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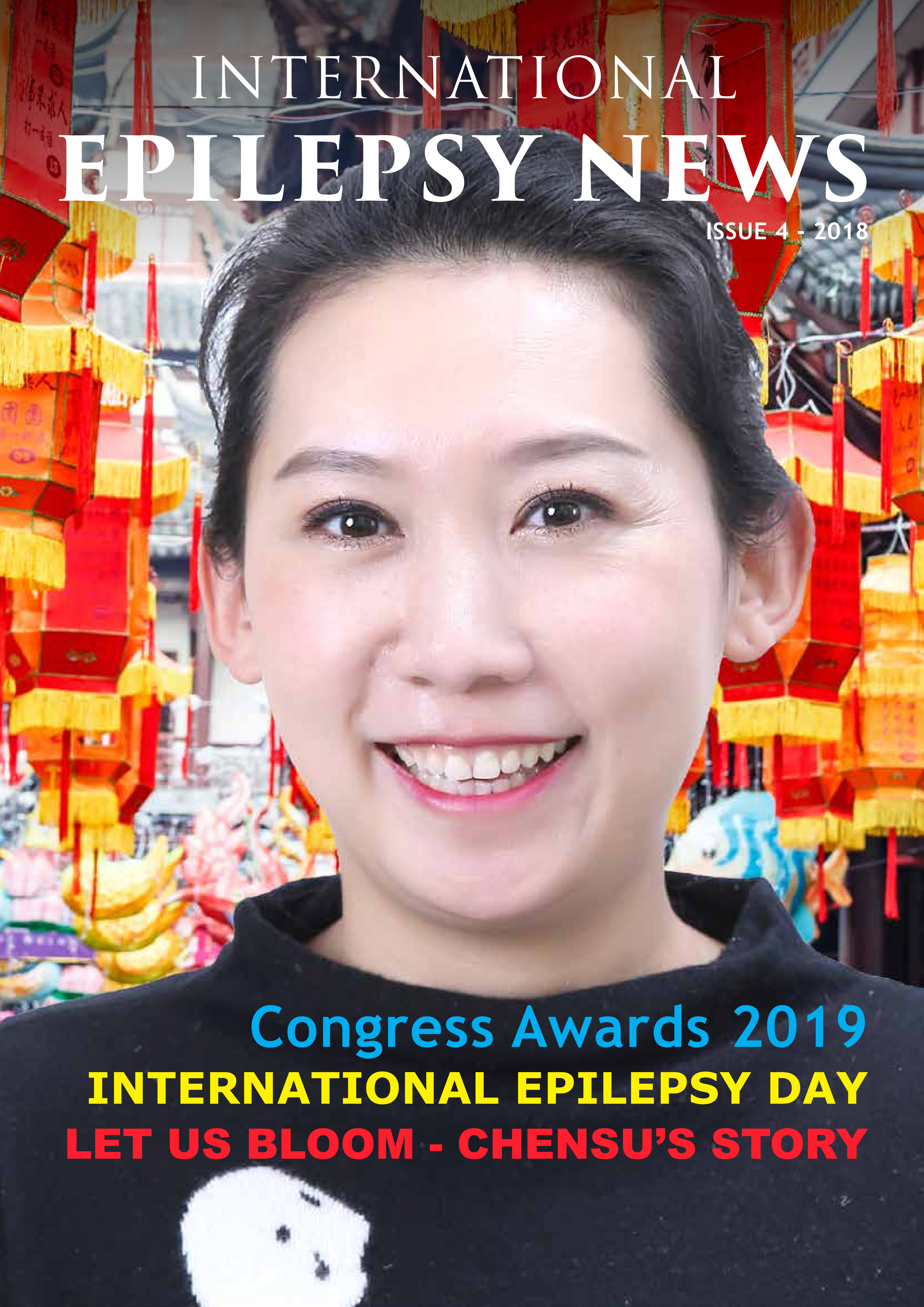

Congress Awards 2019

INTERNATIONAL EPILEPSY DAY

LET US BLOOM - CHENSU'S STORY

INTERNATIONAL EPILEPSY NEWS

ISSUE 4 - 2018

FROM THE EDITOR

If one of the goals of the IBE is to allow the voices of people with epilepsy to be heard, then we have certainly delivered in this issue of the magazine.

Our cover features a photo of Zhang Chensu, a young woman from China who experienced her first seizures when on Chinese New Year holidays on the tropical island of Hainan.

The young Scottish videographer, Fraser Morton, tells us how the death of his brother from SUDEP was the inspiration for his experimental online magazine, A Life Electric, that provides the platform for people with epilepsy around the world to tell their stories.

IBE's International Golden Light Awards, to be presented for the first time at 33rd International Epilepsy Congress in Bangkok, will see young people recognised for making a difference, while the Personal Stories category of the video competition for this year's International Epilepsy Day are truly remarkable. Find the winners on page 18 and access the link to watch them all.

We also bring news of those selected to receive the Lifetime Achievement, Social Accomplishment and Ambassador for Epilepsy Awards in Bangkok and there's lots more to read in this issue of IE News. As always, I wish you pleasant reading.

Ann Little
Editor

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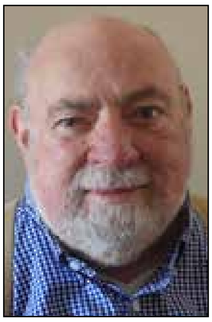

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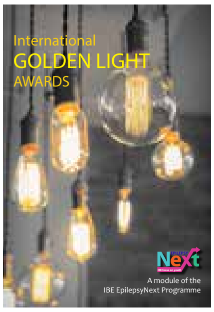

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PRESIDENT'S MESSAGE

DEAR FRIENDS

Since the last issue of IE News, we received the sad news that Margaretha Andersson, a member of the European Regional Executive Committee (EREC), had passed away. Margaretha, or Maggan as she was known by her friends, had been an active member of EREC for six years and news of her death was received with both shock and great sadness but her colleagues on EREC. She will be a great loss to the epilepsy community and to IBE and I would like extend my sincere sympathy to her family and friends.

The new year began with a series of business meetings in London. The International Executive Committee met face to face for the first time since the start of the current term in September 2017. This was the opportunity to review our progress to date and to set our course for 2019 and beyond. We also had a joint meeting with the ILAE, when our collaborative initiatives – Global Outreach, congresses and Epilepsy Alliance Europe – were on the agenda. It was during this joint meeting that the selection of successful candidates to receive the IBE/ILAE awards at the 33rd International Epilepsy Congress in Bangkok were made. You can find the details in this newsletter. I send my personal congratulations to every one of them!

In addition to committee meetings, IBE also organised a one-day strategic planning meeting in London. This involved members of the committee, as well as a small number of additional participants to ensure that the voice of the person with epilepsy, wherever they live in the world, was heard. On a positive note, it was agreed that the strategic plan already in place required only minor adjustment and the main discussion was on how to address the goals set out therein. As a first step, we are creating a multi-faceted Leadership Group, focusing on four major pillars: Shareholder Engagement, Capacity Building, Sustainability and Communications. You will be hearing about the work of these groups in the coming months.

2019 promises to be a busy year, with the 33rd International Epilepsy Congress in Bangkok taking place in June. This will mark the mid-term for most of our committee members. In the case of our regional Vice Presidents, it will mark the start of their new four-year term.

In addition to the General Assembly, a special event in Bangkok for IBE will be the first ever International Golden Light Awards. Chapters have already received information about these awards and how they can nominate people from their chapter. With travel, accommodation and registration fees covered, this is a great opportunity to reward young people affected by epilepsy who have made a change for the better in either their own lives or in those of others.

Last year, many of you helped with a major survey that has provided vital information and statistics for the Global Report on Epilepsy being produced by WHO in collaboration with IBE and ILAE. The report is now nearing completion and we plan to have the official launch during the Bangkok congress. This publication will provide a powerful tool in advocating for change around the world in services for people with epilepsy. Still in the early stages of planning, a European Epilepsy Forum, involving both IBE and ILAE chapters, is scheduled to take place in Brussels in November 2019. I will have more information on this to share with you soon.

So, a busy time ahead!

Martin Brodie

President, IBE

COVER PHOTO

Meet Zhang Chensu, a young woman from Changchun, Jilin Province in China. Despite a diagnosis of epilepsy, she has become a teacher and has plans to follow her dream of becoming an artist. Find out more on page 16.

MEMORIES OF MAGGAN

It was with great shock and sadness that the European Regional Executive Committee (EREC)learned of the passing of its much loved member - Maggan Andersson. Maggan passed away on 28th December, following a short illness.

Maggan first became involved with IBE when she was elected a member of EREC in 2013 and had been working with the committee until shortly before her passing. She had great energy and was a wonderful ambassador for IBE at the European Medicines Agency (EMA), attending a number of meetings as an IBE representative. She also travelled to the European Parliament as part of the IBE delegation at the time of European Epilepsy Day and, more recently, International Epilepsy Day.

Her outgoing friendly personality made her a wonderful colleague, always easy to work with and always happy to talk about how to improve the situation for people living with epilepsy. At a national level, Maggan worked with the Swedish Epilepsy Association and was its President when her final illness was diagnosed.

Maggan will be missed by all who knew her, but remembered with great fondness. Here, her friends at EREC share their memories of a fun-loving colleague:

"Maggan, was such a lovely and outcoming person, passionate in whatever she did, yet always with a smile on her face and living life to the full. She was an excellent ambassador for EREC and IBE and keen to share her personal experience with all she met - whether they were MEPs, EMA officials or other patient organisations.

She will be greatly missed and her 'joie de vivre' is something we should all try to duplicate.

I remember with great fondness attending European Epilepsy Day in Strasbourg in 2014 with Maggan and the rest of the term. Her energy was positively contagious." ***Janet Mifsud, formed member of EREC***

"What can I say about Maggan? Maggan was a shining ray of light, full of life and someone who made the most out of life. She shone a positive light on difficult issues, always focussing on possibilities rather than the negative.

Maggan was not afraid to voice her opinions, and I appreciated her candour. She made me smile, she made me laugh. I will miss her.

Rest in peace Maggan. " ***Caroline Morton, former Chair of EREC***

Maggan lived life to the full and with great joy and energy. She had strong views, was always willing to share them. She enjoyed discussing and debating ideas.

"Maggan was an energetic, thoughtful and knowledgeable advocate for epilepsy and the epilepsy community is the poorer for her loss. It was a privilege and a pleasure to know and work with her, and I will miss her." ***Shirley Maxwell, member of EREC***

Bon appétit!

Norwegian Center for Epilepsy launches new Ketogenic Diet Cookbook

Since the mid-90s, the National Center for Epilepsy has been treating children with the ketogenic diet. Because pediatricians noticed a great positive effect in this group, the hospital started to treat adults with the ketogenic diet, as well. Following the ketogenic diet is demanding and it is hard to maintain the lifestyle over a long period.

Recognising this, two people with epilepsy and a nutritionist from the National Center for Epilepsy contacted the Norwegian Epilepsy Association with the request for more recipes, or even a cookbook, tailor-made for the diet! A cookbook would be a practical tool in the everyday life of those using the strict diet, the patients argued.

Jørn Mandla Sibeko, Assistant General Secretary of the Norwegian Epilepsy Association, took on the challenge. He was granted funds from a foundation, which enabled the project. A cooking class was held with patients from the hospital, and the menu from the class was the beginning of the now completed cookbook.

"We want to make it easier for patients to follow through with their treatment. Hopefully this book contributes to sustaining the patients love of food," says Jørn.

The book is inspired – with photos of garnished dishes, easy to follow recipes, and a cooking vocabulary. The recipes include recipes for dishes using avocado, legumes, fatty sauces, meat, poultry and fish.

HELPING HANDS

In August 2018 Kerala, a state in south India, was devastated by floods the likes of which have not been seen in the past 94 years. Although the Malayalees are used to battling the rains every year, in 2018 the rains took everyone by surprise. All 96 dams in the state were full by mid-August and dam shutters had to be opened, putting the already inundated state in danger of completely drowning. The administration was hampered by the vastness of the task and people came out in huge numbers to help rescue and move victims to shelters. People have lost their houses and belongings and, in many cases, their means of livelihood. Many organizations came forward to help and relief poured from many places.

It was in this scenario that the Indian Epilepsy Association (IEA) Kochi decided to do something to help the flood victims. Most of the medical members of IEA realised that patients were finding it difficult to buy medicines as priorities were for food and clothing and the basic necessities for living. In fact, many people with epilepsy caught up in the flood presented to hospitals with seizures since they could not take their medication with them to the relief camps. So IEA Kochi decided to identify people with epilepsy in the affected regions and to help them financially for a period of four to six months in rebuilding their lives.

An announcement was placed in local newspapers across Kerala asking people with epilepsy in the flood affected regions to apply with the necessary documents, such medical history, certificate from the treating physicians and latest prescription, income certificate and photo ID, as well as certification from the local authorities highlighting the impact of the damage due to the floods. The selection committee consisted of the President, Secretary and Treasurer of IEA Kochi, under the chairmanship of Justice M R Hariharan Nair, a retired Judge of Kerala High Court who is currently Chairman of the Ethics Committee of Kerala University of Health Sciences (KUHS) together with a few lay members. The documents submitted were examined and a final list of 19 persons who met all the criteria was identified. A disbursement plan was worked out depending on the medical needs of the individual patients as well as their income status. Coordination of the project involved a number of people attached to IEA Kochi.

In November 2018, at a public function held in Kochi, Sri. P Sriramakrishnan, Hon. Speaker of the Kerala Assembly officially launched the scheme in the presence of Dr. Subhas G T, National President and Dr. Rajendran, National Secretary General of the IEA. An initial amount of ten thousand rupees was distributed to each of the beneficiaries. Dr. Mathew Abraham, President IEA Kochi welcomed the gathering with Dr. Vinayan KP, Secretary, IEA Kochi introducing the ambitious project. Further amounts will be transferred directly to the bank accounts of each beneficiary in installments depending on their eligibility.

Another 11 persons who saw the announcement of the function and came to the venue to enquire about the financial aid, showing that there were more persons with epilepsy who were not covered in the first phase. It was decided that these people would also be added to the beneficiaries list if they met all the other eligibility criteria as the second phase of the project - “Helping Hands” - and that IEA Kochi would try to raise funds to increase the corpus so that they could also be accommodated.

Epilepsia en Atención Primaria Paraguay
Epilepsy Primary Health Care in Paraguay
Marta Cabrera, President of Asopalep sent us this workshop report

El Hospital Nacional de Itauguá representa un emblema institucional para la salud del Paraguay, por su historia y orígenes que alberga arduo trabajo y compromiso de profesionales de gran renombre en la historia de la medicina paraguaya.

PROGRAMA

Se dispuso un programa general en torno a temas de interés básico como definiciones, nueva clasificación, utilidad de medios diagnósticos, tratamiento farmacológico y tratamiento alternativo. Se intentó ser lo más abarcativo posible en cuanto a las áreas de pediatría y adultos dada la variedad de profesionales a los que iba dirigida la jornada. Tambien se tocaron temas de interés social como lo referente al trabajo, las leyes, el acceso a la información y los derechos de los pacientes con epilepsia.

NUESTROS INVITADOS

Logramos congeniar el tiempo de un gran equipo de invitados locales y extranjeros, trabajando en equipo por la epilepsia, Neurólogos de adultos y Neurólogos pediatras, con un gran enfoque en los aspectos de la detección de Epilepsia en niños siempre un reto por demás desafiante para nuestros médicos de atención primaria. Contamos con el desinteresado apoyo de los invitados extranjeros en representación de ILAE, el Dr Roberto Caraballo quien se abocó a los aspectos científicos del tratamiento de lo básico a lo complejo y en representación del IBE, la Dra. Alicia Bogacz quien enfocó sus charlas en los aspectos sociales y la difusión del plan estratégico OPS/OMS, en un esfuerzo conjunto de ambos capítulos nacionales.

ASISTENCIA

Obtuvimos un record de asistencia para los eventos de este tipo anteriormente organizados por la Liga y otras Sociedades Científicas del área, con un total de 170 asistentes de todas las áreas referentes a las ciencias médicas no solo médicos.

AGRADECIMIENTOS

Deseamos extender nuestro especial agradecimiento al director del Hospital Nacional de Itauguá el Dr Hernán Martínez por declarar al evento de interés institucional, además de los jefes de Departamento en especial el Departamento de Neurocirugía, Neurología, Neuropediatría, Pediatría y Medicina Interna quienes ayudaron con la difusión del evento.

ENCARE SOCIAL

Desde la Liga Paraguaya de Lucha Contra la Epilepsia (ILAE Paraguay) nos comprometemos a seguir trabajando en conjunto con el capítulo nacional de IBE (Asopalep) por la socialización del desafío que representa la Epilepsia en nuestra región. Desde la ILAE en la formación médica continua especialmente en el área de la atención primaria, además del apoyo en los aspectos sociales de la Epilepsia.

Photo: Marta Cabrera (fourth from left) with workshop speakers.

The National Hospital of Itauguá is recognised as centre of excellence for healthcare in Paraguay, with a history that demonstrates the hard work and commitment of professionals of great renown in the history of Paraguayan medicine.

PROGRAMME

A general programme was drafted around topics of basic interest such as definitions, new classification, usefulness of diagnostic methods, pharmacological treatment and alternative treatment. We tried to be as comprehensive as possible regarding the areas of paediatrics and adults, given the variety of professionals to whom the day was directed. The programme topics also touched on issues of social interest such as employment, legislation, access to information and the rights of people with epilepsy.

OUR GUESTS

We managed to attract a great team of local and foreign guests, as never before; adult and paediatric neurologists, with a great focus on diagnosis in children, which is always a challenge for doctors working at primary care level. We had the support of foreign guests representing ILAE, Dr Roberto Caraballo who focused on the scientific aspects of the treatment of the basic to the complex and on behalf of the IBE, Dr Alicia Bogacz who focused her talks on the social aspects and the dissemination of the PAHO/WHO Strategic Plan, in a joint effort of both national chapters.

ATTENDANCE

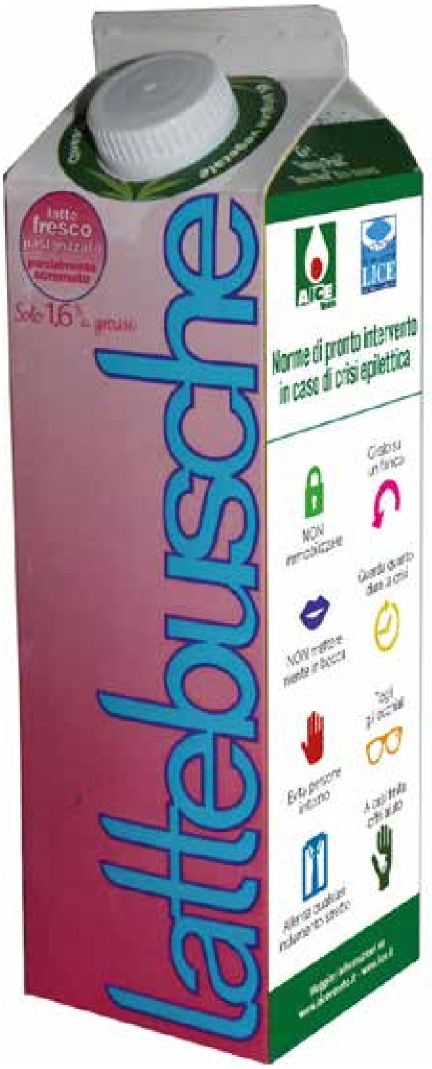
We had a record attendance for events of this type compared to those previously organized by the League and other Scientific Societies on this topic, with a total of 170 participants from all the areas related to medical science; not only doctors but also people with epilepsy

THANKS

We wish to extend our special thanks to the director of the National Hospital of Itauguá, Dr Hernán Martínez, for declaring the event of institutional interest, in addition to the department heads, especially the Department of Neurosurgery, Neurology, Neuropediatrics, Paediatrics and Internal Medicine, who helped with promotion of the event.

SOCIAL ASPECTS

The Paraguayan League Against Epilepsy (ILAE Paraguay) is committed to working together with the IBE national chapter (Asopalep) to address the challenge represented by epilepsy in our region. ILAE medical training continues, especially in the area of primary care, in addition to support on the social aspects of epilepsy.



As easy as drinking milk!

AICE (Italian Association Against Epilepsy - Veneto), LICE (Italian League Against Epilepsy), and Lattebusche, joined forces to raise awareness on how to deal with an epileptic seizure. After all, what is there more common than a carton of milk?

And this is why the Lattebusche co-op, with headquarters in Busche (Belluno) and active in the dairy sector for more than 60 years, have started an awareness campaign on epilepsy.

With half a million people living with it, and 30,000 new cases each year in Italy, epilepsy is a very common condition. Specifically, in Veneto there are 40,000 people affected by epilepsy.

And while it is a very common pathology, it is seen as an obscure disease which should be hidden. This adds to the stigma around it, which is hard to eradicate. This is not true for Lattebusche, which from December 2018 to May 2019 is selling cartons of milk at all points of sale; the cartons of milk will list the 8 rules to follow in case of a seizure.

The awareness campaign is expected to reach at least 1.5 million people. The co-op will also print the rules in 100,000 flyers to be distributed until May.

“Epilepsy is a disease with a lot of fear and scepticism surrounding it”, states Sergio Giordani, the Mayor of Padua, “a completely unjustified behavior, which negatively impacts people who suffer from this condition. This awareness campaign, it’s first and foremost a signal to the public to end the social stigma around the disease and to obtain accurate information on it; it is also a very important information tool for those who find themselves next to someone during a seizure. I thank you LICE, and AICE for this initiative and particularly Lattebusche for their social responsibility demonstrated by their significant collaboration in this campaign”.

The eight rules

But how do you deal with epileptic seizure? Just remember eight simple rules: First of all, the person having a seizure should not be immobilized, but turned on their side. Then, glasses and other constricting clothes should be removed. Do not put anything in their mouth to avoid complications to the patient (and yourself in case of rigid locking). It is essential to avoid confusion: better if there aren’t people around. Finally, only at the end of a crisis, is it appropriate to offer help.

To coincide with International Epilepsy Day, Scottish production company Storm Features launched an experimental online magazine called A Life Electric.

For the past year a Scottish visual journalist has been collecting stories about epilepsy inspired by the death of his brother to the illness. Fraser Morton, 36, from Edinburgh, travelled to India, Indonesia and Australia and found stories as far afield as Bangladesh, Pakistan, Mongolia, San Francisco, as well as in the United Kingdom. His brother Blair died aged 19 due to Sudden Unexpected Death in Epilepsy (SUDEP).

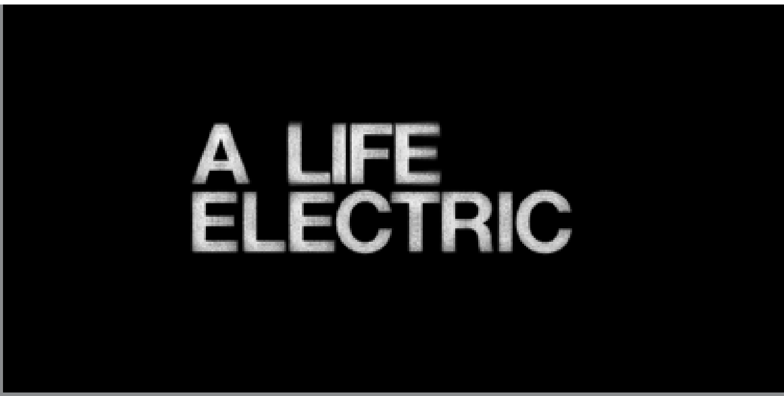
“Epilepsy is a subject of great personal interest to me and my family and a subject I feel is not getting the attention it deserves,” said Fraser.

“As a documentary maker I spend a lot of time travelling for work and in those places I have visited I have found there is huge disparity between healthcare, spirituality and community in cultures worldwide with treatment of people with epilepsy.”

“Violence, persecution, ostracisation, discrimination, polarisation, you will be hard pressed to find a health issue that is as stigmatised as epilepsy on a global scale. It exists, we know about it, but we don’t speak about it.”

Morton launched the online magazine exploring epilepsy and is currently producing a feature documentary to tell the contrasting stories of people living with epilepsy in 2019.

The self-funded online magazine A Life Electric can be viewed here www.alifeelectric.org.



International
Epilepsy Day

TOWARDS A GLOBAL ALLIANCE ON EPILEPSY RESEARCH

International Epilepsy Day event in the European Parliament reports on the unmet needs in the field of epilepsy and the status of epilepsy research priorities at a global level.

The event was organised by Epilepsy Alliance Europe joint task force of IBE and ILAE in Europe and hosted by the European Advocates for Epilepsy MEP group in the parliament.

Two years ago, in February 2017, Epilepsy Alliance Europe organised a very significant meeting in the European Parliament in Brussels to highlight the need for a global effort if appropriate advances were to be made in addressing the unmet needs of epilepsy, both in Europe and around the world.

The meeting heard that, although very little progress had 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 provided a strong rationale for the conduction of potentially ground-breaking academically-driven clinical studies tackling several priority issues that were acknowledged by the epilepsy community:

- prevention of epilepsy;
- prevention of sudden unexpected death in epilepsy (SUDEP);
- optimization of epilepsy surgery;
- worldwide development of mobile health programs to disseminate essential knowledge about epilepsy;
- 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.

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.

The closed invitation-only event was hosted by Brian Hayes, President of the 67-member-strong group of Members of the European Parliament (MEPs) who form the European Advocates for Epilepsy group in the parliament, a number of whom attended the event. Also present were 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 Presidents of IBE and ILAE, 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, including the pharma industry.

> “I wish my daughter simply to be happy”

This very successful meeting led to a follow up event in January 2018, when a Breakfast Briefing was organised and, again, hosted by Brian Hayes MEP. The 2018 event was attended by several MEPs, including Mrs Lieve Wierlinck (Belgium), Seán Kelly (Ireland), Alojz Peterle (Slovenia), Roberta Metsola (Malta), José Inácio Faria (Portugal), and Franc Bogovič (Slovenia). Also present were Stéphane Hogan, Head of Sector for Neurosciences, DG Research & Innovation, European Commission; Anna Graca, DG Research & Innovation with responsibility for epilepsy; and Fredrick Destrebecq, Executive Director, European Brain Council. There to tell the epilepsy story on behalf of Epilepsy Alliance Europe were Helen Cross, Martin Brodie, Lieven Lagae, Philippe Ryvlin, Eugen Trinka, Kristl Vonck, Janet Mifsud, Caroline Morton and Francesca Sofia.

Two other significant events took place in 2018. The first of these was the epiXchange workshop, with seven large EU-funded projects joining forces to organise the one-day event on 23 May, in Brussels. The event was designed to gather a critical mass of epilepsy researchers in order to showcase the latest progress in research aimed to improve the way epilepsy is diagnosed and treated. The projects had been funded mainly through the 7th Framework Programme (FP7).

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. The event provided the opportunity to synergise the results of the seven diverse projects and to identify the several bottle necks which still remain.

Delegates included basic and clinical epilepsy researchers, big and small pharma, and patient organisations. Other participants included 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 bottom up approach is needed to coordinate research and policies with more collaborative research, including public partnerships, public private partnerships, and global co-operation.

On the following day, the EU Research Commission held a workshop titled ‘Shaping the Future of Epilepsy Research’ with a

Delegation to the parliament, from left: Jakob Christensen representing ESBACE; Janet Mifsud, Member EAE; Ann Little, IBE Executive Director; Philippe Ryvlin, Co-chair EAE; Martin Brodie, IBE President and Co-chair EAE; Francesca Sofia, Member EAE; Astrid Nehlig, Editor Epilepsia; Fred Destrebecq, EBC; Eugen Trinka, Chair ILAE-Europe and Member EAE; Michele Simonato, representing epiXchange.

Members of the European Advocates for Epilepsy Group

President: Brian Hayes (Ireland)

Vice President: Nathalie Griesbeck (France)

Members Heinz Becker (Austria), Bendt Bendtsen (Denmark), Franc Bogovič (Slovenia), Michal Boní (Poland), David Borelli (Italy), Paul Brannen (UK), Christian-Silviu Bușoi (Romania), Matt Carthy (Ireland), David Casa (Malta), Nessa Childers (Ireland), Lefteris Christoforou (Cyprus), Kostas Chrysogonos (Greece), Deirdre Clune (Ireland), Miriam Dalli (Malta), Tanja Fajon (Slovenia), José Inácio Faria (Portugal), Eleonora Forenza (Italy), Lampros Fountoulis (Greece), Jens Gieseke (Germany), Theresa Griffin (UK), Jytte Guteland (Sweden), András Gyürk (Hungary), Marian Harkin (Ireland), Anna Hedh (Sweden), Liisa Jaakonsaari (Finland), Anneli Jäätteenmäki (Finland), Barbara Kappel (Austria), Karin Kadenbach (Austria), Seán Kelly (Ireland), Katerina Konečná, (Czech Republic) Miapetra Kumpula-Natri (Finland), Merja Kyllönen (Finland), Giovanni La Via (Italy), Jean Lambert (UK), Marian-Jean Marinescu (Romania), Costas Mavrides (Cyprus), Mairead McGuinness (Ireland), Roberta Metsola (Malta), Tilly Metz (Luxembourg), Ulrike Műller (Germany), James Nicholson (UK), Demetris Papadakis (Cyprus), Dimitrios Papadimoulis (Greece), Emilian Pavel (Romania), Alojz Peterle (Slovenia), Sirpa Pietikáinen (Finland), Pavel Poc (Czech Republic, Dominique Riquet (France), Paul Rübig (Austria), Sofia Sakorafa (Greece), Christel Schaldemose (Denmark), Annie Schreijer-Pierik (Netherlands), Olga Sehnalová (Czech Republic), Igor Šoltes (Slovenia), Maria Spyraki (Greece), Neoklis Sylikiotis (Cyprus), Eleftherios Synadinos (Greece), Claudiu-Ciprian Tânăsescu (Romania), Patrizia Toia (Itlay), Nils Torvalds (Finland), Ivo Vajgl (Slovenia), Julie Ward (UK), Theodoros Zagorakis (Greece), Tomáš Zdechovský, (Czech Republic), Jana Žitňanská (Slovakia).

global panel of speakers from Europe, Asia, Africa, and North and South America, at which it was reported that the upcoming EU Horizon Europe framework for research would be calling for bold inspirational approaches with wide societal relevance, including open science, global challenges and open innovation pillars. Also looking to develop a global perspective, a call under the H2020 project titled 'Coordinating European brain research and developing global initiatives' was underway with the European Brain Council's European Brain Research Area (EBRA) proposal being selected to coordinate the project.

So, it was with this, not-insignificant, background of activities, raising the call for the global perspectives that are now required in research, that a lunch meeting took place in the parliament in Strasbourg on Tuesday 12 February 2019, the day after International Epilepsy Day.

Invitations to the meeting were extended to the 67 MEPs who form the membership of the European Advocates for Epilepsy group and the event was hosted, once again, by Brian Hayes MEP. At the lunch, 12 MEPs, from Czech Republic, France, Germany, Ireland, Finland, Luxembourg, Romania and Slovenia, voiced their support for the 6 million people living with epilepsy in Europe. In turn, the MEPs heard from speakers about the continued unmet needs of people living with epilepsy and the need for improved services, novel new treatments and actions designed to educate the public about epilepsy and, thereby, reduce discrimination.

In welcoming all those present, Brian Hayes highlighted the success of the MEP group since its launch in 2011. He advised that he would be retiring from politics at the end of the current EU parliamentary term but would be happy to assist in identifying an MEP to assume the chair once the elections were completed in May. Of note, the average turnover of MEPs at the time of elections is 50%. This means that about half of the membership of the MEP group would be lost, requiring fresh efforts to rebuild it post-election.

Speaking in Strasbourg, Prof Philippe Ryvlin, co-chair of Epilepsy Alliance Europe, thanked Brian Hayes and the MEP group for the support they had provided over the previous seven years. Notable achievements included the Written Declaration on Epilepsy 22/2011, that had been signed by 459 MEPs and had resulted in major funding for epilepsy research in the Framework Programme 7 (FP7). Many of the projects funded by FP7 now formed the epiXchange network. Other epilepsy projects that had received EU funding since 2011 included E-PILEPSY, the pilot European Reference Network (ERN) project; EpiCARE, an ERN focussed on rare and complex epilepsies; and ESBACE, a project funded by DG Santé that surveyed epilepsy prevalence and cost burden in a number of countries. Prof Ryvlin highlighted the need for a global focus on epilepsy research if progress is to be made in identifying new and novel treatments for the 30 – 35% of people with epilepsy whose seizures currently are not controlled by existing treatments. There were new opportunities for such global research initiatives through the European Brain Research Area (EBRA).

An issue for concern was the lack of support in Europe for the WHA Resolution on Epilepsy, approved by the World Health Assembly in 2015, with report back in 2018. Few countries had addressed the recommendations of the resolution and efforts were now underway for a call to action. While support had been received from some countries including Russia, China and Brazil, there had been no support from EU Member States, despite their support for the EU Written Declaration in 2011. The argument was that epilepsy was too narrow a topic. However, the counter arguments were that epilepsy encompassed several hundred diseases; was sufficiently wide to have been selected for an EU-funded European Reference Network (ERN); 50 million people worldwide had been diagnosed with epilepsy; and it ranked second in the league of years of life lost.

In her presentation, Francesca Sofia, an Italian mother of a young child with epilepsy, said that her biggest wish was for her daughter simply to be happy, adding that this was a wish shared by all parents for their children. Francesca's daughter Bea has a complex form of epilepsy which is resistant to medication. She continues to have seizures and requires a lot of support.

Despite the hardships that life has thrown at her, Bea remains a happy loving 9-year old, who goes to school and who yearns to have friends. But the sad situation is that she has never had a friend and has never been invited to a play-date or party by classmates. Any invitation sent by Francesca to her daughters classmates for play dates or parties have always been declined by their parents. A strong indication that there is still huge misconception and stigma attached to a diagnosis of epilepsy. And if the parents are discriminatory towards Bea, this is likely to run off onto their young children.

Sofia's story of her daughter's struggles shows clearly the continued need for basic education about epilepsy in the community and undermines the reality that many people with epilepsy face - that epilepsy is more than seizures.

Fred Destrebecq, Executive Director of EBC outlined the purpose and expectations of EBRA, a consortium of the Network of European funding for Neuroscience research (NEURON), the Joint Programme Neurodegenerative Disease Research (JPND) and the Human Brain Project (HBP). The EU was seeking projects that would address the problems of duplication and fragmentation of research efforts and that would encourage more collaboration and better coordination of brain research at EU and global levels. This would lead to improved access to research systems and data sources by all stakeholders involved in the neuroscience research area, resulting in better use of the investments that are made in brain research. The critical mass and economies of scale thus achieved would facilitate the development of new global initiatives and quicker translation of successful outcomes to clinical applications.

Huge investment has been provided by the EU for brain research to a number of initiatives. Although the initiatives generated a considerable amount of knowledge and innovative approaches, more coordinated efforts are needed to avoid fragmentation, to identify gaps and highlight priorities, in order to support and foster translation into new health interventions.

The EBRA Consortium will foster alignment and co-ordination of research strategies across European and global brain initiatives; facilitate the emergence of research projects in specific areas in active clusters selected for involvement in EBRA, and provide them with support for effective collaboration, including enabling sharing of data and access to research infrastructures; and increase the visibility of the brain research portfolio as a whole and promote the uptake of EBRA results to key stakeholders.

THE SPEAKERS

Brian Hayes MEP

Brian Hayes served as a member of Dail Eireann (Irish Parliament) from 1997-2002 and 2007-2014, until his election to the European Parliament in May 2014.

He was appointed to three European Parliament Committees - Economic & Monetary Affairs, Development, and Budgetary Control. He is a member of the Delegations to Iraq and South Africa.

Martin Brodie

Prof Martin Brodie is President of the International Bureau for Epilepsy (IBE) and Co-chair Epilepsy Alliance Europe. His involvement with IBE goes back more than 30 years, having served as a member of its board from 2005 to 2009.

His research interests include antiepileptic drug neuropharmacology, randomised clinical trials, prognostic outcome studies, management of epilepsy and factors affecting antiepileptic drug response.

Francesca Sofia

Dr Francesca Sofia is a molecular biologist with a PhD in neuroscience. She specialized in healthcare economics and policy as a research program manager for a major Italian health foundation, dedicated to rare genetic diseases. Her career path changed when her youngest daughter was diagnosed with a rare form of epilepsy in 2011.

In July 2014, she joined the Italian Epilepsy Federation with the aim of fostering epilepsy research. Recently, she founded Science Compass, an enterprise that provides services and tools for effective investments in the biomedical sector to non-profit organizations.

Frederic Destrebecq

Frédéric Destrebecq is Executive Director of the European Brain Council. In this capacity, he is responsible for providing strategic direction and leadership while managing the day-to-day operations of EBC and its ongoing relationships with its member associations and other stakeholders, as well as representing the organisation in various European and national forums.

Prior to this position, Fred served the European Union of Medical Specialists (UEMS) as Chief Executive Officer, and previously as Director for European Affairs.

Philippe Ryvlin

Dr Ryvlin is Professor of Neurology and Chair of the Department of Clinical Neurosciences at University Hospital of Lausanne (CHUV), Switzerland, and Director of the Epilepsy Institute (IDEE) in Lyon, France.

He is President of the European Epilepsy Monitoring Association (EEMA), co-Chair of the Epilepsy Alliance Europe Task Force, founder of the European Network for Epilepsy Research (ENER), and coordinator of the EU funded pilot ERN - (E-PILEPSY).

CONGRESS AWARDS

33rd International Epilepsy Congress
BANGKOK 2019

The IBE/ILAE congress awards are presented biennially at the time of the International Epilepsy Congress, to honour individuals who have made significant contributions, over a long period of time and at international level, in the field of epilepsy. There are three categories: Ambassador for Epilepsy - presented to a maximum of 12 recipients; Social Accomplishment, presented to one individual; and the highest honour, Lifetime Achievement Award which, as its name implies, recognises a lifetime of achievement of an individual.

Lifetime Achievement Award

This is the highest award bestowed by IBE/ILAE and is given to an individual to recognise his or her exceptional and outstanding personal contribution over a long period of time to activities to advance the cause of epilepsy.

Presented to: W Allen Hauser, USA

Willard Allen Hauser is Professor Emeritus of Neurology and Epidemiology at Columbia University where he has taught, done research and treated people with epilepsy over the past 40 years. His accomplishments over five decades include studies on age- and gender-related incidence and prevalence, prognosis for seizure remission, concept on recurrence after acute and unprovoked seizures, studies of mortality, quantification of risk for epilepsy for conditions such as stroke, brain trauma, CNS infection and others, unravelling bi-directional association between epilepsy and co-morbidities, epidemiologic studies of status epilepticus. These studies revolutionized the understanding of epidemiology and risk factors of epilepsy and found the ground of the ILAE operational classification of the disease.

Social Accomplishment Award

Every two years, one person who has carried out outstanding activities aimed at improving the social circumstances of people with epilepsy and those who care for them, over a long period of time, is recognised.

Presented to: Carlos Acevedo, Chile

Carlos Acevedo has served several terms as President of the IBE chapter in Chile and is currently a member of its board. He has also served a number of terms on the board of the International Bureau of Epilepsy. including serving as Secretary General.

Under his leadership, the Chilean League Against Epilepsy became both a national and international recognized Institution for its contribution for people with epilepsy and their families, through many initiatives, becoming a model for similar Institutions throughout Latin America and the world.

In the past number of years, he has devoted his efforts to the development and approval at the PAHO Assembly in Washington, in 2010, of the Strategic Plan of Epilepsy for America and the Caribbean, with ILAE and PAHO representatives. While he has been involved in the implementation of this major plan, he is also currently directing the WHO Collaborating Centre for Education and Service Development for People with Epilepsy at LICHE.

Ambassador for Epilepsy Award

The Ambassador for Epilepsy Award is the oldest IBE/ILAE award, having been introduced in 1968. To date, a total of 325 worthy recipients have received an Ambassador pin to reflect international peer recognition and which is given for the lifetime of the recipient. Twelve Ambassadors will be presented with their awards at the congress in Bangkok in June 2019.

Amza Ali, Jamaica

Amza Ali is founding President of the Jamaican League Against Epilepsy (ILAE chapter) and the Jamaican Epilepsy Association (IBE chapter). His efforts saw the inclusion, in 2004, of epilepsy as one of the 14 chronic conditions covered by Jamaica's National Health Fund. He was responsible for creation of the region's first video-EEG monitoring unit and the establishment of a telemedicine facility (2011-2014) with linkage to Yale's Department of Neurology.

Sándor Beniczky, Denmark

Sándor Beniczky has been the coordinator of VIREPA teaching courses since 2014 and co-director of the Basic EEG course (2012-2018). He has been member of the ILAE Education Commission/Epilepsy-Education Taskforce since 2012, is a member of the ILAE certification taskforce, and participated in developing ILAE´s curriculum for epileptologists. In September 2018, he was appointed editor-in-chief of Epileptic Disorders, the Educational Journal of the ILAE.

Carol Camfield, Canada

A founder member of Epilepsy Nova Scotia, Carol Camfield is best known (with her husband) for developing a population-based cohort that includes every child who developed epilepsy in Nova Scotia 1977-85 with follow up for 20-35 years, providing unique insights on the medical and social evolution of epilepsy, applicable throughout the world. In recent years she has focused on the theme of transition from pediatric to adult care for youth with epilepsy.

Peter Camfield, Canada

Peter Camfield has worked closely throughout his career with Dr. Carol Camfield. He is passionate about international activities in epilepsy, particularly through teaching and clinical research. He has travelled to 24 different countries to teach about epilepsy and clinical research methods and to establish research collaborations. He was a member of the ILAE Commission on Outcome Measurement 1995-1997.

John Dunne, Australia

John Dunne is committed to promoting epilepsy in the Asian and Oceanic region and is chairman of the Asian Epilepsy Academy (ASEPA). He has been dedicated to bringing EEG teaching to countries across our region including China, Indonesia, Malaysia, Thailand, Timor Leste, Mongolia, Korea, India, Japan, The Philippines, Bangladesh, Laos and Viet Nam. In recognition of his commitment to training he was made a member of the *Faculty of Five Hundred.*

Sheryl Haut, USA

Sheryl Haut has pioneered initiatives that promote mentoring and leadership development in early- and mid-career epilepsy professionals globally and advancing the quality of health care for people with epilepsy internationally, through promoting partnerships and exchange of expertise across epilepsy centers in the Americas. She co-chairs the ILAE leadership development task force and was Chair of the ILAE North American Commission 2013-2017.

Presentation of Ambassador for Epilepsy Awards

The Ambassador for Epilepsy Awards, together with the Social Accomplishment and Lifetime Achievement Awards will be presented to these most deserving recipients, by the President of the IBE and the ILAE, during the Opening Ceremony of the 33rd International Epilepsy Congress in Bangkok on Saturday 22nd June 2019.

Matthias Koepp, UK

Matthias Koepp was appointed as Consultant Neurologist at the National Hospital for Neurology in 1999. In 2008, he was appointed Professor of Neurology at UCL Institute of Neurology. From 2005 to 2016 he was a member of the ILAE Commission on Diagnostic Methods, leading the Task Force on Neuroimaging from 2008-2012. This led to a position paper on MRI practice parameters and a neuroimaging course at Montreal Neurological Institute.

Marco Medina, Honduras

Marco Medina is professor in Neurology and Epileptology at the National Autonomous University of Honduras. Past chair of the ILAE Commission on Latin American Affairs, he is a member of the PAHO Plan of Action on Epilepsy task force and Director of the WHO Collaborating Center on epilepsy in Honduras. He is founding President of the ILAE chapter in Honduras and a member of Editorial Board of Epilepsia Open and has received numerous other awards.

Janet Mifsud, Malta

Janet Mifsud set up Caritas Malta Epilepsy Association (IBE) in 1996 and Epilepsy Society of Malta (ILAE) in 1997. She led epilepsy-related activities in Malta, including the introduction of epilepsy in the curriculum of several health care degrees.

She has worked in the epilepsy field at European and international levels, involved in several European Epilepsy Research projects and serving as IBE Vice President Europe for two terms.

Osman Miyanji, Kenya

Osman Miyanji is a Senior Consultant in Paediatrics and Paediatric Neurology in two of Kenya's leading hospitals. He is a founding volunteer director, Medical Advisor and Chairman of the Board of Directors at KAWE (IBE chapter). He has demonstrated that a sustainable epilepsy program can be run effectively in resource limited settings and is passionate about reducing the cost of treatment and making epilepsy care accessible to the poor and needy.

Tatsuya Tanaka, Japan

Tatsuya Tanaka was appointed Professor of Neurosurgery in Asahikawa Medical College in 1997, becoming Professor Emeritus in 2010, and was one of the most active leaders in epilepsy surgery in Japan. He pioneered the Japan Epilepsy Society (JES) scholarship system for young delegates in the Asian Oceanian countries to meet the gap in those underserved areas. He served as ILAE First Vice President and Chair of ILAE Commission on Asian & Oceanian Affairs.

Sanjeev Thomas, India

Sanjeev Thomas is a member of the ILAE Commissions on Medical Therapy of Epilepsy and on Women with Epilepsy (both 2017- 21). He is most widely known for his work for the women with epilepsy and the Kerala Registry of Epilepsy and Pregnancy. He promotes the training of neurologists from Africa and Asia in his Institute and has trained neurologists from Kenya, Bangladesh, Kuwait and Oman. He actively promotes epilepsy through public education.

A **Golden Opportunity** to recognise and award a young person affected by epilepsy in your chapter

Calling on all IBE chapters around the world to submit nominations for the International Golden Light Award, to be presented during the 33rd International Epilepsy Congress in Bangkok in June. The award recognises the contributions of people affected by epilepsy in their community and those who care for them. To be considered, candidates must be between 18 and 40 years of age on 1st January 2019 and be nominated by the IBE chapter in which they are involved. Each IBE chapter is entitled to nominate one person to be considered for the award.

Everyone selected for an International Golden Light Award will be presented with a trophy during the official Congress Opening Ceremony on Thursday 28th June in Bangkok.

Selection of candidates to receive an award will be made on a regional basis with one candidate from each region chosen, based on a written article and the supporting message from their chapter.

PRIZE ENTITLEMENTS

Each candidate will receive the following:

- International Golden Light trophy and scroll
- Return economy (coach) class travel to Bangkok, Thailand
- Accommodation at the congress
- Free congress registration
- Support for one accompanying person (if necessary).

Request a nomination form at annlittle@ibe-epilepsy.org

Closing date for nominations: Monday 25th March 2019

Hello, my name is Zhang Chensu. I was born in 1985, I am from Changchun, Jilin Province in China and I have epilepsy.

During the Spring Festival of 2015, I travelled to island of Hainan to meet with my family; my first visit to the South of China. However, due to the long journey and the sudden change of temperature (the climate in Hainan is tropical), I felt unwell and had a continuous low-level fever.

On the fourth day of the Chinese New Year celebrations, my body suddenly stiffened and twitched. I was sent to Sanya Agricultural Reclamation Hospital and where I was diagnosed with viral encephalitis, which induced epilepsy. Having no knowledge of epilepsy at that time, I experienced repeated seizures, which made me dizzy and sleepy all the time. The inflammation in the hippocampus of my brain also washed away several years of memories.

Fortunately, although in a strange city, my family never abandoned me and with their love, brought me back from death's

ANNUAL DUES 2019

The call for chapter dues for 2019 is about to be circulated. Dues payments are important in funding IBE activities and in helping us support members in disadvantaged regions.

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

This is also a final reminder to those chapters with outstanding dues to settle any such payments as soon as possible in order to safeguard their membership status.

Did you know that you can pay by PayPal? PayPal can be used with any credit card and is the easiest method for both the payer and the payee. 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**

More than 30 chapters based in developing countries continue to have their dues payments covered by the Solidarity Fund. When arranging 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.

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

Let us Bloom - Chensu's Story

door time after time. When my condition stabilized, my husband wheeled me back to Changchun. With a frenetic desire to cure my disease, my family went out of the way to seek treatment for me, which all came to nothing.

Later, I was lucky enough to come to the First Affiliated Hospital of Jilin University and to meet with Dr Lin Weihong and her team, who used excellent medical skills to stabilize my condition, and helped me regain confidence in life with the great love of doctors.

At that time, because of the lack of memory, the repeated illness, and my increasing knowledge of epilepsy, I was caught in desperate anxiety and despair about my disease. All I wanted was to escape from tomorrow, and I even thought of giving up on life. It was the meticulous care of my family and doctor Lin's team and their active and effective encouragement that helped to restore my confidence and rebuild a hope in life.

I stopped tangling with the missing pieces of memory and began to cherish the present. I actively participated in the Epilepsy Society set up by Dr Chen Yu, and became a key member of it. During this process, I established good friendship with many of the fellow patients. We shared secrets with each other, and encouraged each other to fight epilepsy with an optimistic attitude.

In the summer of 2017, I organized a patient gathering on the theme of "let us bloom," in which we performed with singing, a dancing display and a model show. The long-lost passion and fighting spirit of patients were rekindled, and self-confident laughter rang through the audience. We are lucky to have meet Dr Lin's team, and we are grateful for this special home for people with epilepsy, which has made us brand new people.

As my seizures became well-controlled, I started my own business in order to enrich myself. Taking advantage of my major, I became an English teacher. I have tried my best to help children fall in love with English and to grow happily. In turn, the children are also my teachers, whose innocence, courage and curiosity often inspire me. I also have a dream of becoming a painter, which may be due to my love of art since I was a child. Although I choose to study English when I was growing up, the artistic elements have been integrated into my blood. I believe that one day, I will pick up my brush again to depict my wonderful life in art form.

I am grateful about where I stand today, as I have reaped a lot from my illness. I have experienced the selfless love of my family and the doctors; I have harvested sincere love in the process of sharing hardship and suffering; and I have learned more about the preciousness of life. All these experiences make me believe that when God closes a door, somewhere he opens a window. I will strive to live a better life and give back to my family, friends and society.

Save the date!

33rd International Epilepsy Congress

Bangkok, June 22-26, 2019

General Assembly 2019

The IBE General Assembly 2019 will take place at the time of the 33rd International Epilepsy Congress in Bangkok.

Date: Tuesday 25th June

Time: 16:00 - 18:30

Venue: Centara Grand & Bangkok Convention Centre at CentralWorld

We hope to see you there!

And the Oscars go to….!

International Epilepsy Day Video Competition Results

Personal Story

First Prize:

- Linda Cambell (Scotland):
  Zoned Out (1)

Runners up:

- Farah (Fatemeh) Abbasi Siar (Iran):
  My Dream is a world without war (2)
- Ng, Wai Hung (Hong Kong):
  A Big Boy Story (3)
- Delyma Asnydar SS (Indonesia):
  A Sweet And Short Journey of An Epilepsy Warrior (4)
- Yvette Barrera-Molina (USA):
  Some Super Heros Fight Crime, Mine Fights Epilepsy (5)
- Jess McCallum (Australia):
  Jess McCallum She Beast (6)

Educational Video

1st Prize:

- Epilepsy Foundation (USA):
  Taking Charge of the Storm Jr. (7)

Runners up:

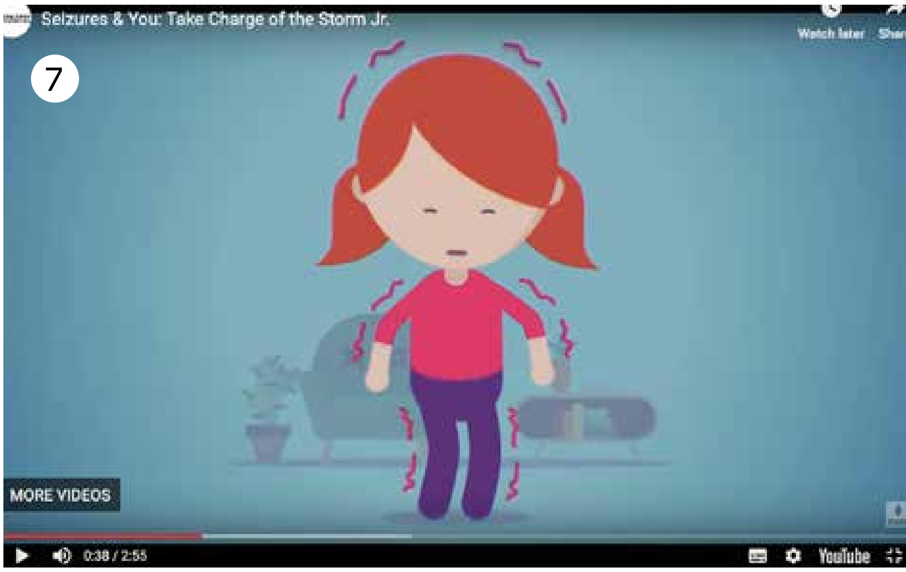
- Cairo University Epilepsy Unit (Egypt):
  Pregnancy Awareness (8)
- Norsk Epilepsiforbund (Norway):
  How to handle an epileptic seizure (9)
- Epilepsy Action (UK):
  Ali's story: taking my medicine (10)
- Youth on the Move (Kenya):
  Njambi's Tonic Seizure (11)
- China Bureau of Epilepsy (China):
  2018 Street Interview About Epilepsy in Shanghai (12)

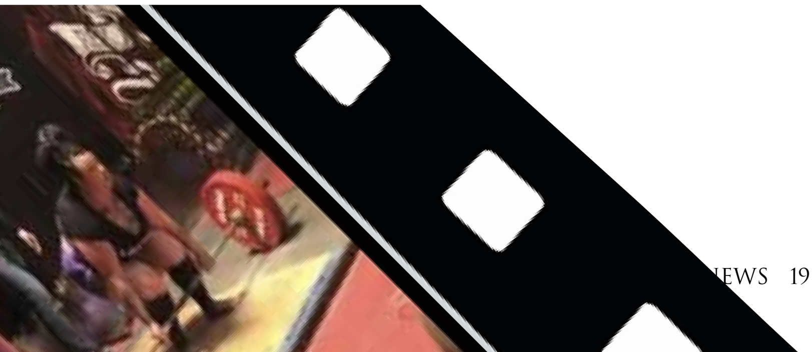
Thank you to all those who submitted short videos to our competition for International Epilepsy Day. There were two categories, Personal Story and Educational. First place in each category receives a prize of US$500, with five runners up in each category receiving US$100.

You can watch all the videos on these links:

You can view all **'Personal Story'** entries here: https://www.youtube.com/playlist?list=PLDtaVe7olIXygWvY-7fb9nRxkdcsS9uRbg.

You can view all **'Educational Video'** entries here: https://www.youtube.com/playlist?list=PLDtaVe7olIXzgS_uzzsnN2xe-7Flp-4diq.





International Epilepsy Day

MONDAY, 10 FEBRUARY 2020

CELEBRATED IN 120 COUNTRIES WORLDWIDE

www.internationalepilepsyday.org

After a very successful
International Epilepsy Day 2019,
let’s get ready for next year!