identifying speakers will be the mandate of our Virtual Congress team.

Accordingly, I will be writing to all our chapters in the coming weeks to provide more information and invite applications for membership of these teams.

Finally, I would like to advise you that the term of the current Management Committee will end at the time of our General Assembly at the Paris congress at the end of August 2021. The process to elect the next President, Secretary General and Treasurer IBE will begin in September and the Election Task Force will be writing to our chapters at that time inviting them to nominate candidates. This will be your opportunity to help us develop a leadership team whose membership is reflective of the mission and objectives of IBE going forward. Please consider allowing your name to be put forward.

There are exciting times ahead for IBE!

Martin Brodie  
President

# COVID-19

## Surviving COVID 19 from a psychological perspective: Advice for people with epilepsy and their families

*Authors: Professor Gus A Baker and Professor Steven Kemp*

### Introduction

In January 2020 the World Health Organization (WHO) declared the outbreak in China of a new coronavirus disease, Covid-19, to be a Public Health Emergency of International Concern. WHO stated that there was a high risk of COVID-19 spreading to other countries around the world. In March 2020, WHO made the assessment that COVID-19 could be characterized as a pandemic.

Our responses to the Covid-19 pandemic at an individual level will vary based on our experience of coping with health issues and other life problems generally. For some individuals and their families, they may develop stress due to the uncertainty of the pandemic and the risk of being infected. Stress reactions can include low or depressed mood, anxiety, frustration, irritability, anger and social isolation.

This article addresses the concerns that people with epilepsy may have about the condition and what practical solutions may be taken to help them cope from a physical, psychological and cognitive perspective.

### Concerns of People with Epilepsy

In preparing this article we asked our colleagues, Dr Sallie Baxendale and Professor Martin Bunnage, both of whom are providing telephone, skype or zoom services for their clients, to identify the concerns that have been expressed to them. These are the concerns their clients have identified:

- Do I belong to a vulnerable group and because of my epilepsy am I at greater risk than others without epilepsy?
- Will a change in routine have an impact on my seizures?
- How do I cope with the impact of the lockdown?
- Will the supply of my antiepileptic medication be affected?
- What will happen about my regular hospital appointments?
- Will my treatment be affected e.g. will I have to wait long for surgery?

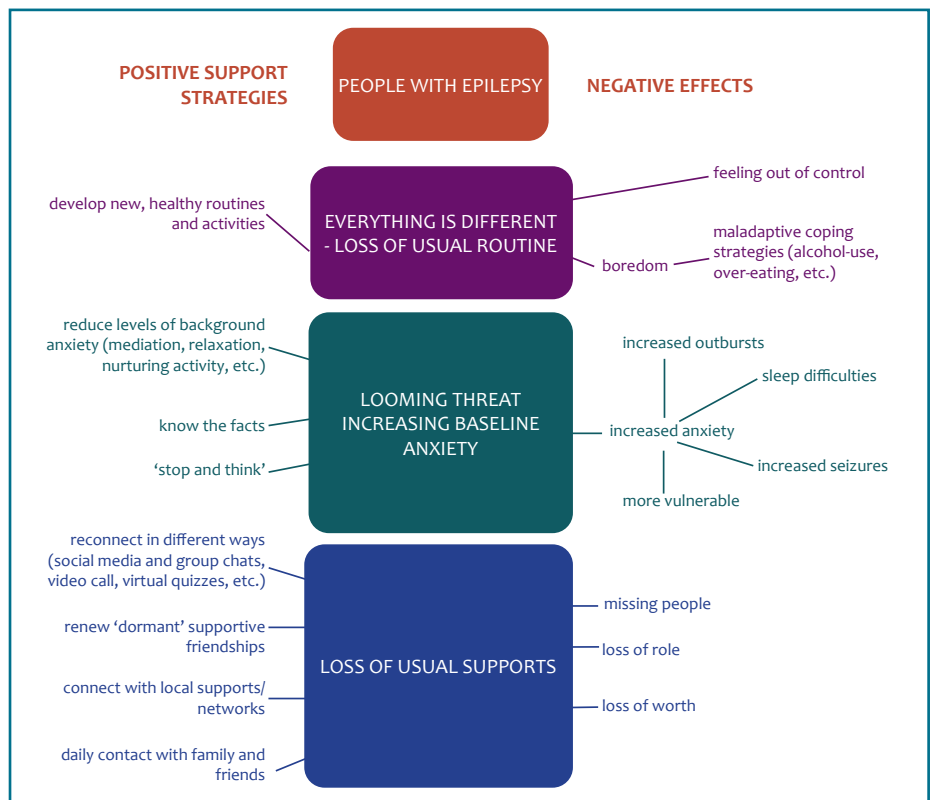
- Can I still contact my neurologist or epilepsy specialist nurse or therapist [neuropsychologist/ counsellor]?

Many of the questions are directed at the medical aspect of epilepsy and the IBE and ILAE will have posted information in relation to them. There will be a number of support organisations in each country that also may assist in helping answer specific questions or at least put people in touch with medical staff who might be able to answer them.

The impact of the Covid-19 will vary from

may be delays in elective treatment e.g. surgery or attending routine appointments - and this can be frustrating and worrying. We know that some epilepsy centres will have made arrangements to support people who attend their hospital.

In thinking about the lockdown, we have created a diagram for people with epilepsy adapted from work done by Dr Lesly Murphy. The diagram highlights the challenges that people with epilepsy might have to face [right side] and the possible solutions [left side].



*Diagram Barriers and Strategies for managing Covid-19 Pandemic*

one person to another. Surprising for some there has been an improvement in the control of seizures, while for others the anxiety of Covid-19 might result in a deterioration. If there is a negative change then that is a reason for seeking medical advice. The Covid-19 pandemic also means that there

It is important to recognise that Covid 19 is an unusual and threatening situation and one where there is a great deal of uncertainty. It is perhaps surprising that most people will feel out of control. So how can we deal with not feeling in control. In this article we want to provide the challenges of

the lock down and provide ideas that might help with managing the situation.

## Feeling out of control

Some individuals may well feel overwhelmed by their thoughts and fears about contracting the virus or managing the lockdown. It is important to recognise that we cannot control what happens in the pandemic nor can we control the decisions made by others e.g. restricting movements, social distancing, closing down workplaces and cessation of employment. However, we can try and control some aspects of our everyday life.

## Suggestions

- Share your thoughts and fears with others including a family member or friend.
- If worry plays on your mind and bothers you or interferes with your day, then ask yourself can you control what you are worrying about? If you can, then spend 10-15-minutes thinking of solutions and plan what you can do now.
- If you are worrying about a problem that you can't control, then try postponing the worry or distract yourself from the worrying thoughts. Or remind yourself that your worry is just a thought and that thoughts come and go.
- Try to pay attention to the present and not think too far ahead at this time.
- Find pleasure in the smaller things that we usually take for granted or don't have time to do, like cutting the grass, cooking and sitting out feeling the warmth of the sun.

## Education and Knowledge

The WHO suggests that you should minimize watching, reading or listening to news about COVID-19 that causes you to feel anxious or distressed.

## Suggestions

- Seek information only from trusted sources and mainly so that you can take practical steps to prepare your plans and protect yourself and loved ones.
- Seek information updates at specific times during the day, not more than once or twice daily. The sudden and near-constant stream of news reports about an outbreak can cause anyone to feel worried.
- Get the facts; not rumours and misinformation. Gather information at regular intervals from local health authority platforms in order to help you distinguish facts from rumours. Facts can help to minimize fears.

The IBE and ILAE websites have provided helpful information how your epilepsy may or may not be affected by COVID 19.

## Communication

Communication is central to our ability to stay emotionally well. Although contact is challenged by the current circumstances it is more important to maintain than ever.

## Suggestions

- Keep in regular contact with loved ones (e.g. via telephone, e-mail, social media or video conference).
- Share your worries over your concerns with people you trust.
- There are a number of helplines and online forums for people with epilepsy.

## Taking care of yourself

In times of uncertainty it is important to look after yourself physically, psychologically and emotionally.

## Suggestions

- Be prepared and know in advance where and how to get practical help if needed, like calling a taxi, having food delivered and requesting medical care.
- Make sure you have up to two weeks of all your regular medicines.
- Learn simple daily physical exercises to perform at home, in quarantine or isolation so you can maintain mobility and reduce boredom.
- If you have a garden, spend some time there or alternatively go for a walk.
- Make sure you get enough sleep and try to maintain a regular sleeping pattern.
- It is important to keep your mind active as well as your body. This could mean learning a new hobby, improving existing skills, making a playlist, etc.

## Maintaining relationships during Covid -19

We don't normally spend so much time at home with our partners and family. We all need to develop a new normal for all being at home together.

## Suggestions

- If you or your partner are working from home, talk about how this is working for you and them. You may need to get creative with the space if you are both working from home. Take turns to share the most comfortable and quiet spot and share childcare so that you can both get some work done.
- Try to deal with bickering by talking about the shared frustration with this virus and realise that we are all in this together.
- Big and difficult decisions or conversations may need to be put on hold while you handle the current situation, and if these issues have been the cause of arguments with your partner, then call

a truce during this time to make living under one roof more bearable.

- Treat each other with kindness and compassion especially as the outside world can feel quite threatening.
- If you are getting frustrated or upset, count to 10, take some deep breaths, walk away and calm yourself down.
- If you're getting frustrated with others in the house, it might be an idea to share how you're feeling by getting in touch with a trusted friend.
- Remember that children will see and learn from how you deal with conflict, so keep this in mind when you are all under one roof together.

## Routine and Structure

Getting into a good routine and controlling your worry, as well as looking after yourself generally, will help with your epilepsy. Regular exercising, cleaning, daily chores, singing, painting or other activities are all important.

## Suggestions

- Keep regular routines and schedules as much as possible or help create new ones for the new environment.
- Write a timetable for the forthcoming week.
- Set yourself goals and build a weekly plan to meet those goals.
- Keep the same routine with taking your medication and with your sleep.
- Use the memory support techniques and reminders that work for you, with regard to taking your antiepileptic medication and for general day to day things. That might be a dosette box for your medication or a Smartphone App to remind you when to take your medication.
- For memory generally, keeping a diary, using lists, notes, a white board with reminders and generally having a routine can all help.

## Final Tips

1. Set a routine. If you are spending more time at home it is important to continue with a regular routine.
2. Stay mentally and physically active.
3. Notice worry triggers and try to limit the time that you are exposed to them each day.
4. Rely on reputable news sources.
5. Stay connected to others.

For more Covid 19 information and support documents go to: <https://www.ibe-epilepsy.org/covid-19-epilepsy-information/>



## RICHARD HOLMES RETIRES

IBE President, Martin Brodie,  
pays tribute

and organising committees responsible for the development of the congress programmes. Richard and I also visited the potential venues together, where we would negotiate with suppliers. It was here that I watched him make the best possible deal for each congress. We considered ourselves a good team - with Richard referring to me as the difficult to please 'boss'. We both knew who the real boss was!

These congresses took place in a "time of plenty" as far as sponsorship from the pharmaceutical industry was concerned. Those halcyon days are, unfortunately, long gone. Our site visits saw several back to back meetings with early starts and late finishes each day - although there was usually the chance to relax with a glass of something alcoholic at the end of the day. As a Scotsman with a love of good whisky, it may surprise people to learn that I introduced Richard to an Irish whiskey called Tullamore Dew, which has since become his favourite. The observant reader will notice the difference in spelling between the Scottish and Irish varieties of the beverage!

Overall, Richard Holmes spent 45 years working in the field of epilepsy, with the last 21 years serving as IDM. I am delighted to pass on my best wishes and those of all of us at IBE to him for a long, happy, and rewarding retirement. I will remember with great fondness the times we spent travelling and working together. It will be difficult to forget too those unplanned incidents, such as our time in Montevideo in 2008 with the organising committee for the Latin American Epilepsy Congress, when Richard was paranoid about avoiding being mugged. Yet of all of us in the group, he was the only one who ended up actually being mugged! Or the time in Mexico City in 2004 when we were taken by our hosts on a visit to the city's museum, only to realise when we were about halfway round that we had been taken there the last time we visited the city several months before.

Well, Richard, here's to you – Slangear or Slainte depending on whether you are drinking Scottish whisky or Irish whiskey!

As you may know, Richard Holmes recently retired as International Director of Meetings (IDM) for IBE and ILAE. I first met him when we both were members of the scientific and organising committees for the Epilepsy Europe Congress that took place in Glasgow back in 1992. The success of this meeting led to the setting up of the biennial ILAE European Congresses on Epileptology, the first of which was in Oporto, Portugal in 1994. The same year, in parallel, IBE held its own European Congress on Epilepsy and Society in Veldhoven, Netherlands. When I became Chair of the ILAE Commission on European Affairs in 1997, Richard, who was by then IBE President, was appointed as a member of my team.

Following my election as ILAE Vice President in 2001, I was tasked by the then president, Giuliano Avanzini, with developing joint regional congresses in Europe, Latin America and Asia and Oceania. This led to my working closely with Richard for an interesting 4 years, since he was by that time the IDM for both organisations.

We carried out onsite inspection visits to Mexico City, Guatemala, Bali, Bangkok, Kuala Lumpur, Madrid, Vienna, Helsinki, and Xiamen. During our visits to numerous places in Europe, Asia, and Latin America, we met members of the relevant ILAE and IBE scientific



## Young Epilepsy launches The Channel

As part of its mission, Young Epilepsy in the UK has launched The Channel to equip young people with epilepsy with knowledge and relevant support.

The Channel has been co-created with its Young Reps and, according to Young Epilepsy, is a place where young people with epilepsy can get information, advice and guidance when they want it, where they want it and written in a language they can relate to.

Similar to a social media platform, The Channel provides information on lifestyle, health and epilepsy related subjects through video, animation and blog posts. Young can leave comments, ask questions directly and contact Young Epilepsy for further support.

<https://thechannel.org.uk/>

# SPAIN CELEBRATES NATIONAL EPILEPSY DAY

Each year since 2006, 24th May has been celebrated by epilepsy groups in Spain as National Epilepsy Day. Despite the difficulties caused by Covid-19 restrictions, the day was still marked in style this year by 26 different groups across the country.

FEDE (Federación española de epilepsia) a federation of 25 epilepsy groups, organised a special walk to raise awareness and as a demonstration of unity. Those who took part by walking for epilepsy were asked to share their steps on social media with the hashtags #MillonDePasos por la #Epilepsia (A million steps for epilepsy). The result was almost 18 million steps and thousands of mentions on Twitter, Facebook and Instagram. The organisers are confident that next year, post-Covid, will be an even bigger event with more people involved and no longer restricted to walking alone. This will result in even greater awareness being raised as large groups walk in show of unity.

Meanwhile, ANPE (Asociación Nacional de Personas con Epilepsia) used the illumination of municipal buildings across Spain as a means of shining a light on epilepsy, including the government buildings in Madrid. This wonderful initiative was shared on social media with the hashtags #24deMayoDiaNacionaldeEpilepsia and #Salirdelasombra.

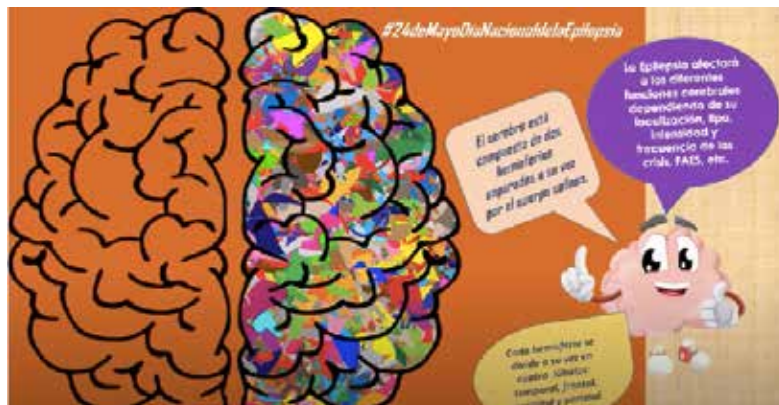
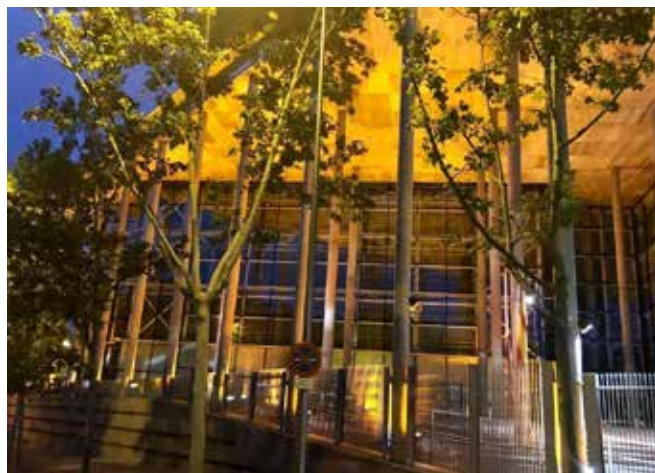
ANPE has also created a special video involving people with epilepsy and their families who tell their very personal stories of living with

a diagnosis of epilepsy. The video is available to view on YouTube: <https://youtu.be/qiCl61ENQ6M>.

## Photos

Left column: logos of the 25 groups that took part in the Million Steps for Epilepsy event and the Thank You note sent to those who participated.

Right column, from top: Asamblea de Madrid and Congreso de Diputados lit up to celebrate National Epilepsy Day in Spain. Screen shot from the ANEP video.





## Making Epilepsy a National Health Priority in Africa Utetezi Project final report

*Final report of the Utetezi Project, written by project coordinator Justine Engole and abridged by Ann Little*

### Introduction

With funding from the BAND Foundation, the Utetezi Project was implemented in six countries: South Africa, Mauritius, Zambia, eSwatini, Kenya and Zimbabwe, as an activity of the IBE African Committee and coordinated by the African Epilepsy Advocacy Project. The project, funded by the BAND Foundation, ran from February 2019 to May 2020.

This article reports on implementation of the programme, as well as its achievements, challenges experienced and recommendations that will inform Phase Two, which begins this month.

### Background

Of the 50 million people worldwide who have epilepsy, 10 million live in the African Region. Tragically, in Africa epilepsy is greatly misunderstood, deeply stigmatized, dramatically underfunded and often ignored by the health care system. Over 75% of people in Africa with epilepsy live in rural or semi-urban areas where treatment is almost non-existent.

In 2015, the 136th session of the World Health Assembly passed a landmark resolution on epilepsy and made recommendations on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications. This resolution calls on all member countries to

address epilepsy by developing and implementing national plans of action. Despite this global declaration, no country in Africa has developed a national epilepsy plan. There has been no political response nor has there been any financial investments in programs that could reduce the epilepsy treatment and knowledge gap at the country level.

The WHA resolution resulted in the IBE African Regional Committee leading a project with the main objective to encourage implementation of the WHA Resolution in Africa.

### Project Goal

The overarching goal of the project, to reduce the epilepsy knowledge and treatment gaps in Africa, was to be realized through the following actions:

- Country specific situational analyses developed.
- Stakeholders mapped out and engaged in the development of the national plans for epilepsy.
- Creation of a multi-sectoral stakeholder taskforce for the development of the national plans of action.

### Program Activity

As a first step, a coordinating office was created and a project coordinator recruited to be based in a space provided at the offices of Kenya Association for the Welfare

of People with Epilepsy (KAWE). A website was built, and brochures and posters were developed, printed and distributed to project stakeholders. A 3-day workshop in lobbying and advocacy training was held in Nairobi for the six IBE chapters involved in the project. An organizational capacity assessment was carried out for all IBE chapters in the African region, supported by a separate fund, and a toolkit was developed to support the advocacy element of the project.

### Development of country specific situational analysis on epilepsy

The situation analysis on epilepsy, carried out by the project implementing countries, was commissioned with the purpose of generating evidence-based data to support advocacy actions for the recognition of epilepsy as a public health concern requiring strategic attention. A guide was developed that facilitated successful collection of data and a report was presented during the workshop in Nairobi. Based on the report, the IBE chapters designed actions plans, set the process for high level dialogue meetings, stakeholder discussions aimed at forming national task forces and the development and approval of national epilepsy plans.

### Stakeholder engagement

An engagement strategy was developed to facilitate stakeholder identification and



engagement. Electronic and print media were used to make Ministries of Health aware of the project. The WHO Africa Office provided cover letters for the project and the IBE wrote letters introducing the project to the Ministries of Health in the respective countries. Monitoring visits were made to Mauritius, eSwatini, Zimbabwe and South Africa with stakeholder engagement meetings. The first meeting for directors of participating countries was held in Kampala in August 2019 during the 4th African Regional Epilepsy Congress, during which project progress was discussed.

Mauritius engaged its Ministry of Health and Wellness, a high level official in its Ministry of Health, and the World Health Organization in advocacy work and successfully mobilized second level stakeholders (persons with epilepsy, parents and disability organisations) as part of the steps towards an action plan for epilepsy.

Zambia held high level meetings with Ministry of Health authorities, made contacts with senior management at the Health Ministry, and identified and engaged stakeholders in the formation of a task force. These engagements resulted in the Permanent Secretary in the Health Ministry making directives for the appointment of a coordinator as a link with Epilepsy Association of Zambia in tracking implementation of the WHA Resolution.

The Zimbabwe chapter engaged directly with technical people in various ministries including the Ministry of Health and Planning Ministry and had direct contact with the Permanent Secretary, Directors and Deputy Directors and other officials from Police and Childcare. This informed the chapter on the processes and procedures involved in policy making and development of action plans.

South Africa held focused engagement with national government departments and the ILAE South African chapter to strengthen working relationships. It carried out organizational capacity building, particularly in terms of implementation of WHA Resolution 68.20 and how this relates to the mandate and work of Epilepsy South Africa. They networked with other IBE chapters in Southern Africa to build cohesion and synergy.

### **Stakeholder task force established**

Zambia, Mauritius and eSwatini had reached advanced stages of establishing a multi-sectoral stakeholder task forces for development of the plan when they were allocated a staff member from their respective ministries to handle drafting of terms of reference for the multi-sectoral committee. In the case of Zambia, finalization formation of a task force was delayed due to preparation for the WHO 146th Executive Board Meeting in February, 2020 and the Corona virus. However, the Ministry of Health is still committed to this work.



Zimbabwe formed a multi-sectoral committee and has a draft national plan of action spearheaded by the policy department in their Ministry of Health.

Kenya partnered with the national epilepsy coordinating committee to lobby government to support establishment of their multi-sectoral task force.

Epilepsy South Africa identified relevant contact persons at the Department of Health, Department of Social Development, World Health Organization South Africa office and ILAE South African chapter. Unfortunately, this work was interrupted by the Covid-19 lockdown but discussions and negotiations will continue when the situation normalizes.

Epilepsy South Africa also established advisory groups at each of its branch offices to inform participants about the WHA 68.20 Resolution. The chapter nominated program representatives who contributed significantly to progress. This strengthened the link between persons with, and affected by, epilepsy and the WHA Project at the National Office. South Africa anticipates reaching agreement with the WHO South Africa office (following support from WHO AFRO) and the Department of Health once lockdown is eased.

### **Development of country specific national plans for epilepsy**

Achievement of objectives was interrupted

by Corona virus lockdowns with participating countries equally affected by these measures. However, South Africa had already drafted an outline based on input from the National Task Force and given their commitment to self-representation by persons with epilepsy, they opted to survey the views and opinions of persons affected by epilepsy. The survey focused on three key areas – Health Factors, Social Factors and Economic Factors - and are available on their website [www.epilepsy.org.za](http://www.epilepsy.org.za).

### **Epilepsy Awareness and Education**

This objective was informed by the situational analysis which revealed wide spread ignorance about epilepsy. The focus, therefore, was to build stakeholder capacity through awareness and education initiatives.

Epilepsy Zambia organized a radio programme during the Tobacco and NCD's Week to sensitize the public about epilepsy. It also organized Focal Point Persons in the ten (10) Provinces, who were willing to work with Epilepsy Zambia. They facilitated at an adolescent psychosocial training workshop, where topics covered included non-communicable diseases such as epilepsy, alcohol and substance abuse.

Epilepsy South Africa developed awareness and education materials, including project and campaign branding. This was aimed at obtaining accreditation by the Health Professions Council of South Africa

(HPCSA) and the South African Council for Social Service Professions (SACSSP) for CPD points. As a result, its Advocacy & Human Rights programme was accredited by the SACSSP for CPD points. They embarked on a review of all education and training materials to address the needs of particular target audiences. Redesign of the Epilepsy South Africa website has resulted in a modern, user-friendly site. They also developed a media campaign as Epilepsy South Africa retains Satellite Brand Communication as a marketing service. The WHA Project was featured in its July 2019 social media campaign.

Epilepsy South Africa strengthened organizational capacity with a specific focus on advocacy and the WHA Resolution, completed adaptation and translation of the IBE Campi videos in Afrikaans, isiZulu, isiXhosa and Sesotho but could not complete recordings due to Covid lockdown. A WhatsApp group was established in September 2019 which was welcomed by persons with, and affected by, epilepsy. The group has been very active during the first eight months of operation and continues receiving positive responses and is an important contact point during the current lockdown.

ESwatini significantly reduced the knowledge gap on epilepsy among people with epilepsy through traditional media, development of promotional materials and implementation of epilepsy wellness



programs at workplaces.

Epilepsy Zimbabwe considered educating people with epilepsy and their families about their condition and support available as the activity that the organization most commonly engaged in. Providing access to clinics and medicine, community engagement and community education/awareness constituted the main activities in their process of project implementation.

### Unfinished work

- One Day Consultative Workshop for People with Epilepsy in Zambia.
- Joint stakeholder consultative meetings for taskforces in eSwatini, Zambia & Kenya.
- Development of a task force and national plans for epilepsy.
- Continued follow up of funders that have potential and promise to facilitate the Utezezi project, such as OSIEA & the Irish Embassy.

### General Project Achievements

- Country specific situational analyses on epilepsy was carried out and evidence based data on epilepsy made available to facilitate advocacy.
- All stakeholders were in agreement on the development of national plans of action. All implementing countries mention that their capacity to lobby and engage with national governments and other stakeholders has greatly improved, opening doors and laying foundations for other projects in other countries.
- There has been improved cohesion and coordination between the implementing countries, sharing best practices and lessons learnt that has helped them advocate better with their national governments.
- The project provided opportunities for the countries involved to network and partner with other chapters in the wider African diaspora through attending the 4th African Epilepsy Congress where best practices and new trends in the treatment of epilepsy were shared.
- Some countries, including South Africa, secured additional funding for the project.
- Improved communication between chapters and World Health Organization offices in the implementing countries.
- The Utezezi project has become a flagship project for some countries who have included it in their strategic plans.
- The project improved communication between most chapters and their membership/branches as there was constant communication on project progress.

- Overwhelming support and commitment was achieved from Mauritius, eSwatini, South Africa, Zambia and Zimbabwe to develop national plans of action.

### Lessons learnt

- Involvement of primary stakeholders, i.e. people affected by epilepsy, significantly contributes to sustainability of advocacy drives and consequently to project success.
- Demonstration of organizational competency builds trust and facilitates successful and influential partnership.
- Legislation regarding policy formulation and development of sector development plans takes a long time and requires perspective planning.
- There is value in learning from interactions and experiences of other sister organizations in Africa.
- Sustainable and consistent communication strengthens efforts to achieve project goals.



## The WHA Project has become one of the flagship projects of Epilepsy South Africa and could be sustained through fundraising efforts

*Marina Clarke*

*CEO Epilepsy South Africa*

### Conclusion:

The Utezezi project has been described by the chapters as “a limitless project, ”a flagship project“ as long as epilepsy is not recognized as a public health priority. Despite slow paced action and bureaucracy, most Ministries of Health and chapters are committed to the successful completion of the project after the COVID-19 pandemic ends. Progress has been slower than anticipated, however, significant progress has been made and the project is on track to achieve its overall goal as evidenced by commitments made by governments for final development of the national plans of action for epilepsy.

Project Implementation Challenges:

- Slow response and government bureaucracy met by all chapters in realising the projects final objectives.

- In most countries, the World Health Organization offices were slow to support the project if they did not get a ‘heads-up’ signal from the respective Ministry of Health.
- General elections in South Africa and Mauritius disrupted progress with chapters having to start the lobbying process afresh post-elections.
- There were challenges of high staff turnover in some countries like eSwatini and Zambia and this affected project implementation.
- The Covid-19 lockdown significantly impacted project progress as staff members at Ministries of Health were involved in COVID response.

### Recommendations

- Chapters should review their advocacy strategies with a view to developing realistic and achievable outputs and outcomes. The project in the next phase needs to have a clear results chain that can facilitate easy determination of project achievements.
- Sharing of existing policies and best practices from other countries is vital.
- Development of materials that are specific to the WHA 68:20 resolution, linking with other UN conventions such as the United Nations Convention on the Rights of Person with Disabilities and the African Union protocol on Human and Peoples rights on the rights of Persons with Disabilities in Africa is important.
- Increased financial support for the project should be considered.
- Extension of participation of other key ministries such as the Ministry for Justice, Health and Social Services can strengthen the advocacy drive for some chapters.
- Close monitoring of the project by the coordinator, especially through visits to participating countries, can help drive progress.
- Investments in epilepsy research should be increased to enable persuasion of decision makers adopt an evidence based decision.
- Having a clear strategic road map to guide future projects is key to success.



*The Utezezi project is supported by funding provided by the BAND Foundation.*

# Keeping up to date on Psychosocial Research

Letter from Professor Gus A Baker and Professor Kheng Seang Lim, co-Chairs IBE Research Commission



As most of you will understand, it is not always possible to keep up to date with psychosocial research in the field of epilepsy. In response to this, we propose to provide a regular briefing document to highlight key findings from recently published research that are relevant to the conduct of the IBE and its members.

The value of being aware of relevant research being conducted in the field can be considered as following:

- Giving us an understanding of applicable research on a regular basis.
- It may make us think differently about a particular topic.
- It can be used to support policy documents.
- It can help us identify areas where further research is required and thus support grant applications.
- It may help us avoid duplication of existing research.

There are a number of key topics that we feel should be the subject of particular interest and these include the following:

- Self-management including education and knowledge; and the application of self-help strategies.
- Stigma interventions aimed at both people with epilepsy and the public.

- Discrimination against people with epilepsy in different life areas (eg. healthcare, education, occupation, insurance)
- Educational and occupational initiatives targeted at different sections of the public.
- Specific interventions for the comorbidities of epilepsy [anxiety, depression, low self-esteem].
- The application of mobile health apps, telemedicine and social media in these areas (self-management, stigma and discrimination, education and assessment for psychiatric comorbidities).

There is little doubt that we would all benefit from knowing and understanding what research is being published and determining its relevance for our own situation as either people with epilepsy, family members, clinicians, carers, researchers and epilepsy organisations.

We therefore plan to trial this initiative over the next 12 months where we produce a briefing document every four months highlighting recently-published relevant research. We are more than happy to accept any recommendations if there is a particular piece of research that you have read that you feel others would benefit from reading also.

Professor Gus A Baker is Emeritus Professor of Clinical Neuropsychology and Honorary Consultant Clinical Neuropsychologist. He has worked in the field of epilepsy for 30 years sharing his time equally between research and clinical practice.

He was made an Ambassador for Epilepsy in 1999.

He is Vice President of Epilepsy Action, Co-Chair of the IBE research Commission and serves on the ILAE Task force for Clinical Neuropsychology .

He is the author of more than 260 publications in the field of epilepsy focussing on the psychosocial consequence of epilepsy and its treatment, neurodevelopmental effects of antiepileptic drug treatment, non-epileptic seizures and impact of newly diagnosed epilepsy. He has presented lectures and workshops in more than 53 countries.



Professor Lim Kheng Seang, is Professor of Neurology in Faculty of Medicine, University of Malaya and Consultant Neurologist specialized in epilepsy in University of Malaya Medical Centre and University Malaya Specialist Centre, Malaysia.

He is a member of the Malaysian Epilepsy Council and past President of the Malaysian Epilepsy Society and Malaysian Society of Neurosciences. Internationally, he is co-chair of the IBE Research Commission and a member of the Research Task Force of the ILAE Commission of Asian and Oceanian Affairs.

He has published numerous papers on epilepsy, especially on the psychosocial aspects of epilepsy, genetics, pharmacogenomics and pharmacokinetics of antiepileptic drugs, quantitative EEG, quantitative MRI research, trials of newer treatment in epilepsy . He is also specialized in non-invasive and invasive epilepsy surgery assessment.



# FLORAL SCENT THAT BENEFITS MANY



How did one Prague non-profit deal with the extraordinary circumstances of a state of emergency? A magic flower. Sniff, it smells good. It is tied to people with epilepsy and it can help those in need.

The non-profit organization Společnost E, IBE's full chapter in the Czech Republic operates a flower workshop, the Arrangement, in Prague, which lost most of its orders in a state of emergency. Theatres, receptions, cafes, weddings ... People with epilepsy and their loved ones work in it. It is often the only achievable way of living for them.

"We didn't ignore it either," says the head of the workshop, Tereza Chvalová. "We definitely don't hang the apron up on a nail or throw pots into the rubbish bin. We leave most of our employees at home for their safety, but we have a couple of hard workers who have prepared a beautiful spring offer. We still create bouquets or flower decorations and we can deliver them contactlessly to the customer's doorstep."

However, there are significantly fewer orders than before the emergency situation, when bouquets were tied in the Arrangement for the National and Company Theatres, the Cirk la Putyka Theater, the Albatros Media publishing house and twelve Prague cafés.

The people in the Arrangement therefore "rolled up their sleeves" and included the Magic Flower in their spring offer. It has one magical feature - it can help those in need. It is a bit more expensive, but at least half of its price goes to online psychosocial counselling for people in need, which Společnost E decided to provide not only

to people with epilepsy and their loved ones during the quarantine period, but to everyone who needs advice in the current situation. For example, seniors.

"A flower is a means for us to help," explains Tereza Chvalová. "Thanks to CZK 600, we can provide 1 hour of professional psychosocial counselling. And to help people who need it."

She recommends sending the magic flower to people who cannot celebrate a special occasion with their family or friends, parents or grandparents who remain in isolation during the quarantine period, as a thank you to doctors or teachers, but also to companies as a reminder to their employees that they do not relax even

special regime. The florist's workshop and the social enterprise Aranžerie are open for them, which is often the only possible source of income for its employees. The workshop is run by the non-profit organization Společnost E, which will celebrate 30 years of continuous work for people with epilepsy in May this year. The organization publishes, focuses on education and awareness, social entrepreneurship and employs social workers who provide professional psychosocial counselling to people with epilepsy. It is free for all interested parties. Společnost E has now decided to expand its advice and offer it to the general public.

"We do not stop working in an emergency. On the contrary, we are aware that not only

people with epilepsy may need our support more than before," says Alena Červenková, President of Společnost E. Společnost E's psychosocial counselling is provided by an experienced team of social workers, a psychologist, a doctor and a lawyer. Everyone has many years of experience with



## A flower is a means for us to help

when working at their new home office, or to clients to stay connected. "This will let everyone know that you care about good things," adds Tereza Chvalová.

Epilepsy is a neurological disease that cannot be completely cured, it can only stabilize. Some people with this disease are able to go to work normally, others need a

epilepsy. The interviews focus on solving the social situation or sharing worries about how to manage life even in a time of pandemic. For moments of personal crisis, a psychologist is available to those interested. People can call for advice, write e-mails and talk on Skype.

"We want to offer what we do well during a company pandemic," concludes Alena Červenková. "Therefore, we will provide free counselling online not only to people with epilepsy, but to everyone who contacts us. Because the need to talk to someone about their fears and worries may not only grow in people with epilepsy."

# European Patient Advocacy Group: an advocate's account

Emma Nott, Secretary of Hope for Hypothalamic Hamartomas, Secretary of ePAG EpiCARE



Hypothalamic Hamartoma with Epilepsy (HH) is a rare and complex brain malformation syndrome, thought to affect 1 in 200,000 people. Its hallmark seizure type, gelastic seizures, are little known and often subtle; this means that diagnosis and treatment can be delayed for months or even years. Around 70% of patients suffer significant co-morbidities surrounding cognitive impairment, behavioural difficulties and autistic spectrum type disorders.

Since 2009 the charity Hope for Hypothalamic Hamartomas has supported patients and care-givers, has worked to spread awareness of this syndrome and its comorbidities, and has promoted research into understanding and treating HH. I have been involved with Hope for HH since 2009 and am currently its Secretary. Running a small charity is time-consuming, and although rewarding, it can be lonely and frustrating too.

The opportunity to join patient advocates for other rare and complex epilepsies was afforded by the creation of ERN EpiCARE and its ePAG in 2017. Representing Hope for HH, I joined this group of committed advo-

cates in late 2018 and was swiftly 'volunteered' to become its Secretary. It became clear that each advocate in the group was effectively an 'expert' in our own particular syndrome or condition, but, perhaps naturally, knew very little at all about other rare and complex epilepsies. And so began a learning curve for us all.

Working effectively as a European collective is challenging. For the first time each of us had to widen our focus from our own, often small, patient communities and consider the diverse needs of the epilepsy patient community as a whole. We come from different countries, have different backgrounds, and experience different healthcare systems. None of us has formal medical training. Each of us is a volunteer; each either suffers from a complex epilepsy syndrome or cares for someone who does; each of us runs our own charity; each has a part or full-time job to pay the bills.

I think it is fair to say that for the first year or two we struggled to find time, direction, or commonality and clarity of purpose. We seemed to me to be single voices – soloists in the same room rather than a choir.

We had plenty of ideas and projects, but would quickly become overwhelmed, often unable to meet our commitments. However, one thing that we all had in common was a determination to improve the lives of those suffering from the rare and complex epilepsies.

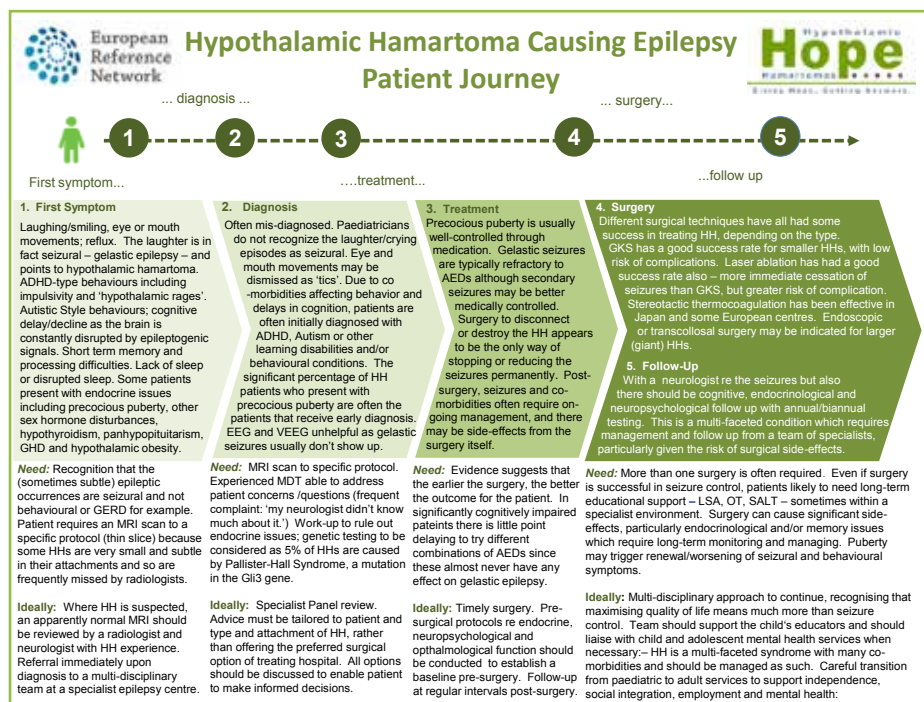
As our discussions grew through our monthly Webex meetings, we became less single-minded about our individual patient communities and began to listen more to each other, learning about each other's syndromes. We understood at last that before we could act effectively, we needed to listen and reflect together.

One particular project, suggested by Eurordis who had seen it work well with ePAGs in other European Reference Networks, was the creation of 'Patient Journeys'. Designed to set out visually and succinctly the key features of individual rare syndromes for the benefit of the busy clinician, the patient journey project gave us something greater than the sum of its parts. When we embarked on this task, we had little idea that it would unify our diverse group and give us clarity of purpose.

## The Patient Journey

The idea, as explained to us, was for each patient advocate to produce a journey – from diagnosis, through treatment, and to follow up – for a typical patient with that particular epilepsy syndrome. The advocate would produce the journey in tabular form which, with help from Eurordis, would be turned into an infographic on a single page or poster. This would enable a first instance medical practitioner such as a paediatrician or neurologist to digest at a glance the salient features of the syndrome, the diagnostic tools and the appropriate clinical pathway.

The creation of a Patient Journey for any rare and complex epilepsy is no easy task. Unlike some of the other conditions in European Reference Networks, the variables within each individual epilepsy are extremely wide, and an early complaint from each of us was, for example, "But there is no 'typical' HH patient," or "there is no 'typical' Ringzo pathway."



However, with focus, thought, and a lot of help from our individual charities, each of us was able to come up with a Patient Journey in tabular form. Matt Bolz-Johnson of Eurordis then worked with us individually to turn our content into a poster using infographics. In the case of HH, I created content which I then circulated to my co-directors and then to our Medical Advisory Board (which just so happens to include three EpiCARE experts). The finished result is published along with this article.

While I am sure that not every possible HH co-morbidity or variable is covered, Hope for HH is happy that the HH Patient Journey poster accurately and comprehensively summarises the key elements of this syndrome and the necessary clinical pathway.

So, the first benefit of a Patient Journey is that it distils something that is rare, little-known even within the medical community and which is challenging in its complexity, into a single poster that can quickly be digested by a busy clinician.

The second benefit of the Patient Journey project was unexpected. During a workshop led by Matt Bolz-Johnson – to whom we owe a debt of gratitude – each advocate presented our Patient Journey to the group. We thereby learned about each other's syndromes and began to see common threads emerging: common co-morbidities, common challenges for the patients, care-givers and families, common unmet needs.

We decided to focus on these unmet needs, describing them and making them the basis for the ePAG presentation at the EpiCARE annual general meeting held in January 2020. We created a poster which we submitted to the European Conference on Rare Diseases 2020 held in May, and which is published alongside this article. The submission was accepted and, although the conference had to take place wholly online, Allison Watson of our ePAG presented the poster, which received very positive feedback.

The project is on-going: some patient journeys are incomplete. However, we aim to publish all ePAG EpiCARE patient journeys ahead of the next EpiCARE conference which is scheduled to take place in Rome in December 2020. Further, each advocate has pledged to build on the patient journey to create two leaflets capturing the salient features of each syndrome – one for the patient, one for the clinician. These will be published and presented at Rome 2020.

This project was time-consuming, but rewarding. To me, it marks a unifying shift in the approach of our ePAG: we now have a strong understanding of our differences and commonalities, a unity of purpose, and a basis from which to focus our efforts to support EpiCARE experts to most effectively understand and meet the complex needs of the patient community.

## The Rare and Complex Epilepsies

Common Unmet Needs within the Patient Community



### Introduction

Rare and complex epilepsies are numerous, diverse and have many, and differing, aetiologies. The heterogeneous and sometimes subtle nature of their clinical presentation and the huge variation in first symptoms often result in a delay in securing a timely diagnosis. For many sufferers there are few or no available treatment options. While seizures are the common hallmark of all rare and complex epilepsies, each syndrome has co-morbidities that are often equally, or more, debilitating.

ERN EpiCARE has been set up to improve the prognosis and quality of lives for the children affected. But with such a large and varied patient cohort, how can the Network best understand and meet their complex and diverse needs?

### Methodology

Patient representatives within the EpiCARE ePAG each detailed the individual needs of their children in a syndrome specific 'Patient Journey'. This documented the natural history of that particular rare syndrome, which they presented to the group in a workshop. As each advocate gained greater insight into the differing aetiologies, complexities, symptoms and prognoses of other rare and complex epilepsies, a number of commonalities emerged – even where aetiologies and seizure types were very different. Advocates then mapped the common needs affecting patients and families across all syndromes and used these to develop a position paper presented for discussion at ERN EpiCARE's Annual General Meeting.

### Results

Seizure control/cessation is the key for each epileptic syndrome. However, it is only one aspect of syndrome management and ERN EpiCARE must widen its focus beyond seizure control and consider the holistic needs of this patient community. Notably, every Patient Advocate emphasized that the specific rare epilepsy that they represented was a complex syndrome that requires a multi-disciplinary approach starting from the point of diagnosis and continuing throughout the patient's lifetime.

After the ePAG presentation of the Patient Journeys and its consequent position paper, ERN EpiCARE agreed to develop and disseminate standards of care based on the identified common unmet needs under a clinical pathway for all patients with a rare and complex epilepsy.

### Summary

Life with a rare and complex epilepsy is a marathon for patients and for those who love and care for them. This should be openly recognized at the point of diagnosis, when the parents need and deserve competent and comprehensive guidance on all aspects of managing syndromes and maintaining the best possible quality of life. Early diagnosis and family-centred communication are the cornerstones of optimizing the family's ability to cope with the complex and usually life-long needs of the patient. Doctors should consider and address the patient's lifelong increased susceptibility to mental illness. More medical understanding of SUDEP – mechanism, risk factors, effective preventative measures – is overdue, as is the provision of detailed and careful information to patients/families about this.

**Common unmet needs highlighted as key priority are:**

#### 1 Early, correct diagnosis

This will require better diagnostic protocols and more frontline training in seizure types, particularly the more subtle types. If seizures are suspected or the patient presents with suspected autism, unexplained 'tics' or developmental delays, epilepsy should be considered as a potential cause. Specialist epilepsy centres should be considered even where MRI scans, CAT scans and EEGs appear normal.

#### 2 Seizure control

Send patients to specialist centres early; develop common prescribing guidelines and surgical pathways; share expertise and experience.

#### 3 Informed families

The tension between seizure control and quality of life should be acknowledged, with side effects from treatment outlined and explained. Being well-informed and supported is central to the family's ability to cope with the patient's complex, life-long needs. There should be discussion surrounding SUDEP.

#### 4 Multidisciplinary Care

Timely access to therapies, equipment and education is crucial to the child's current and future quality of life and independence. Diverse and often catastrophic co-morbidities require cross-specialty cooperation. Input from clinical psychologists at a very early stage should be standard: with a multi-disciplinary medical team, along with parents, driving the child's education plan.

#### 5 Regular Review

Even where seizures are controlled through surgery or medication, the MDT should keep the patient under review. Ongoing psychiatric and psychological assessment and support is vital, with the current transition from paediatric to adult services universally described – across syndromes and across countries – as 'like falling off a cliff'.

#### 6 Rehabilitation

For the young adult, a common unmet need is an adequate rehabilitation programme to support independent/semi-independent living and life opportunities – tertiary education, socialisation within the local community, assisted work opportunities.



Authors: Allison Watson, Emma Nott, Isabella Brambilla, Anita Noordhoff, Torie Robinson, Barbara Nicol, Rosaria Vavassori, Carol-Anne Partridge, Ring20 Research and Support UK; Hope for Hypothalamic Hamartomas-UK; Dravet Italia Onlus; KCNT1 NL; Epilepsy Sparks; Purple Day Spain; IAHCRC Consortium, AHC18+; CDKLS-UK; ePAG EpiCARE.

### About EpiCARE ePAG epi-care.eu

European Reference Networks (ERN) are virtual networks involving specialist health-care providers across Europe. They are part of a broader EU strategy to make the national and European health systems more efficient, accessible and resilient. EpiCARE, the ERN focussed on rare and complex epilepsies, brings together specialized health centres across Europe and offers a coordinated approach for epilepsy diagnostics and treatment by utilizing e-tools and cross-country e-consultancy, thus providing patients with the best expertise available.

Within EpiCARE, the patient and family voices are represented by a group of volunteers with a background in different rare epilepsies from across several European countries. This group forms the European Patient Advocacy Group, or EPAG for short.

### About EURORDIS eurordis.org

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases in Europe and beyond. Its mission is to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level. With a vision to unite, expand and reinforce the rare disease movement of patient organisations and patient advocates around the world, it represents 924 rare disease patient organisations in 72 countries.



## Celebrating International Epilepsy Day in India

*Dr Prof Man Mohan Mehndiratta, Director, Professor and Head of Neurology JSSHS (New Delhi, India), President Indian Epilepsy Association and IBE Vice President South East Asia reports*

To celebrate International Epilepsy Day 2020, Janakpuri Super Speciality Hospital Society (JSSHA) in Delhi, India organised a special event to demystify the current epilepsy care and treatment and to raise awareness about in India.

With sessions in both Hindi and English, the event was attended by about 250 people with epilepsy and their carer providers and 200 healthcare workers from Delhi and Mumbai. A number of people in Japan also attended through video link. Education materials with simple comprehensive easy-to-understand information about epilepsy were given to the people with epilepsy to take home. The eve was organized by Dr (Prof) Man Mohan Mehndiratta, Director, Professor and Head of Neurology JSSHS, Current President Indian Epilepsy Association and IBE Vice President South East Asia.

One of the key themes of the session was Synergy and the sessions in this part of the meeting were used to brainstorm better health care decisions and to find creative solutions. Wisdom and concepts across borders were combined to achieve only one objective – better quality of life. Intra-regional Synergy was fostered by inviting national neurological experts from both 16 INTERNATIONAL EPILEPSY NEWS

India and Japan using web-conference facilities. The aim was to involve people from both across India and from a developed country like Japan.

Promoting intra-regional synergy, Dr (Prof) Man Mohan Mehndiratta spoke about the mission and vision of the institute. The vision aligns with helping improve quality of life of people with epilepsy, inclusivity, empathy towards people with, and synergy of working with teams across the globe. This was followed by an overview of services for people with epilepsy provided at JSSHS in New Delhi. He discussed some challenges being faced by people with epilepsy and laws pertaining to people with epilepsy.

Past President Indian Epilepsy Association, Dr Vrushali Nadkarni, from Indore, Madhya Pradesh followed-up with an expert lecture. She revealed an affordable model of treatment for epilepsy in a private set-up, the awareness programmes being conducted in Indore since the 1970's and the way forward.

Neurologists, Dr (Prof) Lakshmi Narasimhan Ranganathan, Director and Professor, Institute of Neurology, Madras Medical College, Chennai, Tamil Nadu and Dr K Mugundhan, Professor of Neurology at Stanley Medical

College, Chennai, attended the sessions as invited dignitaries. They shared their valuable insights and inputs.

The role of surgery in epilepsy was discussed by Dr Subodh Gupta (in-charge Neurosurgeon Deen Dayal Hospital, New Delhi), while the role of psychological support was discussed by Dr Dweep Chand Singh, Professor of Psychology, Amity University, Noida, Uttar Pradesh. Dr Nirmal Surya, Founder Trustee & Chairman of Epilepsy Foundation, India and Senior Consultant Neurologist at Bombay Hospital, Mumbai shared a rural model of epilepsy in Maharashtra and how this model can be considered on a larger scale across India and for other developing countries as well.

Yoga is an age-old traditional Indian psycho-philosophical-cultural method used to alleviate stress and induce relaxation. It is known to provide multiple health benefits to those who practice it. For people with epilepsy, it can help in seizure control and many factors dealing with overall quality of life issues. However, yoga can't be used as the sole method of intervention. It can be an add-on to Anti-Epileptic Drugs. A young yoga expert Ms Diwasyini Sharma from Mumbai, who has epilepsy, showed the positive effects of yoga in epilepsy. She




demonstrated a few “Asanas” with the audience.

Indo-Japan International Web Conferencing (second in the series) was coordinated by the President of Japan Epilepsy Society and Chair of the ILAE Commission on Asian Oceanian Affairs, Dr (Prof) Akio Ikeda from Kyoto University Graduate School of Medicine, and was attended by people with epilepsy from Kyoto Japan. They shared their views and ideas through live online video interaction. They also shared their queries related to special schools for children with epilepsy such as accommodation for children with epilepsy in school, treatment, social support systems, laws related to driving and marriage, and rehabilitation, medical expense support systems for epilepsy as well as plans to participate in the 13th Asian Oceanian Epilepsy Congress in Fukuoka. It was established that people with epilepsy in Japan are better placed in terms of social and legal reforms. It was also noticed that these reforms are gradually being rolled out in India as well.


Dr (Prof) Martin J Brodie (IBE President), Dr Zarine Mogal (President, Epilepsy Association of Pakistan), Dr Muzharul Mannan (Consultant Neurologist, Dhaka, Bangladesh, General Secretary, Bangladesh Epilepsy Association, Secretary IBE South East Asia Regional Executive Committee) were also invited. They could not participate but they sent their good wishes for the success of the event.

This was an interactive event where attendees raised questions and queries which were immediately answered. To motivate participants, a post-session quiz was organised. This was followed with a token of appreciation to the winners and high tea for all the attendees. Medical Superintendent JSSHS, Dr Ashok Kumar concluded the event with a vote of thanks. The entire event was smoothly coordinated by Conveyer PAES, Dr Amrita Tiwary Vyas, Specialist Nuclear Medicine JSSHS.


The event created a platform which helped in the sharing of epilepsy experiences and helped people with epilepsy and their caregivers to boost self-esteem, improve socialization, psychological health and quality of life, and hence achieve better epilepsy control and care. Parents of children with epilepsy reported improved knowledge about epilepsy, reduced stress related to the disease and reported that they were better able to manage their child's epilepsy as a result of participation. The event helped in motivating people to seek accurate knowledge about epilepsy and will definitely benefit in reducing stigma. People with and their caregivers provided positive feedback and appreciated the program. There is a great demand for additional awareness programs.



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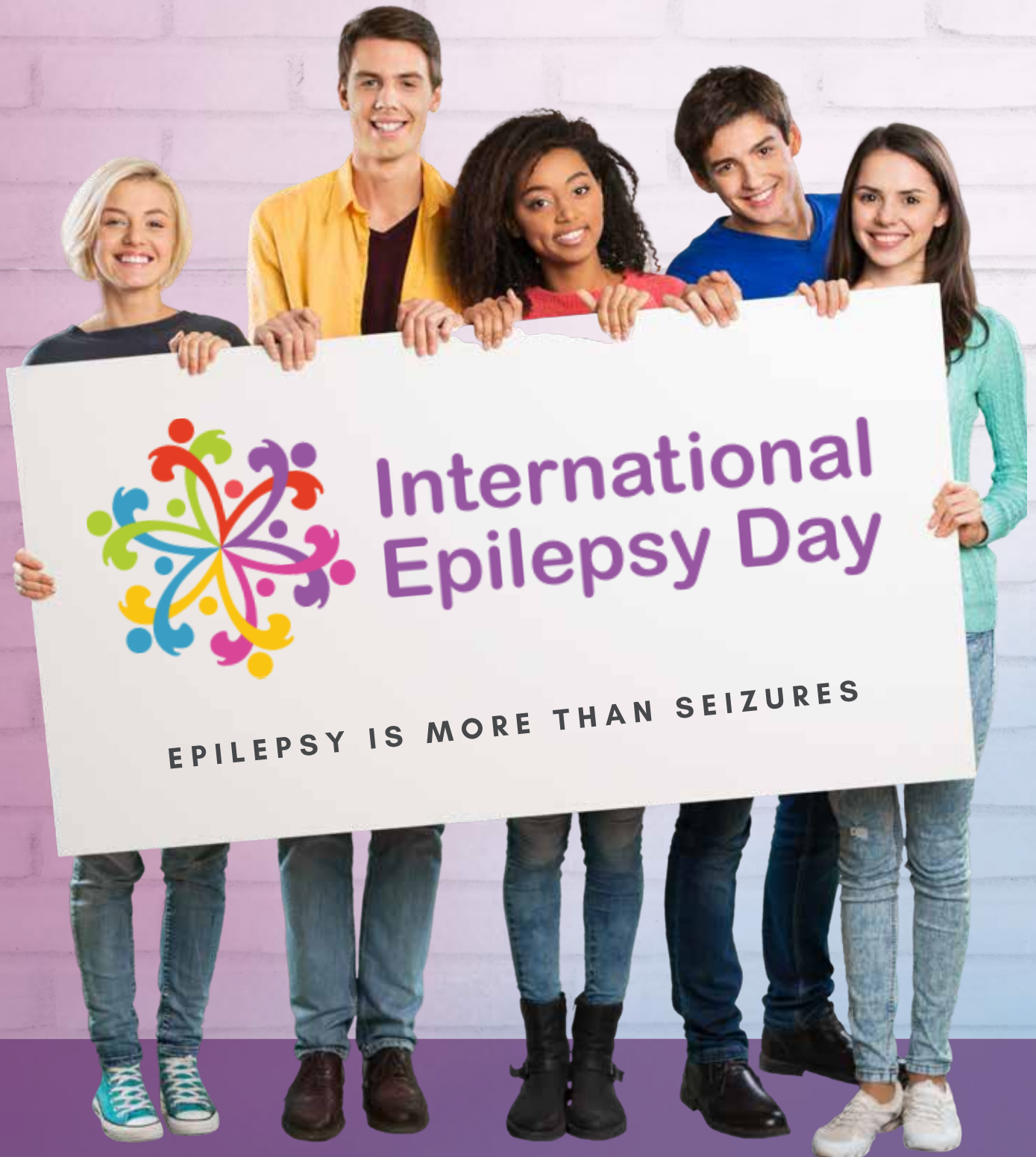


#### Images from top:

- Conference poster
- Dr K Mugundhan, Stanley Medical College, Chennai, Dr (Prof) Lakshmi Narasimhan Ranganathan Madras Medical College, Chennai, and Dr Vrushali Nadkarni, Past President Indian Epilepsy Association from Indore
- Yoga session by yoga expert Ms Diwyasiny Sharma from Mumbai

# SAVE THE DATE!

MONDAY, 8 FEBRUARY 2021



[www.internationalepilepsyday.org](http://www.internationalepilepsyday.org)