

INTERNATIONAL EPILEPSY NEWS

ISSUE 2 - 2018



GOLDEN LIGHT AWARDS

Promising Strategies 2018

WORLD HEALTH ASSEMBLY

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FROM THE EDITOR

This latest issue of IE News features news from the 12th Asian & Oceanian Epilepsy Congress, which took place in Bali in May. In particular, we focus on the Epilepsy & Society symposium, whose programme was specially designed with a non-scientific audience in mind.

Janet Mifsud writes about the importance of the patient voice in research and the need to involve the patient from the start of any new research, in a paper that was first published in *Epilepsy & Behavior*. Also with the layperson in mind, an important new paper has been published on the new classifications of seizures. We include a taster in this magazine, while the full paper can be found on the IBE website.

We include a report on the epiXchange workshop held in Brussels in May, which brought together investigators from seven EU-funded projects; some good news from Iran and Ecuador; a report from Lebanon; as well as news from the World Health Assembly and the three-year report back on the WHA Resolution on Epilepsy.

On a sad note, we mark the passing of Robert Cole, who served as Vice President Western Pacific Region for the term 2013-2017, who died in March. He will be greatly missed by all those who knew him.

I wish you pleasant reading.

Ann Little
Editor



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PRESIDENT'S MESSAGE



DEAR FRIENDS

Over the past months, we have been developing and fine tuning the EpilepsyNext programme, which will be a major focus of my IBE Presidency. Its various modules are designed to support young people through a range of projects and initiatives. Under this banner, the first activity took place at the 12th Asian & Oceanian Epilepsy Congress in Bali at the end of June, with the Golden Lights awards being presented to three young women from Australia, China and Taiwan, who told compelling personal stories of living with epilepsy. I would like to see this initiative rolled out in all seven IBE regions to demonstrate the determination of those who do not allow a diagnosis of epilepsy to prevent them achieving their dreams.

May was a very busy month for me in my role of IBE President, with three major epilepsy events. The first of these took place in Geneva, highlighting the World Health Assembly (WHA) Resolution on Epilepsy. Governments around the world have a role to play in providing appropriate treatment services and legislative support to people with epilepsy and those who care them. The World Health Assembly Resolution on Epilepsy, which was approved in 2015, aims to do just that. The assembly, in May of this year, was an opportunity to provide a three-year report. Unfortunately, while progress has been made in some countries to implement the resolution. The bottom line however, reads 'could do better'. A first step in 'doing better' will be the WHO Epilepsy Report, which is nearing completion and due for launch in early 2019. A special word of thanks is due to the large number of chapters that took the time to complete the detailed survey that will be so important to the final report.

Immediately following the WHA, two consecutive one-day workshops took place in Brussels under the aegis of the European Union (EU). The first – epiXchange – brought together investigators from seven EU-funded projects, most of which will now be coming to an end. The aim was to see how the outcomes of these projects could be best synergized. The second meeting, hosted by the Commission for Research & Innovation, discussed the need for global research alliances and included speakers from Europe, North America and Asia. The need for a global alliance for epilepsy research is a focus of Epilepsy Alliance Europe, the joint task force of IBE and ILAE. The major meeting in May followed previous workshops organised in Brussels via this initiative.

The third event in May was a journey to Lebanon to speak at the annual conference organised by Avance School and Association for Epilepsy and Special Needs. The success of this association is due largely to the unstinting work of its founder Mrs Arlette Honein. While in Beirut, I had the opportunity to visit one of the schools,

and to meet some of the special students. What she has achieved is remarkable and is an example of what could be done for children with epilepsy around the world.

Finally, I would like to draw your attention to the IBE Promising Strategies Program, which has just launched the next round of funding. The deadline for submitting a letter of intent is drawing close, so I would appeal to you to submit your application soon. We will be providing funding of US\$5,000 each to two proposals – and you never know, your association's project might be one of those chosen! You'll find details on how to apply in this issue of IE News.

Until the next time!

Martin Brodie
President, IBE

COVER PHOTO

Pictured with IBE President Martin Brodie, Katherine Height, Shuorong Huang, and Ern-Chun Hong, who were presented with Golden Light awards at the 12th Asian & Oceanian Epilepsy Congress in Bali.



LIFE GAVE ME THE GIFT OF ELLA

Katherine Height, one of the recipients of the GOLDEN LIGHTS awards in Bali, shares her story as a young Mum of a daughter with epilepsy

My name is Katherine Height. I am 25 years old and I live in a regional town in South Australia called Mount Gambier.

In 2009, my whole world changed when I learnt that I was going to be a Mum. Having children was always a dream but wasn't quite on my radar for that time; but I am strong believer in that everything happens for a reason. I knew there would be challenges ahead, being a younger Mum, but I never could have fathomed what truly lay ahead. I had a trouble-free pregnancy and on January 25th 2010, at 9:45am, my beautiful baby girl was welcomed into the world. Ella Grace Gray weighed 7lbs (3.2kgs), was 49cms long with big blue eyes and a gorgeous dimple on her cheek: She was absolutely perfect.

I remember that when she was born she didn't cry and she just arrived looking a little stunned. But her APGAR were okay and when I cradled her in my arms I thought 'wow this is great - a baby that doesn't cry!' Looking back and knowing what I now know, it breaks my heart that I didn't question it but as a new mum those thoughts don't come into your head, you're too

wrapped up in this little precious bundle.

At three months of age, at a Parents Group, Ella experienced what we believe to be her first seizure. We were in a circle singing a song when Ella went limp, blue around her mouth and stared off. We rushed to our local GP and in a whirlwind an ambulance was called and we were on our way to our local hospital where Ella was admitted to the paediatric ward for three days. They ran a lot of blood tests and concluded that Ella had a febrile convulsion due to a viral infection. Those three days were so scary and at that point a seed of fear was planted in my mind.

Over the next 11 months Ella grew, reached all her milestones, giggling, crawling, walking and talking and we could see her bright funny little personality coming through. We experienced more of those random events of Ella staring off and hospital trips but it all came back to more viral infections. November 2012 was when "IT" happened. Ella experienced her first tonic clonic seizure. Still now, I find it so incredibly hard to reflect and talk about that day, the pain and fear is still imbedded so deep and it feels as

though it only happened yesterday.

We were in the backyard having a family get together. Ella stood still and then fell backwards, her whole-body stiffening and then jerking uncontrollably. I remember so vividly the image of my little girl, her whole body being taken over by the seizure, the sounds of it all. In what felt like an eternity, the ambulance arrived and we were taken to hospital straight away. The emergency doctor said Ella had a viral infection, again, as her lymph nodes were raised. However, the paediatrician also came in and said he was going to do a referral to a neurologist at the Womens and Childrens Hospital in Adelaide.

Three months passed and it happened again, two days before we were due to drive to Adelaide to see the neurologist. This time Ella had six tonic clonic seizures within 24 hours. We were initially on the paediatric ward but then moved to the high dependency unit; Ella was given a loading dose of medication to stop the seizures and allow her body to recover. That day my world changed, the paediatrician who had been speaking to the neurologist in

Adelaide came to us and said that it was clear our daughter has a seizure disorder and Ella began her first anti epileptic medication.

That also began our journey of travelling to Adelaide, a 10-hour round trip, to see a new doctor, in a big city, to get answers. What I didn't fully realise at the time was that this also began my quest for answers. Ella's seizures changed and she was experiencing primarily absent/focal seizures, which I believed to be more than 30 a day. Ella had two EEG's, two MRI scans and a PET scan, all under general anaesthetic. She trialled six different medications with different combinations, all over the space of three years, until we finally got a VEEG scan done after my growing concerns and constant emails about Ella's ever increasing seizures. Once again, we were in Adelaide and, after 36 hours of Ella being connected, we were told they had caught enough footage; they had seen what I had been seeing. For me this was a huge win and I had hope again. In July of 2015 our neurologist suggested we look down the path of genetic testing. He explained that bloods would be sent overseas and it would be a little while until we would hear results. Then, in September 2015, while on a school excursion with Ella, I got a call from Liz, our geneticist, and I got what I had been fighting for and hoping for - an answer. She explained that Ella had a mutation of the SLCA2A1 gene - Glut 1 Deficiency. I was so elated sharing this news with family and friends, it had all been worth it. Putting her through all those tests, the travel, the medications: it was all worth it. But by Day 3 reality struck - this beautiful little girl has a rare genetic disorder for which there is currently no cure and the enormity of how much her life would change hit me. I broke down. Knowing that for the past five years she had been living with this and I didn't know was, and is, so hard to cope with.

Within two weeks we were in Adelaide again for seven days and started on the ketogenic diet, with which I have developed a love-hate relationship, under the guidance of a new doctor, someone else I had to put my trust in to help my daughter. Initially it was such a huge learning curve and I remember at the time thinking 'how am I going to do this?'. It's now been almost three years since Ella began the ketogenic diet. It gave us a period of eight weeks' seizure-free in the very beginning but, sadly, that hasn't continued and Ella

is still currently experiencing in excess of 80+ seizures a day. Nevertheless, the diet lifted what I can only describe as a fog and Ella's concentration and cognitive levels improved dramatically. This had a huge positive impact for her at school - not only her education but also her social and emotional development. As well as the diet, Ella is currently on a combination of three anti epileptic medications. We also regularly see an occupational therapist and physiotherapist for Ella's ataxia, mild developmental delay and motor planning issues.

“I didn't give Ella the gift of life, life gave me the gift of Ella”

Until I began this journey, I was completely naïve about epilepsy; I didn't understand the enormity or complexity of this condition. Ella's diagnosis and condition has given me a passion I never knew I had and a sense that this what I was put here to do. As well as fighting for a diagnosis for Ella in the state in which we live, I am also fighting for change and equality. Australia is made up of eight states and territories, six of those recognise epilepsy as a disability and therefore receive government funding and support. One state that does not is South Australia. I created Ella's Purple Promise - a local fundraising initiative in my town - with a motto to celebrate, educate and advocate for epilepsy awareness. All funds raised go towards The Epilepsy Centre based in Adelaide. This centre has been the leading provider of epilepsy support services within South Australia for over 40 years. We have been on the receiving end of the incredible services and support they provide.

I am proud to have raised significant funds for the Centre, I have held merchandise drives, movie nights, golf days and Purple Days at local schools. I have also featured many times in different media outlets including national magazines and radio stations as well as articles in our local newspaper, sharing our story and creating awareness. Throughout all of this, the shining light that keeps me going and is my daily inspiration is my beautiful daughter Ella. I couldn't be prouder of the way she

has handled all that has been thrown her way. She rarely complains; she tries her absolute best and lights up a room with her bright personality and gorgeous smile.

I have learnt a lot from epilepsy and it has truly changed me as a person. I used to like to have things planned, to be in control, but that goes out the window with epilepsy. The best way to describe it is as a roller coaster. I have learnt to coast along the good days, the okay days, to enjoy the ups and the highs and to manage the lows and those moments were you're teetering on the edge, waiting to see where it will take you next. No two days are the same and that's okay; we take each day as it comes.

BUT, in saying that I am thankful for epilepsy, I am thankful because it has given Ella a greater sense of courage, strength and resilience that, as a Mum, I can't teach her. With everything that she has been through as such a young age, I know that whatever challenges come her way, whatever goals she sets herself, she will conquer and she will achieve and I will be right by her side cheering her on as her number one supporter.

I'm not a professor; I don't have a degree; I haven't made it to university yet. I am a Mum: a Mum on a mission to continue to celebrate, educate and advocate for epilepsy, to see a change in the world, a change in how this condition is observed and accepted, to be here when new things are discovered, treatments, medications and the ultimate hope - a cure.

None of this would have been possible without the truly incredible support network I have in family and close friends. And the wonderful relationships I have built with our specialists, nurses and therapists. I would like to thank Robyn Wakefield and Graeme Sheers and the Epilepsy Australia board, Professor Martin Brodie and the IBE organisation and the Asian & Oceanian Epilepsy Congress for this truly once in a lifetime opportunity. This is something I will cherish forever.

To finish I'd like to share a quote that, to me, fits our journey, keeps me going and is something of which I am extremely proud.

“I didn't give Ella the gift of life, life gave me the gift of Ella.”

Photo from left: Martin Brodie, IBE President, Katherine Height and Parthasarthy Satishchandra, former Chair IBE South East Asia Regional Committee. Photographer: Eszter Papp



LAY EPILEPSY ORGANISATIONS: the key for research funding?

Janet Mifsud, University of Malta, IBE Past Vice President Europe (2009-2017) and Martin Brodie, IBE President

During the last decade, various position papers have been published outlining the urgent need for increased funding in epilepsy research¹. Other relevant initiatives have included the work undertaken by the ILAE-IBE Epilepsy Alliance Europe task force to promote epilepsy through a European parliamentary declaration in 2011² and a subsequent workshop in Dublin in 2014³.

In 2015, the World Health Organisation (WHO) passed a resolution (WHA 68.20) on epilepsy⁴ which called, among other things, for a measure of ongoing progress in improving access to care and investment in epilepsy, resulting in increased research capacity with the goal of promoting engagement with civil society and other partners.

These incentives have been successful to a certain extent and, in recent years, the European Union (EU) has funded projects

such as Neuroglia, Neurocypres, Epitar-get, EpimiRNA, EPISTOP, KieKids, EpiPGX, ArMoR, E-epilepsy, Epilepsiae, which have mobilised a critical mass of researchers across a number of countries.

Indeed, DESIRE (Development and Epilepsy: Strategies for Innovative Research to improve diagnosis, prevention and treatment in children with difficult to treat Epilepsy) was highlighted as one such EU project by Research Commissioner Moedes at the opening of the 32nd International Epilepsy Congress in Barcelona in September 2017.

DESIRE focusses on epileptogenic developmental disorders (EDD) and is researching how key functional networks affect age-related maturational processes. The objective is to devise innovative strategies and identify specific targets for treatments that prevent, delay or reverse the long-term

deleterious outcome of EDD therapy.

Such multidisciplinary networks (DESIRE alone has over 25 partners) create the critical mass needed to ensure that Europe maintains a leading role in epilepsy research. A huge variety of skills and resources provide the momentum to unlock key mechanisms of brain development, maturation and plasticity, leading to a better understanding of epilepsy onset and progression.

Translational approaches, including clinical and basic sciences, together with well characterized patient cohorts, whole exome studies, and animal and cellular models, are all essential to explore the molecular and biological pathways of the developing brain. These can then be linked to the clinical, neurophysiological, neuropsychological and imaging features of epilepsy. Only an

integrated approach can lead to improvements in diagnostic methods and innovative targeted treatment strategies.

Yet, despite these successes, data published in recent years clearly indicate that epilepsy is still very much underfunded, compared with other neurological disorders⁵. Indeed, a CORDIS, European Commission Community Research and Development Service search⁶ came up with 234 hits using epilepsy as a search word, while other neurological disorders such as Alzheimer's disease had 1262 hits and Parkinson's disease 974 hits.

Such scientific strategies will not succeed unless lay epilepsy organisations are also involved in these projects, to ensure that deliverables are realised and the necessary impact is achieved at a grassroots level. There remains an urgent need to address the unmet therapeutic challenges and complexities of epilepsy, especially drug

resistance, necessitating more effective treatments with improved tolerability and disease modifying properties that have the capacity to prevent or ameliorate epileptogenesis.

More funding is needed to ensure that cohesive frameworks for the transfer of knowledge and concerted links among basic and clinical epilepsy researchers, big and small pharma, and lay organisations can be maintained. It is essential, too, to identify novel funding opportunities to ensure that the critical mass generated in the framework of these international projects remain financially sustainable.

There is a need to reduce attrition in drug research and development, with faster patient access geared at improving outcomes with minimal delay. There are still too many unmet needs in epilepsy. People with epilepsy need to be given a voice to ensure that awareness about the importance of

basic and clinical research is raised among the public and policy makers to develop sustainable programmes that will facilitate better access to medicines and high-quality health care.

It is time to create a global map of ongoing epilepsy research in easy to understand layman's language. Epilepsy must be recognised as one disease and should be lobbied for as such. The key lies in centralising involvement of persons with epilepsy with scientists and clinicians to ensure the shortest possible transition times from bench to clinic.

Patient organisations should be more than just lobbyists. New models of alliances among all stakeholders are needed, with a focus on identifying solutions that can become an integral part of patient-centred improvements in quality of care, geared at ensuring better lives for people with epilepsy and those who care for them.

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ANNUAL DUES 2018

Chapter dues for 2018 are now overdue. Dues payments are important in funding IBE activities and, if your association has not yet paid, it is important to do so as soon as possible.

Dues may be paid in US dollars or euro and we would encourage as many chapters as possible to choose this currency in order to reduce bank charges.

Did you know that you can pay by Paypal? Paypal can be used with any credit card and is the easiest method for both sides. If you wish to use Paypal, please 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**
- **Provisional chapters: no payment**

In addition, more than 30 chapters based in developing countries continue to have their dues payments covered by the Solidarity Fund.

When settling your dues payment, we would earnestly ask that you consider a donation to the Solidarity Fund to help us to continue to support those chapters who have very limited financial means.

Please contact annlittle@ibe-epilepsy.org with any queries on how to make your association's payment.



12TH ASIAN & OCEANIAN EPILEPSY CONGRESS JUNE 28TH-JULY 01ST, 2018



EPILEPSY & SOCIETY SYMPOSIUM



Epilepsy is no longer an obstacle

Ern-Chun Hung from Taiwan, pictured above left enjoying the congress Welcome Reception, was one of three Golden Light awardees who spoke about living with epilepsy during the symposium. She talked about being bullied at school - 'Kindergarten was supposed to be fun, full of laughter and friends, but there was no place for me.'

Music became her redemption and she studied piano, flute, Zither and singing. She still enjoys playing the piano and singing. She also decided to change and began getting more involved at school, because 'I was the only one who could turn things around for myself.

And so she did, excelling in her college studies and performing on stage. 'Epilepsy is no longer an obstacle, it's a jump stone to a journey of self-discovery', she says.

If you're curious to know more about Ern-Chun, you will find her full story in the next issue of IE News.



It feels like a dream

'As I stand here today, it feels like a dream. However, this is absolutely different from my epilepsy nightmares. It is a beautiful dream come true today'.

These were the opening words of Shuorong Huang - or Li Shu as she is known by her friends. Li Shu was another recipient of a Golden Light award, nominated by her chapter in China. Although she underwent epilepsy surgery, her seizures continued and she felt 'beaten down'. But, eventually, she picked herself up, gave herself a good pep talk, and is now running a very successful online business. In 2018, in order to help people with epilepsy to become financially independent and to create social values, she set up a non-profit online platform called "Eclampsia Home". It's an online shop that helps people with epilepsy to sell home-made goods.

But that's only part of her story - in a future issue of IE News we will reveal the rest of Li Shu's tremendous work.



Traditional beliefs still strong in Indonesia

Traditional healers still play a significant role when it comes to seeking medical treatment in Indonesia. It is very common for the healer to be the first person to be called on when someone becomes ill.

Kadek Kanjani, a speaker from Indonesia, spoke about traditional cultural beliefs in her country and how, even in the 21st century, these beliefs can still impact on how a person with epilepsy will receive treatment. She explained that the norm is for a person with seizures to attend a traditional healer for up to four years before going to trained medical doctor.

Delegates were surprised to hear Kadek, a qualified medical doctor who lives with epilepsy, explain that even she went to a traditional healer at first, due to family pressure.

Kadek is now receiving appropriate treatment from a neurologist, is working as a hospital doctor, is married and has a young family.



Pictured above and below, some of the 100 delegates attending the Epilepsy & Society Symposium in Bali. All photos by Eszter Papp.



RESOLUTION WHA68.20 (2015)

Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications



Three years after its adoption in 2015, the resolution was on the agenda for discussion at the World Health Assembly in May 2018. IBE and ILAE sent delegations to the assembly in Geneva to represent people affected by epilepsy and those who care for them. Both organisation also made oral statements to the assembly.



IBE STATEMENT TO THE WORLD HEALTH ASSEMBLY

The International Bureau for Epilepsy envisions a world where understanding and care replace ignorance and fear of epilepsy. Epilepsy affects people of all ages and all ethnicities. Close to 80% of the 50 million people living with epilepsy live in low- and middle-income countries.

It is unacceptable that 75% of people with epilepsy living in low- and middle-income countries do not have access to treatment. Approximately 65% of these individuals could be treated easily with inexpensive daily medication that costs as little as US\$5 per year. Without access, these people will continue to live in poverty and be at risk.

Worldwide the number of cases of unexpected death in epilepsy is estimated at 60,000 per year. In low- and middle-income countries the mortality and morbidity rates are even higher because of status epilepticus and drowning. In every part of the world, people with

epilepsy and their families suffer from human rights violations, stigma, social isolation, seizure related injuries and discrimination. Persons with epilepsy have access barriers in schooling, employment and health care.

WHO demonstration projects have indicated that it is possible to diagnose and treat most people with epilepsy at the primary health-care level without the use of sophisticated equipment. To do this we need to have a commitment from governments that epilepsy is a public health priority. Progress towards achieving the goals of WHA68.20 has been slow.

On behalf of persons living with epilepsy and their care providers we ask

(1) for a new report on the implementation of the resolution WHA 68.20 to be prepared and discussed again at the 74th World Health Assembly in 2021 and

(2) for the development of a Global Action Plan on Epilepsy.

Designer - Kati Crome
 Embroidered Minds Epilepsy Garden
 RHS Chelsea Flower Show 2018
 Master Plan

Scale 1:20 @ A3

Jan 2018

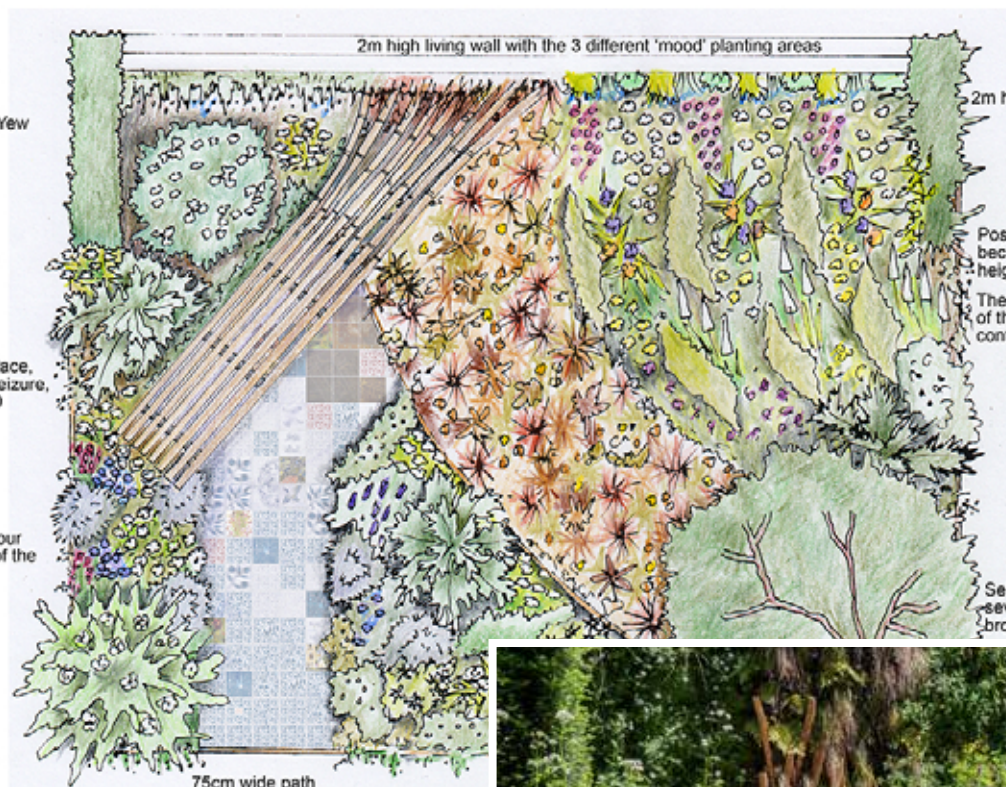
5m x 4m
 Artisan Garden

2m Yew

Hand crafted oak bench,
 provides a calm resting place,
 interrupted by a chaotic seizure,
 an EEG readout made 3D
 Flat length 1.5m

Pre-seizure planting
 Calm, mainly green,
 with touches of subtle colour
 This area, on both sides of the
 path all the same level

Boundary
 in CorTen Steel



Post-seizure planting
 becomes atypical,
 heightened and surreal
 The higher ground level
 of the seizure section
 continues

Seizure planting, chaotic
 severe, uncomfortable,
 brown and copper coloured

75cm wide path
 of specially made tiles with images ref
 through to patterns of neurological dis

Embroidered Minds



A prize-winning garden that described an epileptic seizure

A garden that explored the effects of epilepsy received a Silver Gilt award at the prestigious Chelsea Flower Show in London in May.

Embroidered Minds is a collaboration of award-winning authors, artists, doctors and historians which explores the effects that epilepsy may have had on the family of the famous English designer, William Morris, and the 'conspiracy of silence' around his eldest daughter Jenny, who suffered from epilepsy, an enormous stigma during Victorian times.

The idea for the Embroidered Minds garden goes back to 2016 and writer Leslie Forbes and garden designer Kati Crome. Leslie was working on a book on Jenny Morris.

Leslie also had epilepsy but, unlike Jenny who was hidden away in a sanatorium because of her condition, Leslie was open about her epilepsy.

Tragically, Leslie died from SUDEP in 2016 but the campaign for the garden was kept alive by her husband, Andrew Thomas.

The garden represents different states of a seizure. The pre-seizure area is calm and date with mainly green and white planting, including *Acanthus Mollis*, which were used often in the wallpaper and fabric patterns of William Morris, and *Valeriana officinalis*, which was one of the first epilepsy drugs.

An oak bench, tiled path and foreground garden are interrupted by dramatic, harsh, brown planting, representing a seizure. The planting beyond is more vivid with bright yellows and oranges, blue *aquilegia* and white peonies, associated with the possible heightening of the senses post seizure.

The garden provided a platform for a number of epilepsy associations and involved many art school friends of Leslie, who were committed to celebrating her life.

Some of the plants used in the garden were grown by students attending the Young Epilepsy association's school.

THE GARDEN PLAN

1. The space divided into three planting areas describing the mind before, during and after an epileptic seizure, each area having a different texture an atmosphere
2. To represent the state of seizure, *Prunus serrula* with its textured bark and spiky teasels (*Dipsacus fullonum*) were used. Rust coloured dock (*Rumex flexuosus*) threw jagged shadows on to the walls
3. Valerian and artemisia were included in the design because they are used in the treatment of epilepsy



CLASSIFICATION OF SEIZURES: a guide

In April of this year, the International League Against Epilepsy (ILAE) published three articles on the classification of seizures and the epilepsies. The articles were the first update since 1981 and 1989 and aimed at providing modern descriptions of seizures and epilepsies. The articles related to three levels of terminology – namely seizure types, epilepsy types and syndromes.

A fourth article, which has been published recently, interprets the new concepts documented in the three ILAE papers for an audience of people with epilepsy, those who care for them, and young medical doctors and nurses who may not have specialized in epilepsy.

The goal of the four authors – Martin J. Brodie, Sameer M. Zuberi, Ingrid E. Scheffer and Robert S. Fisher - is to ensure that everyone is speaking and understanding the same language which, the authors believe, is fundamental to optimal management of epilepsy.

The article is now available to read and download from the IBE website: <https://www.ibe-epilepsy.org/the-2017-ilae-classification-of-seizure-types-and-the-epilepsies-what-do-people-with-epilepsy-and-their-caregivers-need-to-know/>

Table: the glossary of terms is one of the tables featured in the fourth article on the classification of seizures

Table 1 Glossary of terms

Absence	A sudden interruption of activities accompanied by a blank stare with occasional deviation of the eyes lasting a few seconds to half a minute with subsequent rapid recovery. Atypical types with other symptoms can also be found
Atonic	Sudden loss of muscle tone lasting a few seconds which can affect the head, body, arms and legs
Automatism	Coordinated motor activity accompanied usually by impaired awareness and often followed by amnesia
Clonic	Symmetrical or asymmetrical jerking of the same group of muscles
Cognitive	Relating to thinking, language, memory and other similar functions
Comorbidities	Conditions associated with or causing the epilepsy
Emotional	A focal nonmotor seizure that can have elements such as fear and joy
Epilepsy	A chronic disorder of the brain characterised by an enduring disposition towards recurrent unprovoked seizures. The diagnosis requires at least 2 seizures occurring greater than 24 hours apart or one seizure with a relevant abnormal electroencephalographic pattern or brain scan suggesting a high probability of a second seizure
Focal	Starting with one cerebral hemisphere either in a specific place in the brain or more widely distributed
Generalized	Originating at some point but rapidly spreading across both sides of the brain
Generalized tonic-clonic seizure	Bilateral convulsion with loss of awareness
Genetics	That part of biological science that is concerned with the study of variation and heredity
Hyperkinetic	Agitated thrashing or leg pedalling movements
Idiopathic	No known or suspected cause other than possible hereditary predisposition
Metabolic	Produced by the processes in body cells that build up or break down natural substances
Motor	Involving movement of muscles in any way
Myoclonic	Sudden, brief contractions of muscles resulting in dropping or spilling things and/or falls
Seizure	Transient symptoms and/or signs due to abnormal excessive or simultaneous neuronal activity of a population of neuronal cells in the brain
Spasm	Sudden flexion and/or extension of trunk muscles which can include grimacing, head nodding and eye movements
Syndrome	Characteristic seizures associated with abnormal investigations that occur together in a recognisable pattern
Tonic	An increase in muscle contraction lasting from a few seconds to some minutes

CONGRATULATIONS!

Head of IBE chapter in Ecuador receives order of merit from the President of Italy



IBE sends its warmest congratulations to Prof Galo Pesantez Cuesta who has received the decoration of “Cavaliere dell’ Ordine al Mérito della Repubblica Italiana”, which was granted by the President and Council of Ministers of the Republic of Italy.

The decoration was presented during an official ceremony which took place at the Italian Embassy in Quito, Ecuador, in recognition of his scientific and social work as head of the National Center for Epilepsy of Ecuador.

Photos: left - the certificate of “Cavaliere dell’ Ordine al Mérito della Repubblica Italiana”; right - Prof Pesantez with his wife Monica and two daughters.

Tuk Tuk to Turkey



SUDEP Action, an IBE Associate Chapter in the UK, has come up with a novel way of raising awareness about SUDEP and, at the same time, raising funds.

The Tuk Tuk to Turkey initiative is the brainchild of the family of Emily Sumaria who died from SUDEP five years ago. Now her sister Amy and parents Rachel and Bharat and friends want to generate something positive from their tragedy.

Tuk Tuk to Turkey will see the family travel from the UK through 21 European countries, to end up in Turkey. The journey will begin in September and it is hoped to complete the arduous trip to Istanbul in this low-tech vehicle within six weeks. With no suspension or shelter from the elements, and with limited horsepower, it won't be the most comfortable of journeys.

So, if you see a Tuk Tuk hurdling past you on a downhill run in the Alps (it's never going to pass you on an incline!) it won't be your imagination gone wild.

Find out more at tuktuktoturkey.com.

ROBERT LESLIE COLE

26 January 1951 - 27 May 2018

It is with great sadness learned of the passing, on 27th May 2018, of Robert L Cole, following a battle with cancer fought quietly and with dignity.

Living in Adelaide, Australia, Robert was CEO of the Epilepsy Association of South Australia and the Northern Territories (IBE Associate Chapter) until his retirement in 2016. He also served as Director, Treasurer and President of Epilepsy Australia Ltd (IBE Full Chapter) over a 10-year period from 2005 to 2014.

He first became involved in the work of IBE through the Western Pacific Regional Committee, which he chaired for the term 2009-2013. He worked on various IBE task forces and working groups, including the Finance working group (2013-2017), and had chaired the IBE Editor's Network and CEO Network in previous years. He was a member of the Scientific Organising Committee for a number of Asian & Oceanian Epilepsy Congresses as well as the 30th International Epilepsy Congress, Montreal 2015.

Robert was elected as IBE Treasurer in 2013 and served on the International Executive Committee for the term 2013 to 2017. His outgoing personality and gregarious nature made him popular to all and he was well known not only in the Western Pacific Region but throughout the IBE community. He will be sadly missed.



Bridging the Gap

Memorandum of Understanding signed between Iran and Afghanistan

Farah Abbasi, from the Iran Epilepsy Association, shares the good news



In a very positive move that will see co-operation and collaboration in the field of epilepsy, the IBE chapter in Iran recently signed a memorandum of understanding at a meeting hosted by Dr Seyed Hamid Mousavi, Chief of the Afghanistan National Charity Organization for Special Diseases (ANCOST). The event took place on 12 July 2018 in the central office of Iran Epilepsy Association (IEA), in Tehran.

At the meeting, the discussions between the IEA executive committee and Dr Mousavi about mutual affairs between IEA and ANCOST highlighted epilepsy activities in Afghanistan. Preparing common proposals for epilepsy epidemiology, organizing common epilepsy conferences, educational meetings for patients with epilepsy in Afghanistan, and other related plans were also discussed at the meeting.

Dr Kurosh Gharagozli from IEA, who is also Secretary of the IBE Eastern Mediterranean Executive Committee - promised to support the link between IBE Eastern Mediterranean Committee and Afghanistan.

Dr Nasabi, CEO of IEA, explained that IEA is a director of the National Rehabilitation Network in Iran and this experience can help NGOs working in Afghanistan.

As IEA celebrates International Epilepsy Day every year, it was decided to celebrate this event in collaboration with ANCOST in the future.

At the end of meeting, IEA brochures, pamphlets, journals and books were presented to Dr Mousavi to serve as resources in public education on epilepsy in Afghanistan.

Photo (left to right): Dr Daryoush Nasabi Tehrani, IEA President; Dr Kurosh Gharagozli, Chair, IEA Executive Committee; Mrs Farah Abbasi, IEA; Dr Dr Seyed Hamid Mousavi, Head of Afghanistan National Charity Organization for Special Diseases

PROMISING STRATEGIES PROGRAM

2018

Improving the quality of life for people with epilepsy in resource poor regions



The International Bureau for Epilepsy (IBE) is committed to finding new and innovative solutions to the problems impacting people with epilepsy and their families world-wide. As part of this commitment, under its Promising Strategies Program, IBE has been providing a limited amount of financial support to IBE chapters on a competitive basis for initiatives aimed at improving the quality of life for people with epilepsy in resource challenged countries or regions.

In the 12 years since it was established, Promising Strategies has provided US\$350,000 in funding to 83 projects in 37 countries. We are now pleased to announce the start of the next selection process, with successful projects being announced in January 2019.



This initial call for Letters of Intent invites IBE chapters to indicate their interest in submitting a proposal for consideration. As a first step, chapters should send a Letter of Intent to arrive at the IBE office no later than 15th September 2018. Successful candidates will then be asked to provide detailed proposals based on a Request for Proposals (RFP).

Please be aware that this is a competitive announcement and that only a very limited number of proposals will be funded based on overall merit as a Promising Strategy.



Members in developed countries may like to be involved in Promising Strategies in a supportive role.

This could be through the voluntary provision of technical support, staff training, or the provision of materials or equipment.

If this is something that is of interest to your association, please let us know.



Award process

Proposals will be scored by the IBE Executive Committee using 'blind scoring'. Two proposals will be selected to receive US\$5,000 each in funding. Applicants will be informed of their selection no later than end of January 2019. Please direct any queries to IBE at the address indicated below.

International Bureau for Epilepsy

7 Priory Office Park, Stillorgan Road, Blackrock
Dublin A94 FN26, Ireland
Email: annlittle@ibe-epilepsy.org

IMPORTANT DATES

Letter of Intent closing date:
15th September 2018

Announcement of approved Letters of Intent and Request for Proposals (RFP):
30th November 2018

Deadline for receipt of RFP:
30th December 2018

Announcement of successful proposals:
21st January 2019

BEWARE THOSE FLASHING LIGHTS!

Incredibles 2 carries warning



Many readers will remember the Pokeman problem with flashing lights, which surfaced more than 20 years ago. In 1997, one episode in the Pokeman TV series, which was one of the most popular TV programmes in Japan at the time, was found to have caused convulsions, nausea and vomiting, and well as other symptoms, in young children watching the show.

More than 600 children were affected, with more than 100 ending up in hospital for treatment. The cause of the problem was bright flashing lights which had the potential to affect people with photosensitive epilepsy. The real issue was not the flashing lights, per se, but the intensity with which the lights flashed. The news became international headlines.

A lot was done in the intervening years to address the issue of flashing lights, as well as the refresh frequency of computer screens - also a hazard for people with pho-

tosensitive epilepsy. TV stations are acutely aware of the problem and issue warnings in advance of news reports or TV show that will have flashing lights.

But fast forward 21 years, and it seems that the problem of flashing lights has raised its head once more. Since the beginning of July, with the launch of the movie Incredibles 2, there have been reports of problems for people with photosensitive epilepsy. Incredibles 2 is the sequel to the hugely popular The Incredibles that launched in 2004 and won an Oscar for the best animated film. The Disney-Pixar sequel contains flashing lights that could trigger seizures.

This time round, however, the industry was quick to react and warnings are now in place alerting cinemagoers to the potential risks for people with photosensitive epilepsy who watch the film. A message at the beginning of the film informs the audience that it contains several sequences that may affect

those susceptible to photosensitive epilepsy.

Photosensitive epilepsy is a type of epilepsy in which all, or almost all, seizures are triggered by flashing or flickering light. Around three people in every 100 with epilepsy have photosensitive epilepsy and it affects girls more than boys. For people with this condition, flashing lights at certain intensities, or some visual patterns, can trigger seizures. And it doesn't have to happen when watching TV or at the cinema. Passing trees or railings where the sun shines through, thus creating a flickering light effect, if done at the correct speed, can trigger a seizure. Even for people who do not have epilepsy, this flickering effect is an uncomfortable sensation and can lead to a headache.

Of course, avoidance is key and forewarned is fore-armed. People who have photosensitive epilepsy, thus alerted, can now avoid the problem.



EPILEPSY CARE GROUP SINGAPORE

INVITES YOUR GREETING

To mark its 25th anniversary of service to people with epilepsy, Epilepsy Care Group Singapore would like to collect a book of messages from supporters and well-wishers as a souvenir of the occasion. If you would

like to join in the celebrations, Sherman Goh, CEO of Epilepsy Care Group Singapore would love to hear from you. You can send your message to Sherman at ecgs93@singnet.com.sg



AVANCE SCHOOL LEBANON

Rising to the challenge

What would you do if your young daughter, having developed complex refractory epilepsy following a fall, was suddenly excluded from schools and ostracised by the parents of her young friends? Most parents would fight back to ensure that their child received the best possible care, as well as social and educational opportunities. Few would turn their homes into a school in order to achieve this. But that is precisely what Arlette Honein did in 1997, establishing a school for children with difficult epilepsy and with other medical issues such as ADHD, in her family home.

This was the beginning of the Avance School and Association for Epilepsy and Special Needs which quickly received recognition by the Ministry of the Interior and the Ministry of Education in the Lebanon.

With pupils ranging from kindergarten stage to almost 30 years of age, Avance provides personal development and education for students with special needs where regular schools cannot provide the required

facilities for academic, professional or social integration. The goal is to allow the younger pupils to re-integrate into regular school programmes and the older students to be able to set out on a professional life.

Now in 2018, Avance is operating two special schools in Beirut - one in Furn El Chebbak and the other in Aley. In addition to children from Lebanon, the school has also welcomed students needing special education facilities who are refugees from Syria, Iraq and Palestine.

In May 2016, a third initiative was launched - the Stephanie Medical Centre for Epilepsy - named for Arlette's daughter, who is now 28 years old. The centre is situated in the suburbs of Beirut, high up on a hill with wide terraces giving views out on to the city below and the Mediterranean beyond. Adding to the Avance School and Association for Epilepsy and Special Needs, the Stephanie Centre provides a clinic for epilepsy diagnosis and treatment, an out-patients department offering services

including psychomotor therapy, speech and occupational therapies, family counselling, and many other services.

A further activity is an annual conference in Beirut. The fifth annual conference took place in May, with a welcome address by Marwan Hamadeh, Minister of Education and Special Education. The international panel of speakers included Martin Brodie, IBE President; Emilio Perucca, ILAE Immediate Past President; Najib Kissani, Peter Wolf, Chanez Triki, Candan Gurse and Ley Sander. Mohammad Mikati, a long-time supporter of the Avance association was also invited to speak. The conference programme was a mix of social and scientific topics including stigma and discrimination, epilepsy legislations, pregnancy and breastfeeding, and precision medicine.

Photos: main photo - delegates and speakers at the conference. Small photo: Martin Brodie (blue shirt), Carol Brodie and Najib Kissani visiting one of the schools with Arlette Honein (white suit).



SOCIAL MEDIA



EMA DIGITAL MEDIA AND HEALTH TOPIC GROUP

Caroline Morton, IBE Vice President, European Regional Executive Committee, outlines a new initiative of the European Medicines Agency (EMA)

In 2017, the European Medicines Agency (EMA), on which IBE has observer status, created a topic group on Digital Media and Health. Its aim is to look at how EMA can use communication channels more widely and ensure easy, consistent and timely access to authoritative, reliable and easy to understand information on medicine. In addition, it hopes to see how EMA can raise awareness on how data and information related to the real use of medicines is being collected and used for research and calls for action.

The intention is to use social media to enhance communication and offer new opportunities for interaction with various stakeholders, and to ensure that information distributed through social media channels meets the needs of its audience. This specifically includes patient organisations and health care professionals.

IBE considers this to be an interesting initiative and one in which we should participate for the benefit of IBE chapters in Europe. The topic group has three streams: social media (led by Caroline Morton-Gallagher), mHealth and real world evidence. The social media stream will look at best practice in the use of social media in organisations and health care professional groups, with a focus on promoting interaction and exchange of information. The group meets primarily via virtual meetings. The aim is to advise the EMA in the development of their social media strategy.

Since the initiation of the Digital Media and Health Topic Group, the different streams have been looking at issues with regards to optimal use of real world evidence, mHealth and social media. The social media stream has focussed on best ways to reach out to specific audiences, with regards to medicine regulation, pharmacovigilance and safety communications.

The results of group discussions were collated and presented at a joint meeting of the Patient Consumer Working Party (PCWP) and Healthcare Professional Working Party (HPWP) at the EMA on 17 April. Representatives from patient organisations, healthcare organisation and EMA staff were present.

Caroline Morton-Gallagher presented the results of the social media stream. First, how to reach out to specific audiences, through identifying the audience in question and tailoring the information to suit that audience; having a different approach for each audience based on their information preferences and, importantly, to reach out directly to target audiences or through current stakeholders to cascade the information.

How to use social media for that purpose stressed that the role of each social media channel must be identified; material already available should be used; and the key message was that social media conversations should be followed up to continue engagement.

This led directly to the question of how to make the best use of social media. It is important to define the desired outreach, i.e. what do you hope to achieve with your social media message? Visual content is key in social media and a picture speaks more than 1,000 words. When posting videos to be sensitive to language barriers and provide subtitles, otherwise the message gets lost in (no) translation. How to amplify outreach identified the potential of inviting influencers from target audiences: to collaborate more and cross-share information with stakeholders.

Optimal use of social media requires a huge investment in time and resources; this is a crucial factor for successful implementation. The use of social media in pharmacovigilance highlighted the potential with regards to faster communication channels and increased engagement, but only if there is active interaction with social media users. There are also drawbacks with regards to data privacy and difficulty in validating reported safety data from interactive fora.

Discussion points raised during the meeting will be followed-up by the topic group and, once actions are agreed upon, these will be presented at the joint working parties meeting at the EMA in September.

In the meantime the EMA is currently working on its social media strategy and a first draft is expected during the summer.

epiXchange 2018



Speakers address the audience at epiXchange 2018

To pave the way for ground-breaking epilepsy research, seven large EU-funded projects joined forces to organise epiXchange 2018 on 23 May 2018, in Brussels, Belgium. The unique global community-building event was designed to gather a critical mass of epilepsy researchers and to showcase the latest progress in research aiming to improve the way epilepsy is diagnosed and treated and thereby increase the quality of life of affected people.

The projects were funded mainly through the 7th Framework Programme (FP7), which provided total funding of 52 million euro.

EPISTOP is investigating the pathophysiology of epilepsy and its consequences, in order to develop a preventative strategy for epilepsy, identify new biomarkers of epilepsy, and develop new therapeutic targets to block or otherwise modify epileptogenesis in humans.

Complimentarily, **EpiTarget** is focussed on identifying biomarkers and multiple basic mechanisms for epileptogenesis in adults, and translating these findings to the clinic by validating the biomarkers in human samples.

EpiPGX aimed to identify genome-based biomarkers for use in clinical practice to personalise treatment of epilepsy, by stratifying patients for clinical trials, preventing relapse and reducing adverse drug reactions.

DESIRE investigates developmental brain processes as well as genetic and epigenetic

factors underlying epileptogenic developmental disorders, with the view to better understand, diagnose and treat early onset epilepsies in children.

EpiRNA focuses on microRNAs changes in epilepsy, and the possibility to develop novel miRNA-based treatments.

EpiXchange (FP7-ITN) also explored innovative gene therapies for treatment in partial epilepsies.

The ERN **EpiCARE** promotes optimal management of rare and complex epilepsies across Europe, but also offer a unique network of clinical centers of excellence to establish successful translational research.

The workshop was organised around research clusters in five key areas:

1. Translational research in biomarkers to develop novel preventive strategies in at-risk patients
2. Genetics of Epilepsies: Therapeutic implications and novel treatment strategies based on optogenetics, gene and stem cell therapies
3. Innovation Therapeutics and Translation with development of anti-epileptogenic therapies
4. Understanding co-morbidities in the epilepsies to better understand their bi-directional pathophysiology
5. Biobanks and databases: basis for translational research to facilitate pre-clinical and collaborative research

A community-building event for epilepsy research

Report by Janet Mifsud and Asla Pitkanen

Participants heard how, despite intensive and ongoing research, epilepsy research still faces several unmet needs, with major gaps in understanding the disease with large economic and societal costs. EpiXchange was a unique milestone with a mix of clinical and basic and translational researchers in one room. Such a holistic approach including basic and clinical researchers in health, genetics, therapeutics, diagnosis, imaging, health care providers, SMEs, patient organisations can bring together the critical mass of research required to lead to improvements in diagnostic methods and innovative targeted treatment strategies.

The meeting provided the opportunity to synergise the results of these diverse projects and identify the several bottle necks which still remain. It helped to create a cohesive framework for the transfer of knowledge among basic and clinical epilepsy researchers, big and small pharma, and patient organisations. It also included the participation of stakeholders such as Dr Karim Berkouk, Dr Stefan Hogan and Ms Anna Graca from the European Commission's Directorate-General Research & Innovation and representatives of the European Brain Council.

The meeting showed how a focus on a bottom up approach is needed to coordinate research and policies with more collaborative research, including public partnerships, public private partnerships, and global co-operation. The upcoming EU Horizon Europe framework for research is calling for bold inspirational approaches with wide societal relevance, including open science, global challenges and open innovation pillars.

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