

INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 54 years

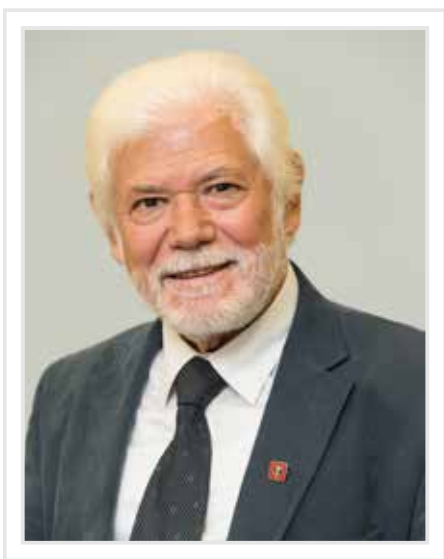
1963-2017



SPECIAL ISSUE:

**International
Epilepsy Day 2017**

PRESIDENT'S LETTER



Dear IBE Chapters, Dear Friends

I am very proud that since we took office back in 2013 one of the major tasks was to create the International Epilepsy Day. A unique IBE/ILAE event that aims to increase awareness and education about epilepsy for the general public, people with epilepsy and those who care for them, many other stakeholders particularly policy makers to a very common but treatable brain disease, EPILEPSY.

The launch of the International Epilepsy Day was back in 2015 in the European Parliament as a continuation of the European Epilepsy Day, the 2nd Monday in February each year connected to St. Valentine's Day.

St Valentine was a priest in Rome who was thought to have had epilepsy and was martyred about AD 269 and buried on the Via Flaminia (the road leading from Rome over the Apennine Mountains) for performing weddings for soldiers who were forbidden to marry and were persecuted under the Roman Empire (Claudius II). While in prison St Valentine healed the daughter of his jailer, Asterius, and before his execution, he wrote her a letter signed "Your Valentine" as a farewell. Contemporary Valentine's Day is connected mainly with romantic love. The modern Valentine's Day customs developed in early modern England include sending cards, and flowers to one's beloved worldwide. IBE and ILAE should imitate this tradition and each year should prepare thousand and subsequently millions of cards signed as IBE/ILAE to be sent around the world, through internet or other modern ways,

A special day for epilepsy

passing useful information about epilepsy. However, the news is very encouraging as every year more chapters and countries around the world have join forces to this celebration.

As you know epilepsy is often an underappreciated health problem and in developing countries, 60% to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery, and due to social stigma. For many years various studies have been performed to study the attitudes towards epilepsy among different selected or not populations, across time and between different study populations. All studies indicate the significant gap in essential knowledge or misconception about epilepsy that exist especially among people living in rural areas, of older age and lower educated level. No doubt some improvement in attitudes has occurred but the main conclusion is that non-scientific influence on disease perception is still predominant in many countries and regions in the world. So our primary task is to increase awareness, education and research for more effective treatment particularly for those who continue to have seizures despite existing therapies.

This year the celebration of the Day was combined with a unique workshop to facilitate research worldwide with researchers and policy makers. It was an excellent experience and very successful event coordinating action plans for the future and promising ways to allocate resources for this. I am confident; whenever IBE and ILAE have joined forces they have succeeded!

With best wishes to all,

Athanasios Covanis
President



International Epilepsy News
Issue 1 - 2017

EDITORIAL TEAM

Editor and Coordinator: Ann Little
Email: ibeexecdir@eircom.net

Regional Sub Editors:

- ⊙ Youssouf Noormamode (Africa)
- ⊙ Chahnez Triki (East Mediterranean)
- ⊙ Anastasia Vassou (Europe)
- ⊙ Tomás Mesa (Latin America)
- ⊙ Mary Secco (North America)
- ⊙ P Satishchandra (South East Asia)
- ⊙ Denise Chapman (Western Pacific)

Advisors:

- ⊙ Athanasios Covanis
- ⊙ Robert Cole
- ⊙ Sari Tervonen
- ⊙ Mike Glynn
- ⊙ Ding Ding
- ⊙ Philip Gattone
- ⊙ Najib Kissani
- ⊙ Man Mohan Mehndiratta
- ⊙ Janet Mifsud
- ⊙ Lilia Núñez-Orozco
- ⊙ Anthony Zimba
- ⊙ Emilio Perucca
- ⊙ Helen Cross
- ⊙ Sam Wiebe

INTERNATIONAL RELATIONS AND PARTNERSHIPS

WHO

IBE is in official relations with the World Health Organisation (WHO).

ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO

IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA

IBE is a member of the European Federation of Neurological Associations (EFNA).

EPF

IBE is a member of the European Patients' Forum (EPF)

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In this issue



Dear Readers

Our special issue of IE News to celebrate the 3rd International Epilepsy Day is full of news on IBE activities to mark the day. In 2016 more than 40 countries around the world celebrated the event and we hope that, this year, that number will increase.

We have been using Campi, the mascot for International Epilepsy Day to promote

various events in the lead up to the actual day and, those of you who use social media will have seen him crop up on Twitter and Facebook with charming little videos. Now, for International Epilepsy Day, we are launching the second of our website videos with Campi and his friends. This time Campi visits Dr Christina Langoustina at her surgery.

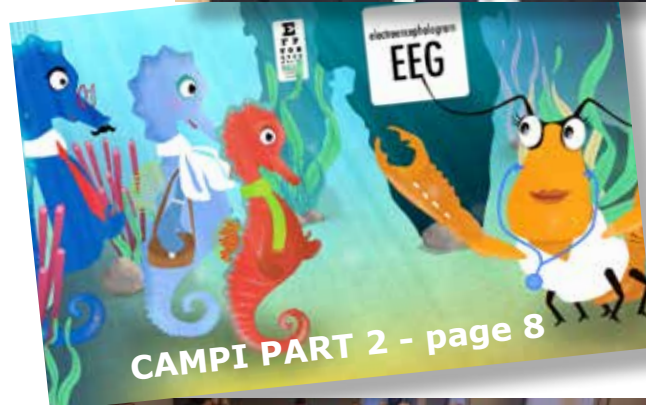
The response to the Art Competition for International Epilepsy Day was amazing - both in terms of the number of entries we received and in the quality of the artwork itself. I am sure you will agree when you see the pictures on page 4.

A major workshop, on the need for a global alliance on epilepsy research, took place in the European Parliament on 7th February, and had distinguished participants from both Europe and North America. You'll find a report included in this issue.

Finally, following the close of the elections to fill the officer positions on the IBE International Executive Committee 2017-2021, we present the President-, Secretary General- and Treasurer-elect. There is also an interview with President-elect Martin Brodie for you to enjoy.

Until next time - good reading,

Ann Little
Editor



Coming in the next issue



Regional Epilepsy Congresses 2017
4th East Mediterranean Epilepsy Congress, Luxor, Egypt
epilepsyluxor2017.org
3rd African Epilepsy Congress, Dakar, Senegal
epilepsydakar2017.org

CREATING ARTISTIC WAVES!

Art competition to celebrate International Epilepsy Day 2017



The art competition to celebrate International Epilepsy Day 2017 was a fantastic success, attracting 140 entries from 25 countries around the world. We received entries from Aruba to Australia, from Malta to Malaysia and from Sweden to Sri Lanka. Of the entries, 23 were submitted by children under 12 years of age and the remaining 117 entries came from adults. Among the artistic pieces submitted were paintings, photos and photo montages, sculptures, beadwork and embroidery as well as videos and music.

There were two categories - one for those aged under 12 years and the other for those over 12 years of age. In each category there was a first prize of US\$500 and two runners up prizes of US\$250.

The judges were delighted with the quality of the artwork submitted to the competition and, while they found it very difficult to make final decisions on the prize-winners, working independently

their final choices in both categories were strikingly similar. The members of the judging panel were Susanne Lund (Sweden), former IBE President; Harmiena Riphagen (Namibia), Secretary of the IBE African Regional Executive Committee, Ding Ding (China), IBE Vice President South East Asia, and Galo Pesantez Cuesta (Ecuador), Vice Chair of the IBE Latin American Regional Committee.

A gallery featuring all the entries is now available to view on epilepsy.org. Postcards have been created from the winning entries and these will be presented to the Members of the European Parliament in Brussels to celebrate International Epilepsy Day.

The prizewinners as well, as some of the other entries, will also be displayed during the 32nd International Epilepsy Congress in Barcelona in September.

OVER 12 YEARS CATEGORY

First Prize (top left)

Artist: Lungelo Dube, Swaziland

Title: A whim of courage

Lungelo said: The painting tells a profound story of beauty, courage and the constant battle of epilepsy. On the surface, beauty is not only an aesthetic to be relished by the beholder and third parties, but also skin deep. Epilepsy is a disease anyone can have; it shouldn't be seen as something bad but, rather, as a trait of the individual that's a part of their beauty.

Runner Up (below left)

Artist: Jinkun Liu, China

Title: Window

Jinkun said: I see myself on a window after a seizure.

Runner Up (below right)

Artist: Vahid Darvish Zadeh, Iran

Title: Hope in darkness

Vahid said: The dark effects in around picture are negative attitudes toward epilepsy. Electricity is shown as a seizure mechanism. The hands tied with a purple bracelet shows the colour of epilepsy and its involvement. The two fish swimming in circles and also the beautiful butterflies show life flow, hope and happiness.



UNDER 12 YEARS CATEGORY

First Prize (right)

Artist: Molly Foote, USA

Age: 11 years

Title: Epilepsy: a self portrait

Molly said: I have epilepsy. I have learned that I am hardly any different to anyone else. But, I have a different perspective because of epilepsy. People with epilepsy are just as beautiful.



Runner Up Prize (below left)

Artist: Yihao Lai, China

Age: 7 years

Title: Simple and Happy

Yihao said: Although I have epilepsy I still feel happy.

Runner Up Prize (below right)

Artist: Warnakulasooriya Sanjana, Sri Lanka

Age: 10 years

Title: No worries!

Warnakulasooriya said: Children with epilepsy have a bright future.



IBE would like to thank all those people, both young and not so young, who submitted their artwork to the art competition. The standard was extremely high and the creative talents of the artists was clear to see.

Unfortunately, we could only award six prizes but we hope that, on the next occasion we organise a similar competition, that you will once again consider taking part. Thank you all!

THE BIG PICTURE



International
Epilepsy Day

Monday 13 Feb
2017

We're putting Epilepsy
in the Picture!

Let's get **#EpilepsyDay** trending
around the World on February 13th



1. Take a selfie
2. Share on social media with the hashtag
3. Help raise awareness!

@IntEpilepsyDay

#EpilepsyDay

TAKE IT

SHARE IT

HELP US

Our Selfie Campaign encourages everyone to help us to put epilepsy in the picture by sharing a photo on social media. The idea is to frame your face (or the faces of you and your family or friends) in the photo, using a picture frame or any other sort of frame you might consider. You could use your hands to make a 'heart' frame or even a window frame. This is the chance to think big and consider unusual 'frame' options. Help the world to get the full picture on epilepsy!

CAMPI VISITS THE DOCTOR



Campi was created in 2016 as a cute little seahorse mascot to tell young children about epilepsy. Why a seahorse? The Seahorse is genus Hippocampus, so named because of its brain-like shape. So, there is a connection to epilepsy.

The first animated video - 'Crisis at School' - was launched for International Day 2016 and introduced Campi the Seahorse, his classmates Tuna and Cala and their teacher Mr W Hale.

The video can still be viewed on epilepsy.org where you can see Cala, Tuna and their teacher, Mr W Hale, taking care of Campi when he has a seizure in the playground.

We received excellent feedback from the video and have now moved forward to de-

velop the second in the series of videos in time for International Epilepsy Day 2017.

For International Epilepsy Day 2017, we have created the second in the series of Campi videos. This time, Campi goes to visit Dr Christina Langoustina at her surgery, with his Mum and Dad. In the video, Dr Langoustina explains to Campi and his parents some of the reasons why people can have a seizure and the tests that are done to confirm a diagnosis of epilepsy.

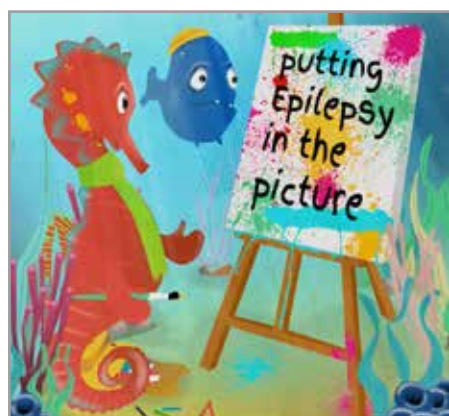
Campi is also reassured that, once his diagnosis is known and he is prescribed the correct medication, his seizures should be controlled and he will be able to live a normal life, just like before.

If you would like to have the videos with

subtitles in another language, please contact elizabeth@epilepsy.org who will be able to help you.

In the meantime, Campi has been kept busy helping us promote other activities around International Epilepsy Day. Did you catch him on Facebook and Twitter announcing our Art Competition with a cute little mini video? He will also promote our selfie campaign 'Putting yourself in the Picture for International Epilepsy Day' and we produced a special mini video to celebrate Chinese New Year.

So, watch out for this cheeky little fellow and, when you see him, please 'share' him with your friends. We hope he will bring a smile to everyone's lips!



Epilepsy does not hinder progress

My name is Leocardia Miti Makamo, I am married to a loving and caring husband and we were blessed with a daughter when I was 42 years old. I am a person living with epilepsy but no longer on treatment. Having experienced epilepsy, it gives me pleasure to encourage the world to join the fight against epilepsy by giving hope to other with the condition.

It was between 1993 and 1994 that I was caught up in a condition that drove me to social, spiritual, psychological, physical and family confusion. I had just completed grade twelve and suffered from meningitis. Two years later I was diagnosed with epilepsy.

It was not easy to accept the condition as no one in my family had the courage to explain to me what was happening. My seizures only occurred during sleep, so I didn't believe when my parents told me I was having attacks. Sometimes on waking, I found that I had bitten my tongue or had wet the bed, which was embarrassing for me.

My parents tried their best by taking me to prayer meetings and consulting many people for solutions to my problem, but to no avail. I lost interest in everything and I lost a lot of weight. While all these things were happening, I started asking myself what had I had done to deserve this. Despite everything, God was always with me and my family. I had to accept my condition and to learn how to live with it.

I started asking myself what had I had done to deserve this

My parents took me to the local clinic where I was prescribed a drug called Phenytoin, to which I reacted with extensive rashes all over my body. My skin peeled and my eyes were affected.

Having being subjected to this condition for a long time, I felt very lonely and spent much of the time in bed. The isolation brought a lot of pain to me and my family. I had seizures every month and this brought shame to me and my family. I was also having memory lapses to the extent that I could not remember what I was doing at times. As I was always in my bedroom I decided to start writing articles

in order to forget about my feelings.

While I was in hibernation I lost a lot of friends, but that did not worry me much as God and my family were always on my side, I kept praying that one day God, who saved Job in the Bible, would also save me.

In 2003 my parents and my aunt, who worked at Chainama Hills Hospital as a nursing assistant, heard about the Epilepsy Association of Zambia and took me there for a consultation. The Association received me well and put me on medication. After a few months, the rash disappeared and my health improved greatly.

The Association introduced me to many other young people with the same condition and encouraged me to become a member. I was a youth chairperson from 2004 to 2008 and we did a lot of community work.

We need to fight and fight until we win this battle

After few months, I reported back to work at the Ministry of Local Government and Housing. My work mates were amazed to see me in good health. The Ministry's administration also supported me by allowing me to attend the Association's activities and meetings. I continued working with the Association and from time to time the Association leadership gave me opportunities, together with other youths, to explain our situation on national TV and radio.

Epilepsy can be treated or controlled, depending on the cause. Many people, especially in developing countries, need a lot of training on epilepsy first aid. It is sad that, in this age and time, many people feel that nothing can be done for people with epilepsy. The stigma surrounding people living with epilepsy is real; few are accepted and supported by society at large, making families uncomfortable to openly speak about their situation. We need to fight and fight until we win this battle.

Let us sensitize people, especially during International Epilepsy Day every year. I would like to pay tribute to my late father, my mother, the Epilepsy Association of Zambia Leadership and the Government through all the Ministries I have worked

for, and all my friends. To all of you I say a big thank you for your prayers and encouragement.



Photos:

Top: Leocardia at work

Middle: Leocardia's wedding day

Bottom: Leocardia with her baby daughter and friend



Living real dreams despite epilepsy

Sari Tervonen, CEO, Finnish Epilepsy Association, shares Juha Karjula's story with us

Juha Karjula, a 38-year-old kindergarten teacher, obtained his university Master's degree despite having refractory epilepsy. He had a tonic-clonic seizure when he was a high school student. The diagnosis was given quite soon after the seizure, however the cause of his epilepsy is still unknown. The first antiepileptic drug did not stop his seizures, so he was prescribed a second and then third one. Strong drugs resulted in unbearable side effects, for example, causing speech problems. There have been different phases in his drug therapy. Nowadays Juha is on three antiepileptic drugs and he has been seizure free for more than a year. The last seizure occurred after he had forgotten to take two of his pills.

In his experience, it is important to have good communication between a person with epilepsy and their neurologist. If needed, a support person or a family member, someone who knows a patient's everyday life and wishes, could act as

'interpreter' between the doctor and the patient to ensure the patient is understood. In this way Juha had good interaction with his doctor and found a way for mutual understanding with his doctor about how he wants to be treated.

It is important to have good communication between a person with epilepsy and their neurologist

Juha feels he is living his dreams - enjoying his career and loving his wonderful family. There is a wife Anne and sons Taavi who is 11, Tiitus who is nine, and Tuure who is seven. They are living in Eastern Finland, in Kuopio. Sport is an essential part of the family's leisure time. Two children play football, which demands Dad to hand



Photo: Hannu Miettinen

around the sport field. He plays basketball himself. With his own friends, he is eager fan of board games. The whole family enjoys the fabulous Finnish countryside, boating on bright, blue lakes and wandering through wild, green forests. Juha is also lucky to enjoy nature trips just with the older children, who know in practice what to do if Dad has a seizure.

Juha is also a trained peer supporter for other people with epilepsy. In this role, he attended the adaptation/rehabilitation courses organized by the Finnish Epilepsy Association. The peer support model is recognized as a part of the governmental rehabilitation model of people with chronic illnesses. However "family business" has put this activity on hold until the children are older. This will happen fast as all parents know. Which means that Juha might soon act as peer supporter on adaptation training courses targeted for people with epilepsy.

Leadership Development Training Opportunity

An invitation to young IBE chapter representatives to receive leadership development training and the opportunity to network with other rising leaders from around the world at the 2017 ILAE Leadership Development Program.

Made possible through the financial support of the International League Against Epilepsy (ILAE)

About the ILAE Leadership Development Program

The Leadership Development Program is a great chance to receive leadership training and the opportunity to network with other young leaders from around the globe.

Session topics will include:

- The Science of Communication
- Strategic Planning
- Conflict Resolution & Negotiation
- Planning and Management of Operational Budgets
- Management Essentials
- Assessing and Leveraging Your Leadership Style
- Opportunities to Lead within IBE.

Successful candidates will receive the following:

1. Admission to the 32nd International Epilepsy Congress taking place in Barcelona, Spain 2 - 6 September 2017;
2. Admission to the leadership training course 2 - 3 September 2017;
3. Brief afternoon social with former students of the leadership program;
4. Certificate of completion.

Limited travel and accommodation support will be available for some awardees.

How to apply:

Interested applicants are required to submit the following items:

1. Brief statement describing why you are interested in the program and how you think you would benefit from participation;
2. Short CV - which should include your date of birth and be no longer than one typed page;
3. Letter of support from the IBE Chapter of which you are a member.

Applications should be submitted by email to ibeexecdir@eircom.net as a .pdf file no later than 3 April 2017.

Eligibility

Any current, active IBE Chapter representative is welcome to apply. Strong preference will be given to young leaders (under 40 years of age) and, dependent on applications, efforts will be made to ensure a wide global spread.

Requests for further information or clarification on any aspect of the training course should be sent to: ibeexecdir@eircom.net.

This is a wonderful opportunity for young and enthusiastic future IBE leaders to improve their management and leadership skills and IBE is grateful to the ILAE for generously offering to support up to 10 IBE-selected delegates to attend.

On behalf of IBE, I would encourage as many of you as possible to submit applications.





MANAGEMENT 2017 COMMITTEE 2021

IBE is pleased to announce the results of the recent elections to fill the Officer positions (President, Secretary General and Treasurer) on the International Executive Committee for the period 2017-2021.



President-elect is Prof Martin Brodie (Scotland). Prof Brodie has previously been a member of the IBE International Executive when he held the office of ILAE Treasurer from 2005 to 2009. He has been involved in other IBE activities, including chairing EUcare – a joint task force of IBE and ILAE, which was active from 2001 to 2009.

He has received the IBE/ILAE Ambassador for Epilepsy award, the ILAE CEA European Epileptology Award, the Epilepsy Lifetime Service Award from the ILAE UK chapter and the William G Lennox Award from the American Epilepsy Society.

In his election statement, Prof Brodie said: “Epilepsy care should be an equal partnership involving all stakeholders and so we must harness our best talents – wherever these might be found – to convey our message loudly and clearly to the world. We must encourage the general public to listen and learn; ask policy makers to safeguard the rights of people with epilepsy; seek funding to increase research into epilepsy – both scientific and social; and empower people with epilepsy to stand up for themselves. Already the IBE has tremendous global connections – to the WHO, to PAHO, to the UN through its ECOSOC status, and to the ILAE.

However, we must continue building more and better networks to form suitable partnerships geared at attaining our goals. We have to look beyond the epilepsy community, and broadcast our message widely, if IBE is to attain a more meaningful place in this increasingly complex and challenging world.”



Mrs Mary Secco (Canada) has been elected as Secretary General. Mrs Secco has also previously served on the IBE International Executive Committee as Vice President North America for the term 2009-2013. She is currently co-chair of the IBE/ILAE Global Outreach Task Force and Chair of the IBE Regional Executive Committee North America.

Mrs Secco served as the Executive Director of the Epilepsy Support Centre, a community based not for profit organization in Ontario, Canada from 2001 to 2013 and, for the past 3 years has been involved on a grant funded program to develop and evaluate a patient education intervention to improve the knowledge and self-management skills of persons with epilepsy.

In her election statement, Mrs Secco said: “The unanimous passing of the Epilepsy Resolution at the 68th World Health Assembly in Geneva in 2015 marked a turning point for people with epilepsy across the globe. It provides IBE chapters with a powerful tool to engage governments to take concrete action to improve epilepsy care and to take steps to reduce the treatment gap.

The Resolution identifies that ‘epilepsy’ is a major public health issue which has been inadequately addressed to date. The Resolution is what IBE chapters, current and past executives have been working towards for many years and we must now grasp this opportunity and make sure that we do not fail in the role we play in its implementation. It Resolution aligns closely with IBE’s Strategic Plan and we need to ensure that it translates into effective actions.”



Mr Anthony Zimba (Zambia), who is the current IBE Vice President Africa, has been elected as Treasurer. Mr Zimba has been Vice President Africa since 2009.

Mr Zimba work as Epilepsy Specialist at Levy Mwanawasa hospital in Lusaka, Zambia. He is the founder and Chair of Epilepsy Association of Zambia, which was formed to address the needs of people with epilepsy and their families who are often stigmatized and usually denied their basic human rights in Zambia.

Since the establishment of the association, Mr Zimba has been involved in the creation of epilepsy clinics at government health institutions; the launch of the Global Campaign Against Epilepsy in Zambia, epilepsy conferences and symposia, teaching courses and public awareness programs in schools and in the community.

In his election statement, Mr Zimba said: “I believe I have a number of valuable qualities I would bring to the position of a treasurer in IBE. My experience of treasury work dates as far back as 1998 when I held various positions as a treasurer in a good number of Associations. This is in addition to the booking keeping and accounts option subjects I did at school. I would like to assure you that, I have the energy and passion to serve our organization diligently.

The elections to fill the seven Vice President positions – Africa, Eastern Mediterranean, Europe, Latin America, North America, South East Asia and Western Pacific - on the International Executive Committee have begun.



BARCELONA



Getting ready for Barcelona

An opportunity to participate in the ILAE Leadership Program and the attend the IBE General Assembly

IBE GENERAL ASSEMBLY

The IBE General Assembly meeting will take place on the afternoon of Tuesday 5th September. All IBE chapter representatives are welcome to attend.

This will be the first assembly meeting to be held under the new Constitution and Bye-laws, which were approved during the assembly meeting held in Istanbul in 2015. The assembly will also mark the end of the current term of office of the International and Regional Executive Committees and of some of the current Task Forces.

At the end of the assembly, the formal stepping down of current committees will take place and the members of new International Executive Committee will be introduced.

Final reports of committees and task forces will be presented for approval by the General Assembly and new chapters will be officially ratified.

Also planned to take place as part of the non-business element of the meeting, is a workshop focussed on issues of particular relevance to IBE chapters - more details coming soon!

ILAE LEADERSHIP PROGRAM

Elsewhere in the magazine (page 9) you will find details of the ILAE Leadership Development Training Program, which will take place at the congress and, at which, up to 10 places have been reserved for IBE delegates.

The program is a great chance to receive leadership training and the opportunity to network with other young leaders from around the globe.

Any current, active IBE chapter representative is invited to apply for a place on the training programme and strong preference will be given to young leaders (under 40 years of age). Dependent on applications received, successfully chosen delegates will reflect a wide global spread.

This is a wonderful opportunity for young and enthusiastic future IBE leaders to improve their management and leadership skills and IBE is grateful to the ILAE for generously offering to support up to 10 IBE-selected delegates to attend.

Requests for further information or clarification on any aspect of the training course should be sent to: ibeexecdir@eircom.net.

The closing date for applications is 3rd April 2017.



How did you first become involved in the field of epilepsy?

After qualifying, I trained in general medicine with a special interest in clinical pharmacology in Glasgow and then in London. When I returned as a consultant in the University Department of Medicine in Glasgow, I started to explore the effects of the antiepileptic drug, carbamazepine, on liver enzymes and the metabolism of hormones.

It then became apparent to me that a number of new antiepileptic drugs were in development across the world and so I set up the first epilepsy clinic in Scotland, in 1982, to provide a base for my clinical trial programme.

My database now consists of more than 8,000 people with epilepsy, who are attending, or have attended, my epilepsy clinics. This has allowed me to study outcomes in response to treatment over a 30-year period, resulting in the publication of more than 20 clinically relevant papers.

And that's how I became an academic epileptologist!

Your involvement with ILAE and with IBE goes back quite a while. Can you tell us more?

I was appointed Secretary and then Chair of the European Commission of the International League Against Epilepsy (ILAE)

between 1993 and 2001, during which time I helped set up the biennial European epilepsy meetings. Between 2001 and 2005, I was elected as a Vice President of ILAE and was given the role, by the President, of helping him to develop the other regional agendas and congresses around the world.

"My database now consists of more than 8,000 people with epilepsy who are attending, or have attended, my epilepsy clinics"

Between 2005 and 2009, I was appointed Treasurer of ILAE and so also served over that time-period as a member of IBE Executive Committee. I've treasured many invitations to speak at IBE-sponsored meetings throughout this period.

We have heard you talk about the Teenage Epilepsy Agenda - known as TEA Room for short. How did it all begin?

In 2003, some colleagues and I set up the charity, Scottish Epilepsy Initiative. Its major project was the TEA Room, a safe website for teenagers with epilepsy to talk among themselves and to share life experiences. The platform was initially set up in 2010. It has recently been restructured and is attracting many youngsters from around

the world (<http://www.thetearoom.org.uk>). Discussions are not limited to health issues, but include a range of subjects from sitting a driving test to going to a concert. This gives teenagers with epilepsy a chance of having normal everyday conversations with supportive peers. My plan now is to extend our services to provide education and training opportunities to users of the website.

As President-elect, you have probably been considering how you would like to lead IBE over the next four years. Can you share with us your future plans for the Bureau?

My goal is to involve as many people and chapters around the world in helping to devise our global agenda. I will ask every chapter to provide their suggestions for projects, fundraising initiatives and strategies for their country and region. IBE must work harder to provide better support in assisting its members in achieving their goals.

Little can be done without money and I plan to appoint a finance committee to develop a global fundraising strategy aiming at raising a target amount of \$20million. I hope that this global project will develop its own momentum, not just over my 4-year term but for many years to come.

IBE must also play an active role in networking with other NGOs pursuing



Photos: Ann Little

MARTIN BRODIE

IBE PRESIDENT-ELECT

At the time of the IBE General Assembly in Barcelona on 5th September, the current International Executive Committee will present its end of term report, thereby completing its term of office. At the close of the assembly the new committee will assume office with Martin Brodie as President.

IE News Editor, Ann Little, recently caught up with Martin to learn more about his background and interests and his plans for IBE. Here's how he answered her questions.

similar aims. As part of this exercise, more effort will be made to support the agenda of the Global Campaign, particularly in resource poor countries. I will also do my best to fight stigma and discrimination, wherever it appears around the world, during my time of office.

This gives teenagers with epilepsy a chance of having normal everyday conversations with supportive peers

I am also very excited about an invitation I have received from Steven Schachter, Editor of *Epilepsy & Behavior*, who has invited IBE to submit a monthly article to the journal. IBE is free to choose whatever topics it considers most appropriate.

In his invitation, Steve says that "It's a chance for you to speak from a 'bully pulpit' to point out issues that are facing persons with epilepsy and their families worldwide, such as poor access to appropriate healthcare and effective medications, stigma, inadequate government research funding in epilepsy, scant specialists, etc. and to offer solutions or approaches and how readers can get involved'.

So, this is my invitation to all IBE chapters

to suggest topics that you think should be highlighted and a chance for you to have your name listed as author.

No man is an island, and so I will be counting on the support of the other recently elected members of the IBE Management Committee - Mary Secco (Secretary General) and Anthony Zimba (Treasurer) to assist in steering IBE over the coming four years. I believe that we will make a most effective team.

As I write, the nomination period for the regional Vice President positions is coming close to the deadline. I hope that as many of you as possible will consider allowing your names to go forward to stand for election. We need a strong and committed International Executive Committee if we are to deliver to the chapters services of the highest quality.

Lastly, with some colleagues I published in 1999 a short book entitled "Fast facts: epilepsy" for doctors managing people with epilepsy. This is now in its 5th edition. I would like now to co-author a similar volume for people living with epilepsy and their families, that will explain the classification of seizures and the epilepsies, together with their modern investigation and management.

This book will also include discussion of all available medical and surgical treatments,

Martin Brodie pictured in his beautiful garden at his home just outside Glasgow.

highlighting their potential advantages and adverse effects.

When you have free time, what do you do to relax?

I'm afraid, I only have 2 gears-"on" and "off". I enjoy talking and listening to people, including those with epilepsy and their families. I don't find this stressful and so my clinical work is not onerous. I read a lot of fiction and follow sports on TV, especially football. I also enjoy taking our two little dogs, Harvey and Lily, out for their walks!

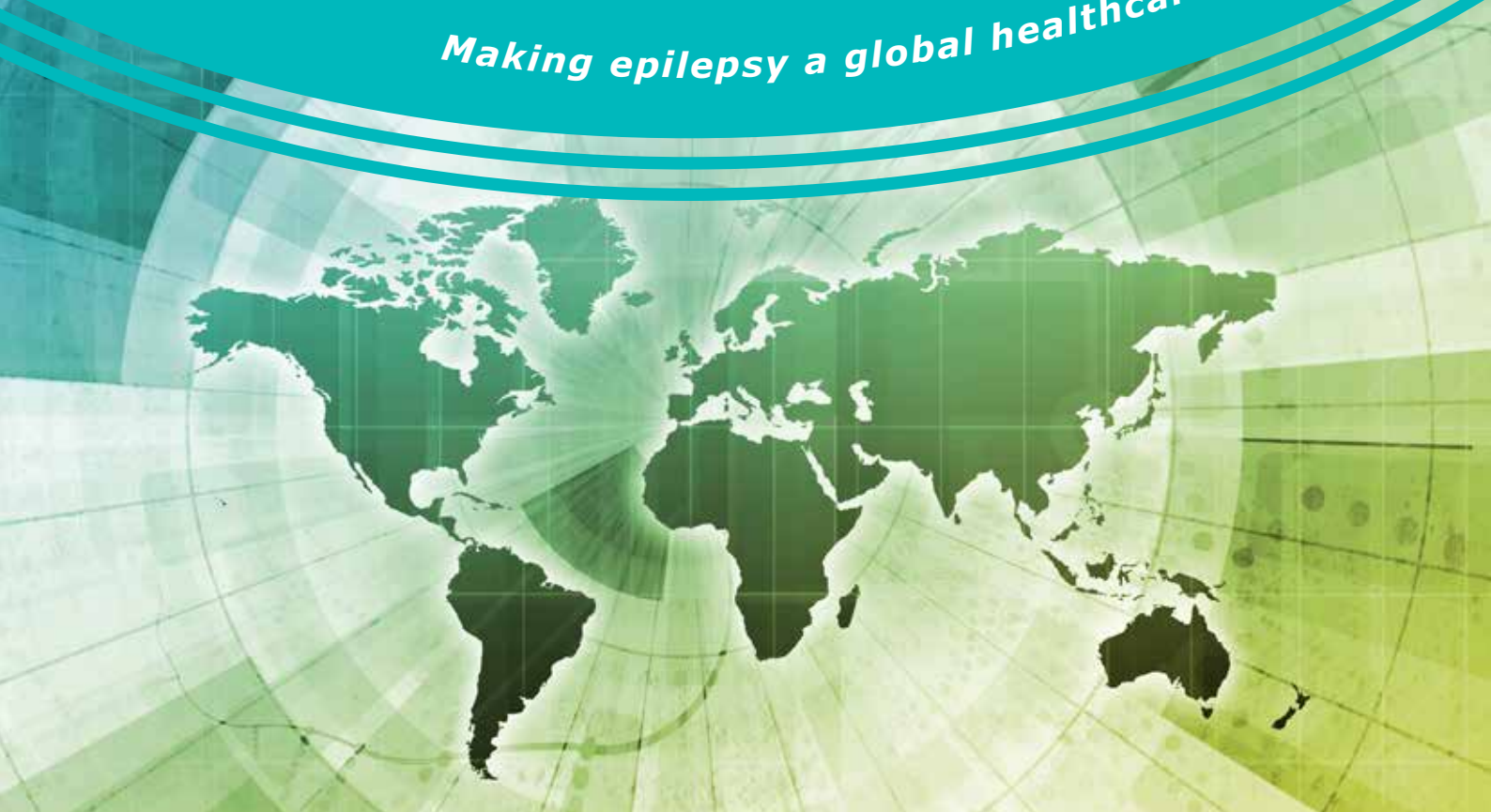
My garden is another pleasure I enjoy whenever I can. It's a space that has taken many years and an enormous amount of hard work to create and develop but it is now a peaceful sanctuary. When the weather is fine, I enjoy spending some time there relaxing and contemplating.

I've no plans to retire, but I would be prepared to do so should this interfere with my major goal of taking our organisation forward.

As things stand, I'm looking forward very much to working for IBE and planning for a busy agenda over the four years of my presidency. I hope that everyone will help me achieve this goal!

TOWARDS A GLOBAL ALLIANCE ON EPILEPSY RESEARCH

Making epilepsy a global healthcare priority



Today marks a Milestone!

So spoke Brian Hayes MEP (Member of Parliament), on opening the workshop in the European Parliament in Brussels on Tuesday 7 February.

Mr Hayes is President of the European Advocates for Epilepsy Working Group - a group of cross-party, cross-national MEPs with particular interest in epilepsy.

Mr Hayes explained that the purpose of the meeting was to see how resources in the US, EU and, possibly Asia, might be pooled so that each region was not working in a silo but as a joint collaborative unit.

The European Written Declaration on Epilepsy in 2011, which was supported with the signatures of 459 MEPs, and the more recent WHO Resolution on epilepsy, approved unanimously by the World Health Assembly in 2015, recognised the importance of the issue. The workshop would also demonstrate to the European Parliament "the quiet but deliberate work

that has been going on since 2011", Mr Hayes added.

Background

Although very little progress has been made in improving medical outcomes of people with epilepsy during the last decades, a large amount of data derived from extensive pre-clinical research has become available which provides a strong rationale for the conduction of potentially ground-breaking academically-driven clinical studies tackling several priority issues consensually acknowledged by the epilepsy community:

1. prevention of epilepsy;
2. prevention of sudden unexpected death in epilepsy (SUDEP);
3. optimization of epilepsy surgery;
4. worldwide development of mobile health programs to disseminate essential knowledge about epilepsy;
5. assembling of a very large well characterized cohort of persons with epilepsy that could be participate in all the above projects and in the development of personalized therapies for seizures, syndromes and related comorbidities.



Photo: Janet Mifsud

All of these objectives would require recruitment and financial capacities that could only be achieved at the global level, and justify the building of a global alliance program for epilepsy research.

Despite a number of major research calls funded by US National Institutes of Health (NIH) and by the EU during the last decade, financial support for epilepsy research lags behind most comparably prevalent or severe neurological and non-neurological disorders.

Accordingly, no significant progress has been made in reducing:

1. the incidence or prevalence of epilepsy,
2. the proportion of patients whose seizures remain treatment-resistant,
3. the death toll resulting from the disease.

Currently, 65 million people suffer from epilepsy worldwide, one third being refractory to treatment and at an increased risk of sudden death (SUDEP, about one every 10 minutes worldwide), suicide and seizure-related fatal accidents.

Thanks to significant advances in pre-clinical research and technology, several interventions could now be proposed to tackle the above issues. However, testing these interventions would represent a huge clinical research challenge due to the major cost and recruitment difficulties of such clinical trials.

Both limitations could be effectively addressed by multinational collaborative efforts.

Prompted by previous successful global research initiatives, notably in the field of traumatic brain injury (TBI), the American Society for Epilepsy (ASE), ILAE and IBE have worked over the last 18 months on the opportunity to develop a project addressing the above issues.

A specific task force was set-up by ILAE/IBE to define potential research topics that would deserve or require a global approach. This work was built on previous efforts from the epilepsy community to delineate priorities in epilepsy research in the US, Europe and the Asia-Oceania region.

In parallel, the global epilepsy scientific community was contacted soliciting further proposals. Suggested priorities and proposals were consolidated and ranked through a web-based survey that was again disseminated to the community.

The workshop in the European Parliament on 7 February hosted by the European

Photograph captions

Previous page: Brian Hayes MEP

Top: Emilio Perucca, ILAE President; Nessa Childers MEP; Janet Mifsud, IBE Vice President Europe

Middle: Phil Gattone, President & CEO Epilepsy Foundation, Emilio Perucca, Stéphane Hogan DG Research; Athanasios Covanis, IBE President; Vicky Whittemore, NIH

Bottom: Round table discussion at the workshop



Foreground photo: Ann Little



Photo: Ann Little

Advocates for Epilepsy working group and chaired by Brian Hayes MEP. The closed invitation-only event, addressed the opportunity to develop a global alliance research program in epilepsy, along the example of what has been done for TBI.

It was attended by some of the most senior representatives of a number of agencies and associations from Europe and North America. These included the Head of Sector for Neuroscience at DG Research, the Head of the ERN program at DG Santé, the NIH Program Director of Epilepsy, the Scientific Director of the Institute of Neurosciences of the Canadian Institute for Health Research, the President and the President-elect of ILAE, the President of IBE, the President of the American Epilepsy Society, the President and CEO of Epilepsy Foundation of America, the Chair of the Epilepsy Panel of the European Academy of Neurology, the President of the European Federation of Neurological Associations, and a number of other stakeholders.

The scene was set for the discussion by Mrs Francesca Sofia, the mother of a child with Dravet Syndrome, who spoke passionately and with great emotion on the isolation and loss of control that had followed her daughter's diagnosis. She told of the loneliness, stigma and discrimination to which her daughter was subjected and how her quality of life continued to worsen, not only because of her epilepsy but also, because of the side effects of her medication.

In closing the workshop, Mr Hayes, urged that the momentum established at the meeting be maintained. This was an important initiative and should not be allowed to die. "MEPs are interested in providing support. If we have something concrete to give, then they will get behind us", he said.

MEETING PARTICIPANTS

- ***Brian Hayes MEP: President, European Advocates for Epilepsy working group of MEPs**
- **Sean Kelly, MEP**
- **Nessa Childers, MEP**
- **Marian Harkin MEP, represented by her assistant**
- **Michał Boni MEP, represented by his assistant**
- ***Stéphane Hogan: Head of Sector for Neuroscience, Unit: "Non-communicable diseases and the challenge of healthy ageing", Health Directorate of DG Research & Innovation**
- ***Enrique Terol: Seconded National Expert. Policy officer, DG SANTE**
- ***Vicky Whittemore: Program Director of Epilepsy, National Institutes for Health (NIH), USA**
- ***Anthony Phillips: Scientific Director, Institute of Neurosciences, Mental Health and Addiction, Canadian Institutes of Health**
- ***Emilio Perucca: President, International League Against Epilepsy (ILAE)**
- ***Samuel Wiebe: Treasurer and President-elect, ILAE**
- ***Helen Cross: Secretary General, ILAE and Co-chair, ILAE Global Research Priorities and Advocacy Task Force**
- ***Athanasios Covanis: Co-chair, ILAE-IBE Epilepsy Alliance Europe Task Force and President, International Bureau for Epilepsy (IBE)**
- ***Philippe Ryvlin: Co-chair, ILAE-IBE Epilepsy Alliance Europe Task Force**
- ***Eli Mizrahi: President, American Epilepsy Society (AES)**
- **Philip Gattone: President & CEO, Epilepsy Foundation of America and IBE Vice President North America**
- ***Francesca Sofia: Scientific Director, Federazione Italiana Epilessie (FIE), Italy and mother of a child with epilepsy**
- **Janet Mifsud: IBE Vice President Europe**
- **Gay Mitchell: Member of Epilepsy Alliance Europe and former MEP**
- **Kerif Ferath: Vice Director of the Neuroimaging Research Laboratory (LREN) and Project Leader of the Medical Informatics Platform of the Human Brain Project (HBP) CHUV, Lausanne**
- **Eugen Trinka: ILAE Commission on European Affairs**
- **Massimiliano Coppola: father of a child with epilepsy**
- **Paul Boon: Chair, Programme Committee, European Academy of Neurology (EAN)**
- **Ann Little: Executive Director, International Bureau for Epilepsy and President, European Federation of Neurological Associations (EFNA)**
- **Xavier Hormaechea: Director Public Affairs, UCB**
- **Eimear O'Brien: Head Patient & Stakeholder Engagement, Neurology Patient Value Unit, UCB**
- **Marcus Glynn: Parliamentary Assistant to Brian Hayes MEP**
- **Heather Clarke: EU Senior Policy Office, EFNA**

* denotes speaker

ANNUAL DUES 2017

The call for Chapter dues for 2017 will be made in the next few days. Dues payments are important in funding IBE activities and are necessary to help us to introduce new activities and expand those that are already in place. Once again, this year we are encouraging those chapters based in Europe to make their payments in euro. This will reduce bank charges for both the sender and the receiver of dues funds. The dues levels are:

- Chapters: US\$175/€165
- Associate Chapters: US\$125/€115
- Subsidised rate: US\$30/€28.

In addition, more than 30 chapters based in developing countries have their dues payments covered by the Solidarity Fund. We would earnestly ask that you consider a donation to the Solidarity Fund, at any time, to help us to continue to support those chapters who have very limited financial means. Please contact ibeexecdir@eircom.net with any queries on how to make your association's payment.



How one parent changed the course of SCN8A Epilepsy support and treatment

*Photo: Ryan Collerd
The Cute Syndrome Foundation 2017
SCN8A Clinician, Researcher, and Family
Gathering
Text: Shelley Frappier*

"Hello, I'm Nico. Did you know that because I had so many seizures in my first two and a half years of life my 5 year old sister thinks all babies have seizures?"

Juliann Bradish and I first met online, in January 2015, in the days after my daughter Esmé's first Whole Exome Sequencing showed the second of her four genetic mutations—this one located in the gene SCN8A. I ran a foundation, the Cute Syndrome Foundation, which had funded research for Esmé's initial diagnosis of PCDH19 Epilepsy, and I was eager to start working on SCN8A as well. While doing research on SCN8A, I was introduced to Juliann, whose daughter Adeline also had a mutation in SCN8A and who ran a support group for parents of children with SCN8A.

Mutations in the gene SCN8A are associated with severe epilepsy that is intractable in around 70% of cases, as well as significant developmental delays, medical fragility, and a heightened risk for SUDEP. At the time Juliann and I met, there were just over 50 diagnosed cases of SCN8A Epilepsy in the world. Two years later, the family support group has grown to include more than 120 of the approximately 160 diagnosed cases of SCN8A Epilepsy, including cases from 22 countries on five continents.

In October 2013 when Juliann, a former pharmacist, received the news that her daughter Adeline had an SCN8A mutation, she quickly started looking for other affected families. She also began working closely with Michael Hammer, PhD, the geneticist who isolated the first case of SCN8A Epilepsy in his daughter, Shay, soon after her death in 2011. In 2014,

recognizing the need to provide support for the growing population of affected families, she set up the Facebook group. Juliann quickly understood the advantage, not only of providing support to families as they navigated the day to day pressures of life with SCN8A, but also, of helping to collect and share data that would support the group down the line.

Juliann's vision for the family group was one that included families in the most up-to-date understanding of research and clinical treatments, as well as in the process of collecting data about mutations and phenotype in preparation for registries and clinical trials. As a result, the SCN8A community has been able to have greater impact and more information than would be expected of a disease community of this size. For example, it was within this support group that the trend of individuals with SCN8A reacting adversely to the drug Keppra was first noted. This knowledge resulted in a huge improvement of the standard of care for treating individuals with SCN8A.

In 2015 Juliann joined me at the Cute Syndrome Foundation, and brought her family outreach work under the umbrella of the Cute Syndrome Foundation. As a result, we have been able to formalise much of the work she started in 2014. Recognizing the need to educate clinicians, who might only see one case of SCN8A in their practice, about the differences between SCN8A and SCN1A, with the help of clinician advisors experienced in treating

SCN8A, we developed SCN8A Clinician Information and Reference Guide in order to provide guidelines for the identification and treatment of SCN8A. We helped to fund and support the SCN8A registry and interactive website, SCN8A.net, run by Michael Hammer.

The trend toward parents acting as citizen scientists in the understanding and treatment of rare disease is, of course, undeniable. And as more and more rare diseases are recognized and best understood only by small groups of parents, researchers and clinicians, this trend will necessarily continue. Juliann's work with the SCN8A community is a wonderful example of how a small but well organized and motivated community can very quickly improve the quality of life for their children.

Awareness Day

Close to the International Epilepsy Day, held annually on the 2nd Monday of February, Shelley and Juliann have created an awareness day of CSN84, on February 9th, as an International SCN8A Awareness Day in honor of Michael Hammer's daughter Shay's birthday, launching an awareness campaign to help raise awareness of those affected by SCN8A.

You can contact the SCN8A family support group by email: scn8afamilies@gmail.com. For more information about SCN8A and the Cute Syndrome Foundation visit: www.thecutesyndrome.com.

FUTURE CONGRESSES

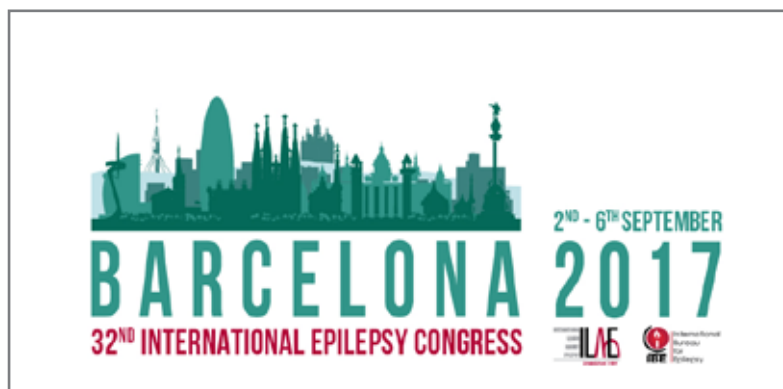
epilepsycongress.org



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