

A person in a red jacket is walking away from the camera on a dirt path in a forest. The path is dappled with sunlight and shadows from the surrounding trees. The forest is dense with tall, thin trees and lush green foliage. The overall atmosphere is peaceful and natural.

INTERNATIONAL EPILEPSY NEWS

ISSUE 2 - 2021

IBE Elections 2021-2025

Photosensitive Epilepsy

Origin of the epilepsy flame



INTERNATIONAL EPILEPSY NEWS

ISSUE 2 - 2021

FROM THE EDITOR

In this issue we include a very interesting report on photosensitive epilepsy, written by Dorothée Kasteleijn-Nolst, who has worked in the field of photosensitive epilepsy for more than 30 years. It's a fascinating report and brings us up to date with the latest developments in screens, computer games and even architectural trends.

Almost 70 years ago, the flame symbol now used by a huge number of epilepsy associations, including IBE, was first introduced. The work of a well-known British cartoonist and illustrator, Haro Hodson, the story behind the design was first published in IE News about 20 years ago. To mark IBE's 60th anniversary, we are publishing the story again in this issue.

Next month, the 13th Asian & Oceanian Epilepsy Congress will take place as a virtual meeting. The programme includes a special IBE symposium and the presentation of the Asian & Oceanian Golden Light Awards. You can read more about arrangements for the congress, starting on page six.

Water and epilepsy have never been good companions. So you may be surprised to read the Sailing for Epilepsy article in the magazine. Find out how Phil Haydon, a person with epilepsy, is sailing to raise awareness.

You can also find an update on the IBE elections, read about a new initiative to improve diagnosis in a rare epilepsy, and learn more about current activities in this issue of the magazine.

Happy reading!

Ann Little
Editor



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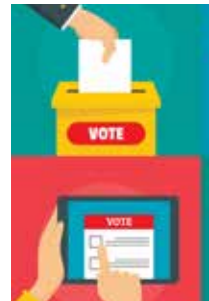
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raise awareness

EDITOR: Ann Little

REGIONAL SUB-EDITORS:

Action Amos, Hassan Hosny, Tomás Mesa,
Natela Okujava, Deirdre Floyd,
Man Mohan Mehndiratta, Ding Ding

ADVISORS: Martin Brodie, Mary Secco



Published by International Bureau for
Epilepsy, 208 Nesta Business Centre,
4-5 Burton Hall Road, Sandyford, Dublin
D18 A094, Ireland. ibe-epilepsy.org.

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aspects of epilepsy are not intended
to be taken as advice; they are not
intended to replace medical care.

PRESIDENT'S MESSAGE

DEAR FRIENDS

One would expect time to drag slowly during the Covid-19 lockdown but, as many of us have found, the months seem to fly by and already we are approaching the mid-way point of 2021.

Our time has been well spent with the successful International Epilepsy Day and 50 Million Steps campaign. The Latin American Epilepsy Congress, held virtually in February, attracted the highest number of participants to date for our IBE symposium.

Our Global Teams programmes have got underway, and I am really pleased to see the extent of progress that has been made. The Youth Team is particularly active and has already had a number of Zoom meetings with enthusiastic participants, while the Research and Professional Development Teams are still finalising their membership lists. These initiatives bode well for the future of IBE and have proven to be excellent vehicles for attracting people who are interested in working closely with us.

There have been ongoing discussions, too, on the structure and format of the proposal for an IBE Academy, as many avenues and options are being considered. This initiative will require slow and measured consideration in order to ensure that the training modules and their content provide the appropriate knowledge to give participants the expertise needed to play a pivotal role in the future provision of epilepsy education and care around the world. This will be one of the largest and most challenging initiatives developed by IBE over the next decade.

At a European level, the Epilepsy and Pregnancy Campaign attracted almost 1,000 responses to the first survey. Its aim was to establish how much women of childbearing age in Europe were aware of the risks associated with having epilepsy and being, or considering being, pregnant. A report on the results of the survey is being compiled and, having seen the first draft, I can assure you that this information will be extremely important in highlighting the knowledge gap in this area.

The coming months will see an equal, if not greater, flurry of activity. First up will be the 13th Asian and Oceanian Epilepsy congress in early June. Originally this meeting was scheduled to take place in Fukuoka, Japan, but now it is happening, like everything else, as a virtual event. During the congress, we will be awarding six amazing young people with an IBE Golden Light Award and I send my personal congratulations to each recipient. The IBE Symposium at the congress will be attractive, not only to people living in the region, but, for everyone with epilepsy and their care providers around the world.

We are planning a number of IBE activities at the 34th International Epilepsy Congress in late August (again a virtual event), during which we are organising a full day of activities with three two-hour



sessions that will be of interest to all IBE stakeholders. The awards ceremony at the congress will highlight the provision of our International Golden Lights award. This is another occasion that will allow us to focus on the selfless achievements of young people with epilepsy, whose actions have made a change for the good of others, or who have achieved great things locally or internationally despite having a diagnosis of epilepsy.

Finally, the election process, which started last September to find the next IBE Management Committee, is now coming to a close with the identification of those people filling the relevant positions on the regional executive committees. My personal congratulations go to Francesca Sofia (president), Gus Baker (secretary general), and Graeme Shears (treasurer) who, with myself, will make up the next management committee. The newly elected International and regional committees will begin their terms at the time of the IBE General Assembly at the international congress, which will take place virtually on 3rd September. We are currently working on plans for the meeting with the aim of making this event as interactive as possible. I will reveal more about this in the coming weeks!

With best wishes

Martin Brodie
President

Golden Lights at the **13th Asian & Oceanian Epilepsy Congress** 10 - 13 June 2021

The IBE Golden Lights awards are an opportunity to recognise and reward young people affected by epilepsy - either because they have epilepsy or have made a significant positive impact on the lives of others who have the condition. The aim is to show that people with epilepsy do not have to be defined by their epilepsy but who embrace the call of the International Bureau for Epilepsy to 'bring epilepsy out of the shadows and into the light'.

These six worthy candidates, nominated by their chapters, will be presented with their awards during the Epilepsy & Society Symposium at Asian & Oceanian Epilepsy Congress in June. By attending the virtual symposium, you will have the opportunity to hear them recount their remarkable stories and see them receive their award.

The IBE Epilepsy & Society Symposium takes place on Sunday 13th June and you can find out more about the programme and how to register at <https://www.epilepsycongress.org/aoec/ibe-day/>.



Chris Ang, Singapore

Chris is a young man with epilepsy who is an extremely dedicated volunteer supporting the cause of Epilepsy Care Group (ECG) Singapore through his active participation in its executive council, activities such as dragonboating, and as an outreach representative for ECG in the IBE Youth Team.

He holds a degree in Marketing and works as a financial adviser with an insurance firm. This provides him with the opportunity to meet people with pre-existing medical conditions and assist them in making better decisions when dealing with their finances. In addition, it allows him to speak with parents to let them know that it is important to ensure that their children are protected before they have any medical conditions.

Salim Baredhwam, Malaysia

Losing both parents as a young boy and subject to déjà-vu experiences which he now knows were seizures, growing up was not easy for Salim. Yet, despite the difficulties he faced, he was an excellent student at school and went on to graduate in Business at the Malaysian Science & Technology University. Salim was eventually diagnosed with epilepsy in 2010 following his first major generalised seizure and status epilepticus. He has been an active executive member of the Malaysian Society of Epilepsy since 2017, contributing to many public awareness programmes organised by the society. He has appeared in national TV and radio to talk about his experience and challenges of living with epilepsy. He hopes, one day, to become an international epilepsy advocate and inspire others. A keen sportsman, winning many medals in Karate.



Meng-Leo Chou, Taiwan

Meng-Leo has struggled through epilepsy diagnosis, drug dose adjustment and the recurrence of seizures after a seizure-free period in his early epilepsy journey. However, despite these difficulties, he has achieved great academic success and has proven himself to be a person with a positive attitude and indomitable spirit toward epilepsy.

Meng-Leo plays a dual identity as a person with epilepsy and a physician training to be a neurologist. Despite a culture of social stigma around epilepsy in Taiwan, he gladly accepted the invitation to lead a six-member group of young adults with epilepsy as speakers at a national conference as part of the Taiwan State Party's implementation of the UN Convention on the Rights of Persons with Disabilities, demonstrating excellent leadership skills.



Dan Kumajai, Japan

Dan was a medical student when he suffered a tonic clonic seizure and his world was thrown into turmoil. Prevented from many student life social activities resulted in depression and he struggled to remain focussed on his studies. Yet, despite these challenges, he received his medical degree and, encouraged by colleagues and teachers, he is now studying to become a plastic surgeon. He joined Japan Epilepsy Association and contributes greatly to its work, first by providing a column in the association's magazine under a pen name and, more recently, in a programme produced by the Japan national broadcasting company in which he spoke freely about his epilepsy, giving hope to hundreds of others. How he lives his life is an example of how to meet the challenges of epilepsy while not allowing them to prevent anyone achieving their goals.



Divyasyini Sharma, India

Divyasyini is a young woman with epilepsy who has taken it as a challenge to spread awareness about the condition. She has been providing yoga therapy as an adjunct therapy to more than 500 epilepsy patients in Mumbai and is involved in a large double blinded randomized control trial to provide evidence as to whether there is a beneficial effect of yoga therapy in controlling seizures in epilepsy. She has presented as a speaker at a number of conferences in India and has also used her yoga classes to raise awareness about epilepsy.

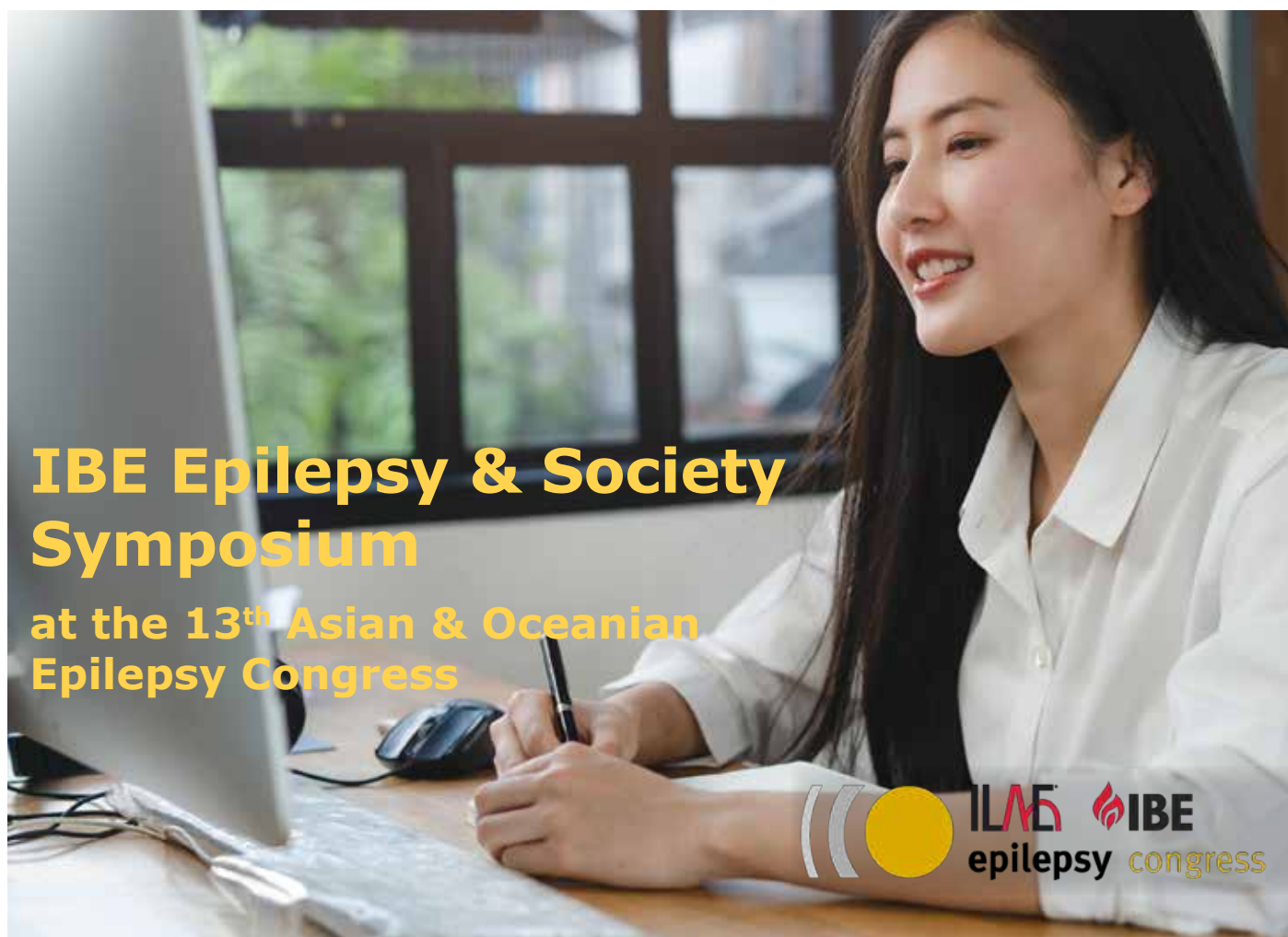
As a 17-year old student, her ambition is to become a lawyer. As a qualified lawyer, she believes that she will be able to fight for the legal rights of people with epilepsy in India in the areas of education, employment and social life.



Bin Wang, China

Bin Wang has been a shining light among people with epilepsy. He graduated with a master's degree in Translation and Interpretation and worked as assistant to the CEO of a major company before having his first seizure - which was attributed to long working hours. With his professional expertise as a translator, he has devoted himself to the China Association Against Epilepsy and the local community. He has helped translate the personal stories of people with epilepsy from around the world, and shared his own story at meetings organised by CAAE to show that people with epilepsy are no different to others, encouraging them to develop their skills for a better quality of life. He has built a community of people interested in learning English. His positive attitude is testament to his aim to bring epilepsy out of the shadows.





Join us for the IBE Epilepsy & Society Symposium
as part of the 13th AOEC congress programme

Date: Sunday 13th June 2021

Time: 09:00 - 17:30 Japan Standard Time

REGISTRATION NOW OPEN!

Topics include:

Epilepsy & Covid-19

Driving with Epilepsy

Golden Light Awards with personal testimonials

Review of the Special Art Exhibition

Delegate Registration Fees:

- High Income Countries: US\$30 up to 14th May, US\$45 from 15th May
- Upper Middle Income Countries: US\$20 to 14th May, US\$30 from 15th May
- Lower and Middle Income Countries: US\$15 to 14th May, US\$20 from 15th May

Links:

- Download the Epilepsy & Society Programme [here](#)
- Register for the symposium [here](#)
- Find out if you qualify for reduced registration [here](#)
- For any questions on registration, please email registration@ilae.org
- For any general queries on the symposium, please email aoec@epilepsycongress.org

*Organised by the IBE Regional Executive Committees Western Pacific and South East Asia.
All presentations and discussion will be in English.*



Artwork from
Art Around Epilepsy
Japan Epilepsy Society

ART EXHIBITION AT THE 13 AOEC

Announcing an Art Exhibition taking place at the 13th Asian & Oceanian Epilepsy Congress

Anyone, of any age, can take part, including people with epilepsy and their carers, doctors, nurses, social workers, etc. Entries will be exhibited on the Art Exhibition Gallery as part of the virtual 13 AOEC with three artworks selected to feature at the IBE Epilepsy & Society Symposium taking place virtually on Sunday, 13 June 2021.

SUBMISSION RULES

- Any of the following art media are acceptable for the exhibition:
 - Painting or drawing
 - Photomontage
 - Pottery
 - Sculpture
 - Beadwork, embroidery or needlework
- A contestant may submit up to a maximum of 3 pieces of art.
- Submission can be made using a scan or photo of the artwork. Scans or photos should be between 1MB - 3MB file size or should be spread over multiple emails. The quality of scans or photos is the responsibility of the entrant.
- Each entry must be the original work of the contestant, have a title (in English) and also include a short description of the artwork and its meaning (maximum 200 words).
- By submitting an entry to the art exhibition, the contestant agrees to grant IBE, free of charge, the right to publish photographs of the artwork online, in other IBE media, or as part of an exhibition.
- All entries should be sent to 13554357579@163.com before the closing date of 21st May 2021. No late entries will be accepted.
- The entries will be judged by independent judging panel which will select the 3 pieces for presentation at the IBE Epilepsy & Society Symposium, on 13th June 2021. The artists of these pieces will be invited to make a short presentation via Zoom at the symposium. If you do not wish to be considered for the oral presentation, please indicate this when submitting your piece of art.

email address for all entries to the exhibition: 13554357579@163.com

CLOSING DATE FOR SUBMISSIONS IS THE 21 MAY 2021

<http://epilepsy.med.kyoto-u.ac.jp/art-and-epilepsy>

Photosensitive Epilepsy



Dorothee Kasteleijn-Nolst has worked in the field of photosensitive epilepsy for more than 30 years. Her newly published book, ***The Importance of Photosensitivity for Epilepsy*** (<https://www.amazon.nl/Importance-Photosensitivity-Epilepsy-Dorothee-Kasteleijn-Nolst/dp/3319050796>) is a detailed and comprehensive study of all aspects of photosensitivity.

As an epileptologist working at the children's department of the Dutch Epilepsy Centre Meer & Bosch (later known as SEIN) in the 1980's, Colin D Binnie, a world renowned British electroencephalographer, taught me to read EEGs and how to optimize epilepsy care with proper use of the EEG. It is fascinating to see the dynamics of the epileptogenic brain-print in relation to its clinical expressions or... in other words: it is possible to see the underwater process in people with epilepsy and this helps to better diagnose, choose the best treatment and evaluate the effect of treatment.

With Peter Jeavons and Graham Harding as protagonists, special interest in photosensitive epilepsy was transferred through Colin Binnie to the Dutch centre. I had several adolescents under my care who were photosensitive and, with EEG registrations with intermittent photic stimulation (IPS) and black and white striped pattern stimulation, I understood that photic stimulation creates a kind of "stimulus and answer game", being different from the general "wait and see policy" in epilepsy diagnostics in general. This has led me to choose photosensitivity as my PhD subject. Between 1981 and 1989 I investigated 100 patients with a photosensitive EEG response and 100 age and sex matched epilepsy patients without such a reaction. Thanks to the advice of Pierre Vinken, former CEO of Elsevier, who had worked at Meer & Bosch as a neurosurgeon, my thesis was published as supplement of *Acta Neurologica Scandinavica* (Photosensitivity in epilepsy: electrophysiological and clinical correlates, *Acta Neurol.Scand.*1989;125:3-149).

After receiving the Gowers Prize Young Physician's award in 1986 on the topic of "Photosensitive patients: symptoms and signs during IPS and their relation to seizures in daily life", I was sure that the subject of photosensitivity was seen as important by the epilepsy community. And so, an international network of physicians interested in the subject arose, leading to standardization of stimulation procedures. This procedure helps in getting maximum information with the least risk of provoking seizures in susceptible patients. It also made international research efforts feasible, such as the Nintendo European videogame-study².

Further spreading of knowledge on photosensitivity (how to recognize, diagnose and treat patients in the EU community) was



Technically better color TVs with remote control became the norm in the 80s, yet, despite this, the public recognized that certain commercials with flicker and striped patterns, were provocative

made possible thanks to the Marie Curie Excellence Grant of the European FP6- research program. Central to this endeavour was University Sapienza in Rome, Italy and my work still continues to be teaching, advising and further unravelling epilepsy in general thanks to photosensitive patients!

How photosensitivity first became more widely known in the lay epilepsy community

With the introduction and spread of TV screens in the home in the 1950s- 60s, persons with epilepsy started to recognize that coming close to the TV screen for on and off switching of the TV provoked seizures. The TV produced not only a 25/30 Hz constant



In 1997, 618 Japanese children were admitted to hospital emergency departments with headaches and seizures after having watched the Pokémon cartoon on TV

flicker (mainly frequency dependent), but also unstable black and white images, thus adding to its epilepsy evoking effect in susceptible people. Similarly, teenagers reported tonic clonic seizures or massive jerks while dancing in the flashing white and colored lights of discotheques.

Technically better color TVs with remote control became the norm in the 80s, yet, despite this, the public recognized that certain commercials with flicker and striped patterns, such as the Golden Wonder advertisement, were provocative and this led to its immediate withdrawal.

However, a much wider public was reached with reports of children who had seizures when playing videogames. Typical is the child sitting close to the screen in the early morning hours playing Nintendo on the TV. Headlines like “Nintendo kills my son” in the 1990’s led to international studies and subsequent warnings on the package insert of video games.

And then, in 1997, over a short period of time, 618 Japanese children were admitted to hospital emergency departments with headaches and seizures after having watched the Pokémon cartoon on TV.

Although some newspapers were considering this outbreak just mass hysteria, scientific studies showed that 15 Hz flashing images of deep red and blue in this cartoon, in particular, had evoked seizures. In Japan, rules were then introduced according to the UK rules to restrict broadcasting of potentially provocative programmes.

Changes since then

The old gas-filled tube-TV disappeared completely from the living room and replacement by screens with liquid crystal and higher image refresh rates reduced the likelihood of getting seizures for persons with (susceptibility of) photosensitive epilepsy. Provocation was no longer coming primarily from the screen itself (or screen in combination with a program or videogame), but more and more from shown content of programs, advertisements or videogames.

In the new millennium a broad variety of TV screens and visual display units (VDU) came to the market and screen time increased gradually: children and adults alike use VDUs at school, for work, to play, to communicate.

New challenges and dangers

Within a few years TV screens and public screens for adver-

tisements have increased drastically in size and contrast (High Definition screens). This means that more of the eye and brain is stimulated at the same time with the consequence that seizures more readily occur. In this case, curved TV screens are even more of a problem.

Because children and adults are exposed to a variety of screens at home, school, work or in museums etcetera, it has become less obvious that a seizure is provoked by a certain screen or program.

To make it even more complicated: since computer-generated cartoons full of pure red colour, flashing lights and striped patterns of high contrast can, nowadays, be watched at any time of the day and in different situations (in the bedroom for example), myoclonic jerks, absence seizures and even longer lasting focal seizures can easily pass unnoticed by parents and peers.

The impact of virtual reality glasses for photosensitive patients is still unknown and might depend on colour, pattern and flashing of the images.

Screen time on average was 5, respectively 8 hrs./day in children and adolescents in 2019 (see Wikipedia). During the COVID-19 pandemic this has increased significantly because people spend more time indoors. Whether longer exposure would be an important issue is not clear - some patients complain of this effect.

Another danger is the dramatic increase of use of striped patterns in clothing, interior decorating and architecture.

In the same way that video game and cartoon producers need to know more about the potential provocation of seizures when using artificial colors, architects and lay people also need to learn more about high contrast stripes.

Finally, quite unknown is the fact that fluorescent lights at home, in shops, buildings, metro stations etcetera can be provocative. When malfunctioning due to ageing, irregular flashes occur at a lower frequency than the original 100 flashes/sec. New developments in lighting are compact fluorescents and high energy LED lamps. These types can also produce flashes, especially when low quality drivers/starters are being used. Therefore, lamps should perform optimally in order not to be a source of provocation, especially to those who are photosensitive to the higher flash frequency ranges.

Because children and adults are exposed to a variety of screens at home, school, work or in museums etcetera, it has become less obvious that a seizure is provoked by a certain screen or program





Another danger is the dramatic increase of use of striped patterns in clothing, interior decorating and architecture



Lamps should perform optimally in order not to be a source of provocation, especially to those who are photosensitive to the higher flash frequency ranges

New developments in lighting with the use of various colours are underway.

<https://commons.wikimedia.org/w/index.php?curid=102772>

It is important to recognize a stimulus, because in many cases avoidance of the stimulus – using a different screen, increasing distance from screen, use of tinted glasses, different programs, different type of lamps - can be helpful in preventing seizures. Covering one eye with a hand is very effective when suddenly confronted with a provocative visual stimulus. But first of all one needs to figure out to which stimuli one is sensitive (not everyone is pattern sensitive or sensitive to fluorescent lights or deep red colors).

Dissemination to the general public of knowledge of these wide variety of potential hazards is more important than ever before.

How photosensitive epilepsy is diagnosed

It is very important is to figure out in what circumstance a seizure occurred: did it happen while playing a video game or watching a particular program, or was it during driving in a car with flickering sunlight through the trees?

Flickering sunlight is a very strong visual stimulus that is often recognized as cause of a seizure (see cover image). A tonic clonic seizure is usually the result and the reason to go for further investigation to the hospital. If specifically asked for, jerks or absences have already been provoked by other visual stimuli.

Although sensitivity can be very specific - only at a close distance to a HD TV screen or under faulty fluorescent lights in the biology classroom, for example - in most photosensitive patients several stimuli are provocative, although one more strongly than the other.

An EEG investigation with intermittent photic stimulation (IPS) at flash frequencies between 2 and 60 flashes/sec can detect a sensitivity for visual stimuli in general. The wider the range of flash frequencies that produce an epileptiform abnormality in the EEG, the more sensitive the person is and thus more likely to respond with seizures to a variety of different visual stimuli.

If a person is sensitive to IPS, pattern stimulation (black and white stripes with high contrast) is necessary as well; about 40% of IPS sensitive patients are also pattern sensitive. With these two measures, a risk analysis can be made and advice given (see above for all different types of visual stimuli). Pattern-sensitivity usually goes unnoticed (absences) while sensitivity to flashes is accompanied by jerks in the eyelids, face, neck and arms or the whole body. Repeated measures after use of anti-seizure medication can show complete or partial suppression of the epileptiform reaction to IPS and thus help in treating the epilepsy in the most appropriate way.

The EEG can also help in confirming sensitivity to specific videogames: the child/adolescent/adult can bring the special game to the laboratory and EEG registration can reveal whether or not this is provoking epileptiform abnormalities.

Photosensitivity being a “stimulus and answer game” gives the possibility for patients to learn about what stimuli in daily life are evoking epileptiform discharges and (minor) seizures: feelings during the IPS and pattern evoked epileptiform discharges during the EEG can be used to screen one’s own environment¹. More in depth investigations also teach us about mechanisms of epilepsy in general.

References:

1. Kasteleijn-Nolst Trenité DGA, Binnie CD, Meinardi H. **Photosensitive patients: symptoms and signs during intermittent photic stimulation and their relation to seizures in daily life.** J.Neurol. Neurosurg.Psychiat. 1987, 50:1546-1549.

Young Physician’s award of the Gowers Price received at the Golden Jubilee Conference and Northern European Epilepsy Meeting, September 1986 York, UK

2. Kasteleijn-Nolst Trenité DGA, Martins da Silva A., Ricci S, Rubboli G. Tassinari CA, Segers JP. **Videogames are exciting.** Epileptic Disord. 2002 ,vol.4, no 2:121-128

EPILEPSY & PREGNANCY CAMPAIGN

- survey update



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

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

Concentrating on those countries from which the highest number of responses were received - Ireland, UK, Germany, Italy, Spain, Russia, Croatia, Czech Republic and Poland - a report is now in preparation and is due to be completed in June.

Of particular significance are open comments provided by a large number of respondents which will play an important role in directing the focus and content of the multi-faceted toolkit, which is the major output of the campaign.

The campaign working group, which includes a number of young women from across the European region, would like to thank all those who took the time to answer the survey and share their personal experiences. The survey was totally anonymous.

Once ready, the report will be made available on the IBE website and circulated to the IBE database. It is planned to launch the toolkit in September.

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

SANOFI 

ANNUAL DUES 2021

CALL FOR PAYMENT

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

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

The dues levels are:

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

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

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

Improved diagnosis hopes for rare epilepsies

Ring20 Research and Support UK CIO [Ring20] announce a new non-profit partnership

Photo © Cerdwen Hughes

The average time to achieve a diagnosis for a rare disease is four years. For those people living with Ring Chromosome 20 Syndrome [r(20)] - a rare epilepsy - the diagnostic odyssey can be even longer (over 20 years has been reported) and it is believed that many individuals remain undiagnosed or misdiagnosed for the cause of their epilepsy.

Diagnosis is important for several reasons: better treatment options may become available to optimise health outcomes; larger cohorts of patients with a specific rare disease attract greater interest for research; and patient families can seek support from patient groups in the form of information and networks to reduce the sense of helplessness and isolation. Being unable to achieve a cause for your symptoms precludes the individual access to all the above and optimal care for improved Quality of Life.

Ring20 Research and Support UK CIO [Ring20] is excited to announce a new partnership with Illumina, Inc. to support awareness raising about the role of whole-genome sequencing (WGS) in diagnosing rare disease (use WGS to improve the shortcomings of current r(20) diagnostic approaches and benefit many more patients and their families). A two-phase project commenced in January 2021. Phase I will focus on education and awareness activities for r(20) patient families to ask questions about their diagnosis and the possibilities of genomics (aligned with the Charity's aims), alongside drawing up an exemplary ethical framework and consent documentation for participation in scientific research. This will enable a 2nd phase where the scientific partnership will work on unravelling the genomes of r(20) patients to identify new cases and develop an effective diagnostic test for the future.

Allison Watson is co-founder of Ring20, a charity that supports people living with Ring Chromosome 20 Syndrome, an ultra-rare disease that affects her young adult son. She is also co-lead for ePAG EpiCARE ERN for rare and complex epilepsies.

She said: "Delivering a presentation on r(20) at the Wellcome Genome Campus to an audience of rare disease researchers, scientists, healthcare professionals, industry and patient advo-

cates, I took the opportunity to ask if anyone might be able to help with our diagnostic challenge and Illumina came forward. Fifteen months later, we are announcing a partnership with a major industry player with whom we can collaborate to try to reduce the r(20) diagnostic odyssey. If we can unravel the genome of r(20) patients we might discover more about the changes in DNA that haven't yet been detectable and that might just hold some clues to identifying more targeted medical therapies."

R(20) occurs in two forms with mosaic being the most common. In current practice, individuals with mosaic r(20) syndrome do not have any detectable deletions or duplications in their DNA and hence can only be diagnosed by the older cytogenetic test of karyotyping where the 'rings' are viewed under the microscope. Because of potential low-level mosaicism, at least 100 cells must be sent for testing - which is 3x the requirement for normal chromosome testing.

Ring20 Research and Support UK CIO [Ring20], an Associate Chapter of IBE, are a volunteer run UK based patient group supporting families, individuals and healthcare professionals who are affected by, or who come into contact with, r(20) - an epileptic encephalopathy originating from a rare chromosome disorder characterised by difficult to treat seizures, cognitive decline and behaviour disorder.

Ring20 provide information and support services for patient families across the world via their website and regular communications, including social media. As a charity we also promote the advancement of research into this under-researched rare epilepsy syndrome and have raised funds for a Natural History and Biomarker study which we hope to commence once researchers reconvene to the desks post-COVID.

Only 200 r(20) patients in the world have been described in medical literature to-date, however with 1/30,000 to 1/60,000 live births presenting with a ring chromosome (with ring chromosome 20 being one of the more prevalent rings) the number of cases is potentially much higher. www.ring20researchsupport.co.uk

Save the **DATE**



An invitation to mark your diaries for two important events in September!

Wednesday 1st September

IBE Day at the 34th International Epilepsy Congress

Three (3) two-hour virtual sessions on:

1. Making Epilepsy a National Health Priority - intersectoral collaboration
2. Empowering Youth to Raise their Voices
3. Best Practices to address the Psychosocial Impact of Epilepsy

Plus presentation of the International Golden Light Awards

Friday 3rd September

IBE General Assembly 2021

The IBE General Assembly will be held virtually this year. This is the opportunity for everyone to participate!

More information will be circulated in the coming weeks as arrangements are finalised.



From the Archives

HOPE AND ENLIGHTENMENT

First published 20 years ago by kind permission of the British Epilepsy Association - now Epilepsy Action

Haro Hodson emerged from Victoria underground station. He pulled his trilby hat down and turned his collar up against the cold late afternoon of a February Thursday in London. It was 1952. He walked down a busy Victoria Street towards Parliament Square. Big Ben sounded the quarter hour in the background. He didn't want to be late for his meeting and he was trying to keep warm. He still hadn't got used to the cold British winters ever since he had returned from active service with the army in India during the Second World War.

As he walked, he played out in his mind how the meeting might go. Which one would they like? Maybe none of them. He tightened his grip on the small briefcase he was carrying, trying to reassure himself. They're bound to like one of them he tried to convince himself. He didn't really know any of the members of the committee he was heading to meet. Except of course for Sheridan. It was Sheridan who had got him into all this in the first place.

Hodson was an artist and a writer. Like many others of his generation, his education and career had been interrupted by the war and only now was he beginning to find his feet. Barely two years earlier he'd joined the staff of the London Observer newspaper as an illustrator. Not long afterwards in 1951 an acquaintance, Sheridan Russell, had approached him with an unusual request. Russell worked as an almoner – a sort of medical social worker - at the National Hospital in Queens Square in London but his interest in contemporary art brought him into contact with the Haro Hodson's of this world. Russell was also involved with a new charity.

Russell had told him, "we need someone like you Haro who can write and draw a bit, someone with a bit of creative flair. We're setting up a publications committee; you'd be perfect for it. There's no money in it of course but it's a good cause."

How could a twenty eight year old idealistic artist just beginning to break through resist such flattery? Hodson accepted the challenge.

He reached his destination, 7 Victoria Street. The meeting started at 5.30pm. He had ten minutes to spare. He made his way down to the basement where the charity had its office. Just off to the side was a larger room used for meetings. Nervous and uncomfortable Hodson edged his way into the room already full with people. Irene Gairdner, the charity's honorary secretary recognised him and smiling she took his hat and coat and handed him a cup of tea. As he turned, Sheridan Russell saw him from across the room and broke off from another conversation. His face lit up in welcome, "Ah, the man of the moment. Hodson old man, how are you? Got the drawings I hope? Looking forward to this immensely. All very exciting. Let me introduce you to everyone."

The others in the room paused and looked towards him. Russell

started with Lady Cynthia Colville, the Chairman of the committee, followed by the six others. He finished by saying, "Irene Gairdner you know already of course."

"Yes, it's very nice to meet you all", said Hodson unconvincingly.

The business of the meeting proceeded slowly. Hodson sat quietly at the far end of the table doing his best to make himself invisible and waiting for his moment to come.

"And now we come to the medallion. Mr Hodson, you have something to show us I believe?" Lady Colville's words woke him up and Hodson scrambled for his briefcase. With fumbling fingers he extracted three cards and placed them face down on the table. He looked up to see everyone staring back at him expectantly.

With a deep breath he began his presentation by repeating back to the committee the brief they had given him. "We need an emblem we can use in all aspects of our work. We especially need a pin badge and something we can put on the front of our publications. We need something distinctive. Something immediately recognisable as our own. Something that tells people who we are and what we're all about. In short, we need something that symbolises the whole cause." Hodson was off and running, feeling more comfortable now he was on familiar territory.

He turned over each card in turn explaining what he had done and how the design attempted to fulfil its function. Each card had a different drawing on it; his attempts to capture the essence of the new charity and of epilepsy in a simple and precise form. He turned over the last card but this time he didn't speak. Nobody spoke. They all just looked at the card. Sheridan Russell broke the silence. "A brightly burning candle", he said, "of course. It's perfect. A symbol of hope, of enlightenment." He looked up and smiled at Hodson, "that's the one."

There was unanimous agreement. This was what they were looking for. This was the symbol for their new charity – the British Epilepsy Association. Lady Colville said, "after all that excitement I think we'll have a short break for some tea. Thank you very much Mr Hodson." Hodson finally relaxed and smiled.

British Epilepsy Association was not the world's first lay organisation for epilepsy ever created. However, its emergence in 1950 came at a time of heightened interest in what lay organisations could do. Its early achievements and strength of purpose soon aroused the interest of likeminded people in other countries and it rapidly became a source of inspiration for others. Its growing range of literature and copies of its newsletters were sent all over the world. Everything carried the brightly burning candle and the symbol quickly became

synonymous with the Association and by extension increasingly linked with epilepsy. In the 1950's as other national epilepsy associations began to form they looked for a suitable emblem of their own and they rarely looked further than the brightly burning candle. Its symbolic significance of hope and enlightenment resonated everywhere.

In 1961 at the 9th meeting of the International League Against Epilepsy held in Rome and at the League's request, British Epilepsy Association organised a meeting of representatives from 15 countries titled, 'The Role of the Lay Organisation in the Treatment of Epilepsy'. At the conclusion of the meeting Dr Abraham Mosovitch from Argentina proposed what is now called the 'Mosovitch motion' calling on those present to form an International Bureau for Epilepsy. The final part of the motion proposed:

"To use the emblem of the candle for this activity because this was already being used by associations in Britain, Australia, Canada, Sweden and New Zealand."

With the birth of IBE and its adoption of the candle image it was assured that national epilepsy associations to be developed in the years to come would also use the candle as their symbol.

Back in London on that cold February evening in 1952 the meeting was over. Haro Hodson stood in the darkened doorway of the offices of British Epilepsy Association. He was happy that his ideas had been so warmly received but he had no idea then what he had just set in motion or how far his candle concept would travel. Although he continued to help and support British Epilepsy Association for many years to come, nothing else he ever did for it was to have such a momentous and far reaching impact as his candle design. Once again, he turned his collar up and pulled his hat down against the cold. With the newly adopted candle design back in his briefcase, Haro Hodson stepped out of the shadows of the doorway and walked back up Victoria Street.

Fifty seven years later it is September 2009. An 86 year old man lives quietly in Oxfordshire in England. He opens the morning post starting with an unfamiliar looking large envelope. Inside is a letter from the British Epilepsy Association. The man reads the letter and then empties the remaining contents of the envelope face down on to the table in front of him. He turns the papers over in turn to see numerous pictures of different candle based logos from around the world. A smile of recognition slowly spreads across his face.



Haro Hodson is pictured with Jane Brown, who worked for many years as a photographer at the Observer newspaper. The photo was taken in June 2009.

All of the people in this story are real and all of the events portrayed actually happened. Only the words attributed to the characters have been interpreted.

Note from the editor: In researching Haro Hodson, in advance of republishing this story, I discovered that he had died earlier this year, at the age of 97 years. It seems almost fitting that he died on Monday 8th February - International Epilepsy Day 2021.



IBE ELECTIONS FOR THE TERM 2021-2025

The election schedule, which began last September, is now drawing to a close. The election of the three officer positions - President, Secretary General and Treasurer - was completed in March and we have reached the final phase in the elections of positions on the seven Regional Executive Committees. In addition, the election of a Vice President North America (to fill a vacancy following the resignation of Susan Pietsch-Escueta) has also been completed.

Balloting on the position of Vice President Europe is now underway, with voting confined to chapters in the European region. There are two candidates standing for this position - Michael Alexa (Austria) and Thomas Porschen (Germany). Voting ends on 9th June and the start of the term of all those elected will begin at the time of the General Assembly on 1st September. We will introduce the members of all seven Regional Executive Committees in the next issue.



**MICHAEL ALEXA
AUSTRIA**

As a person with epilepsy, I want to share my personal perspectives and experiences with the EREC board.

As a team player, open-minded and communicative person, I'm strongly convinced that different points of view

and working methods will expand my own work within the EREC. I see it as a personal challenge and enrichment to be part of this prestigious board. I always have – and always will – try to support others – that's my main goal for working at the Austrian Epilepsy Association.

I will put in the same amount of motivation and dedication in my future work for the EREC board if my election should be successful.



**THOMAS PORSCHEN
GERMANY**

I am 55 years old, married and have a daughter. I have epilepsy and I am seizure-free.

As a new Vice Chair of the IBE European Regional Executive Committee, I would be able to provide over 30 years of experience

in the field of epilepsy patients. My main focus is on epilepsy self-help, counseling, internet as a medium and surveys. The exchange between multipliers and patients as well as their relatives is another important focus.

As a person who works in health education, I know that it is important to work with all agencies (GOs and NGOs) to win them for our cause. This is where I see my role with the EREC.



Francesca Sofia, President

Meet the International Executive Committee 2021-2025

Term starting on 1st September



Gus Baker, Secretary General



Graeme Shears, Treasurer



Martin Brodie, Past President



Action Amos
VP Africa



Hassan Hosny
VP East Mediterranean



Natela Okujava
VP Europe



Tomás Mesa
VP Latin America



Deirdre Floyd
VP North America



Man Mohan Mehndiratta
VP South East Asia



Ding Ding
Western Pacific



Helen Cross
ILAE President



Ed Bertram
ILAE Secretary General



Alla Guekht
ILAE Treasurer

The term of the Regional Vice Presidents (VPs) ends in 2023.
Three members of the ILAE Executive Committee are ex-officio members of the IBE International Executive Committee with a reciprocal arrangement in place.

When Phil Haydon was 15, he was biking home from school when a drunken teenager threw a house brick that struck him on the forehead. This accident caused Phil to develop epilepsy. He has managed to be seizure free for many years and, despite early struggles, has had a successful career as an internationally recognized neuroscientist.

Phil can still feel the sensation of being hit in the head that caused a depressed compound fracture of his skull, which then triggered post-traumatic epilepsy. He initially suffered from absence and tonic-clonic seizures, was in and out of hospital and was eventually fitted with a vitallium plate to take the place of the missing two-inch diameter piece of skull. The medication to control his seizures made it very difficult for Phil to concentrate and study when he went back to school. He gradually managed to apply himself and drew inspiration from his Gran, who lived by the motto “I can and I WILL”. His parents, Jose and Tony, met with teachers and encouraged them not to go easy on him in class. They also pushed Phil to continue to live as normal a life as possible. To this day Phil still wonders how they had the strength to encourage him to return to a semi-normal life, despite going for a year with a piece of missing skull.

“I am sure it must have aged them and I don’t know, as parents, how they had the inner strength to do this,” says Haydon.

Despite struggles in high school and frequently napping in class, (Phil says “due to the medication”), he went on to university to study Physiology. He found that he had an aptitude for research and, influenced by his personal connection to learning about and treating brain disorders, earned his doctorate. He currently runs an active laboratory studying a range of neurological disorders, including epilepsy, as the Chair of the Department of Neurosciences at Tufts University School of Medicine, in Boston. Phil has not let epilepsy prevent him from

living a full life. He is fortunate that his seizures have been medically controlled for over 40 years. After his injury he could have focused on what he couldn’t do, but instead he found ways to participate in activities he enjoyed, with appropriate modifications. He wore an ice hockey helmet while playing cricket and no fastballs were allowed. As an adult he took sailing lessons – and was hooked. Phil then gradually expanded into racing and offshore sailing. He carefully monitors his sleep deprivation and ensures he takes his medication on his regular schedule.

Phil started the non-profit organization Sail For Epilepsy with a mission to inspire people to take One More Step towards living a fuller life, with the necessary safety guardrails in place. He plans to sail the oceans of the world to:

- inspire people with epilepsy
- raise awareness for those with epilepsy
- raise funds to support research into the causes of intractable epilepsy
- educate the population about epilepsy

A proportion of all funds donated to Sail For Epilepsy immediately flow through to their partners, Tufts University School of Medicine and Epilepsy Foundation New England, to support research and community outreach. The balance is used to support the Sail For Epilepsy program.

Sail For Epilepsy will post photos, videos, and blogs as they sail. A boat tracker is available on the Sail For Epilepsy website and they plan to have real-time interactions with people living with epilepsy while underway. During port stops, Phil and his small crew will engage with the local epilepsy community to share his story and hear about ways others are living a full life, despite epilepsy.

When he casts off, Phil will be sailing for more than himself: he is sailing for anyone else with epilepsy, their families, their caregivers, and anyone who has decided

to take an extra step to live a fuller life. He also sails for those who have been lost as a result of epilepsy, to honor their memory and to raise funds for research, so that a future generation of people with epilepsy will have better seizure control.

He hopes that his story will inspire you to join the One More Step Challenge and embark on your own personal voyage. The One More Step Challenge encourages people with epilepsy, their families, and their caregivers to share ways that they are challenging themselves to live fuller lives.

Haydon mused, “Can you imagine if one person got inspired and it changed their life? What if one person learns that epilepsy doesn’t have to be awful and they told their family and friends? I think big things can come from little steps.”

To recognize the courage of the One More Step Challenge participants, Sail For Epilepsy will add their first names to the hull of their boat so that these Virtual Shipmates can join the exciting voyage. Several times a week during the upcoming voyages, they will pick one Virtual Shipmate to feature. By sharing these inspirational stories, Sail For Epilepsy will raise awareness not only about epilepsy but about ways that people with epilepsy aren’t letting this disorder prevent them from living their fullest life possible. Featured Virtual Shipmates will receive a Sail For Epilepsy flag that was flown on the day they were highlighted, with the noon position and their name written on the flag.

Follow the Journey:

Website: <https://www.sailforepilepsy.org>

Facebook: <https://www.facebook.com/sailforepilepsy/>

Instagram: https://www.instagram.com/sail_for_epilepsy/

Twitter: <https://twitter.com/sailforepilepsy>

YouTube: <https://www.youtube.com/channel/UCfoXohTLPk3MoeEMnmw7Vjw>

Sail For Epilepsy is sponsored in part by Neurelis, Inc. and UCB.



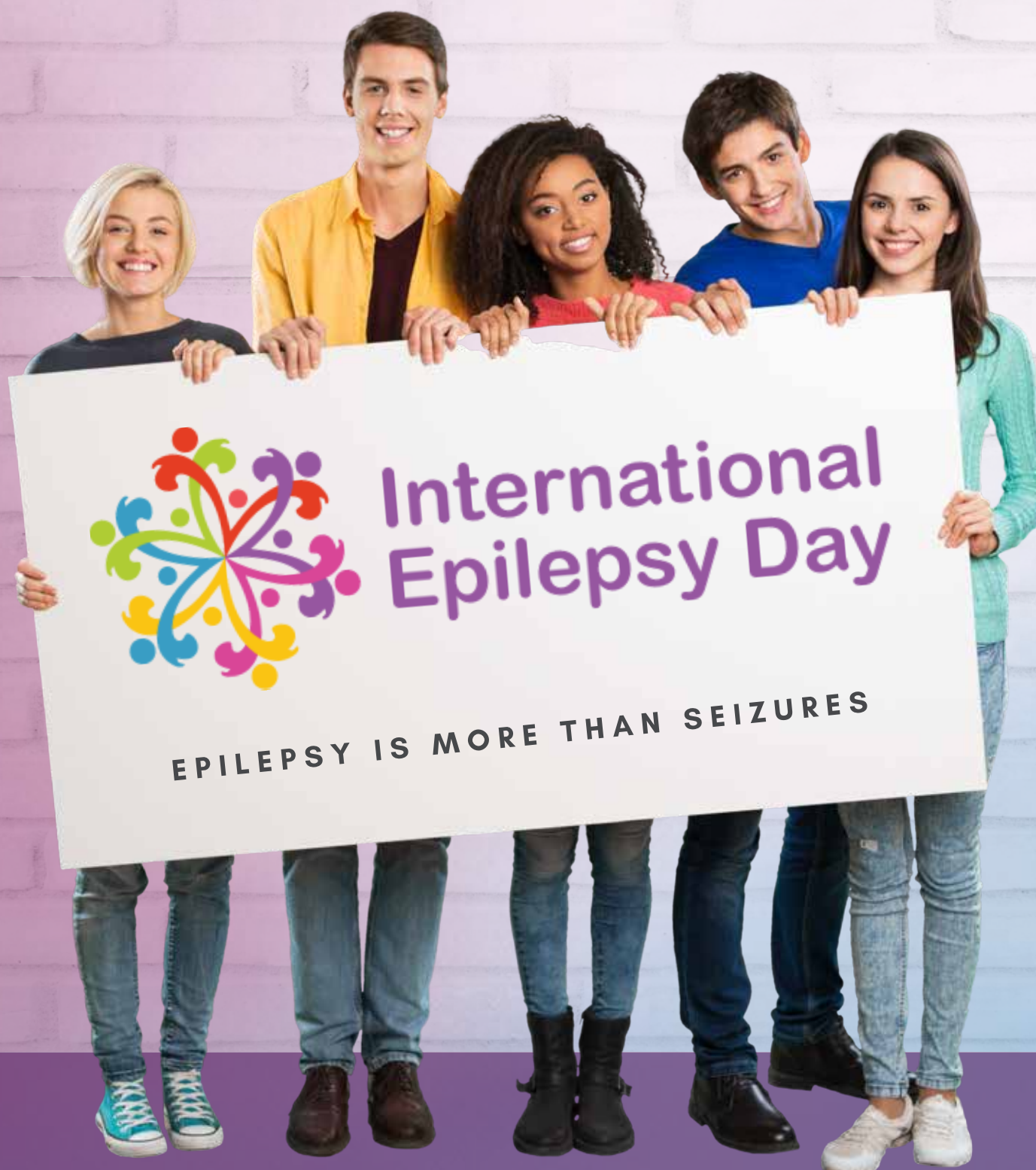
Sailing for a fuller life

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USA
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Sail 4 Epilepsy

SAVE THE DATE!

MONDAY, 14 FEBRUARY 2022



www.internationalepilepsyday.org