NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 2 2014

INTERNATIONAL Epilepsy News

1963-2014

Reporting epilepsy news for 51 *years*

Serene Low - talented artist

A Malawian Dream

Ebola in Sierra Leone

PRESIDENT'S LETTER

News, and more news!

Dear Friends

There's a lot of news to tell you about - some good, some promising, and some quite sad.

Starting with the good news: we have had two very important and successful congresses in the past few months - the Asian & Oceanian Epilepsy Congress in Singapore, and the Latin American Epilepsy Congress in Buenos Aires.

During the Opening Ceremony in Singapore, I was very pleased to present eight awards to very worthy Outstanding Persons with Epilepsy, who live busy and creative lives despite their epilepsy. These people are testament to a strong determination not to allow their epilepsy to dominate their lives.

The Latin American meeting is unique, since it is the only IBE-ILAE congress where almost all of the presentations are in Spanish. Nevertheless, this was a great opportunity to meet with IBE members and supporters from the region, especially during the meeting of the Latin American Regional Committee, where I also met people from Paraguay and Bolivia - two potential new IBE member associations!

In September, my home city of Athens was the venue for a meeting of the IBE International Executive Committee. There was much to discuss at this meeting, including the review of the Constitution which is being carried out by the Governance Task Force and which is expected to be ready for presentation to the General Assembly in Istanbul next September. We also discussed the review of IBE's Strategic Plan for the coming years and a small task force has been charged with this task.

Our Management Committee and the International Executive Committee will continue to communicate by conference calls and the next face-to-face meeting is due to take place in March 2015.

With much to promise in the future, a newly created Legislation Task Force, chaired by Hanneke de Boer, recently had its first conference call and will shortly present its plan of action. The task force will consider a number of issues including driving, employment and discrimination.

Also looking to the future, as you all know, we are busy preparing for the first International Epilepsy Day next February and I hope that all of you will play a part in celebrating this very important event. In the coming weeks and months you will be hearing much more about plans and preparations for next February's launch.

However, I must end on a sad note. You will all be aware of the horrific details of the Ebola disaster in West Africa and a report in this newsletter brings us news on how this has impacted on our member association in Sierra Leone. Our thoughts are with our friends in Sierra Leone and the other badly affected nations and we hope that the battle against the spread of the disease will shortly be won, before there are too many more unfortunate deaths.

With best wishes to all,

Athanasios Covanis
President

International Epilepsy News
Issue 2 - 2014

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).

In this issue

Dear Readers

What a bumper crop of news we have for you in this issue of IE News!

In August we celebrated the 10th Asian & Oceanian Epilepsy Congress in Singapore where eight very worthy recipients were presented with Outstanding Persons with Epilepsy Awards. From Australia, Malaysia, India, China, Japan, Singapore and Taiwan, each had demonstrated great determination to live fulfilled lives despite their epilepsy. We showcase one of the recipients in this issue of the magazine - Serene Low - whose artistic skills are truly remarkable.

From Japan comes news on driving regulations for people with epilepsy and the work of the Japan Epilepsy Association to ensure that any changes made are fair and appropriate.

Moving across continents to Africa, we are all very aware of the devastation that the Ebola virus is having in Liberia, Guinea, Sierra Leone, and Nigeria. Max Bangura from Sierra Leone tells us how the virus is affecting people with epilepsy in his country. Also from Africa come reports from Malawi, Madagascar and Zimbabwe.

From Europe, there are happier stories of the newly revived European Advocates for Epilepsy group in the European Parliament and, on a lighter note, a successful summer camp in Sweden.

Until next time - happy reading.

Ann Little
Editor

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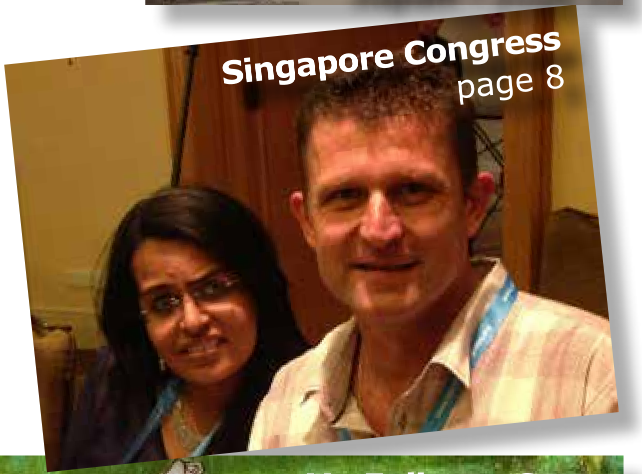
Driving Regulations in Japan - page 12



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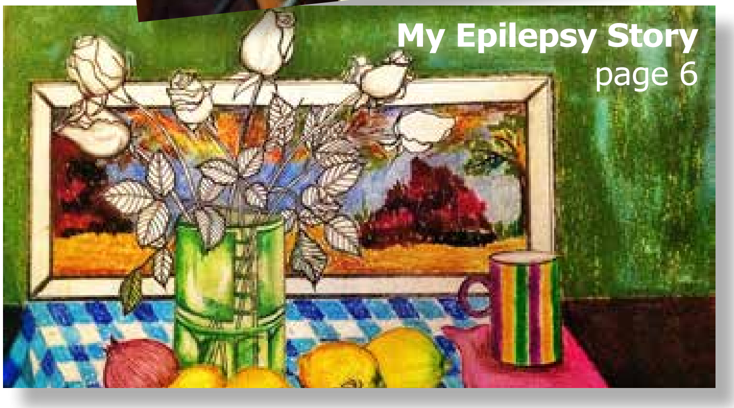

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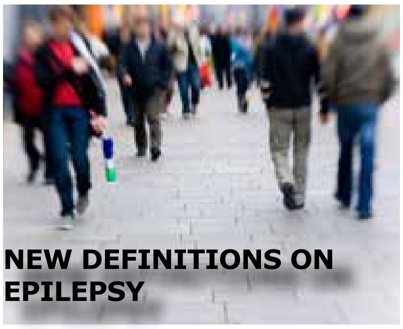
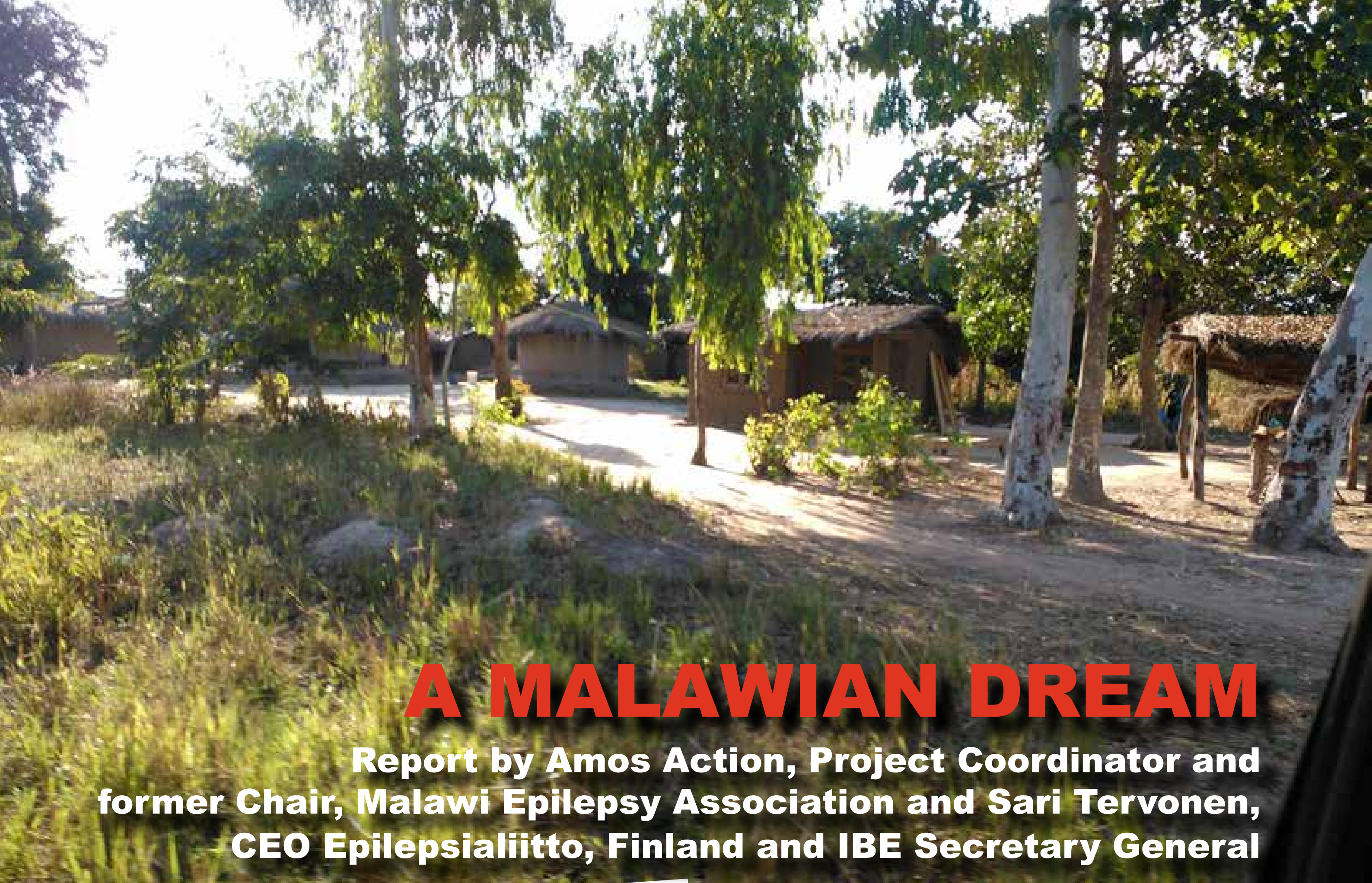
Coming in the next issue



NEW DEFINITIONS ON EPILEPSY

YOUNG ADULTS SUMMIT

MEMBERS SURVEY
What you told us!



A MALAWIAN DREAM

Report by Amos Action, Project Coordinator and former Chair, Malawi Epilepsy Association and Sari Tervonen, CEO Epilepsialiitto, Finland and IBE Secretary General

Martha Chilewe (pictured left with her mother), is now 18 years old and developed epilepsy at 18 months, as a result of malaria. When she was six years old she suffered a tonic-clonic seizure, with no further seizures until, at the age of 15 years, her epilepsy became severe. Martha, who lives with her mother and sister, became familiar with a traditional healer but, fortunately, a nurse convinced the family to use appropriate medical treatment. Martha has been bullied at school, but has not become despondent; she holds on to her dreams.

Malawians have a dream to give education to children and young people with epilepsy

In Malawi people with epilepsy are discriminated against, much like in Africa in general. It is very common that children with epilepsy do not attend school.

Because of prejudice and lack of medication people with epilepsy have no human rights. Even their own parents and family members are ashamed of their child´s epilepsy, and hide the child to prevent him or her having social contacts.

Malawi Epilepsy Association is running a project to support children and young people with epilepsy to go to school. Education is a way to make one´s dreams come true and an opportunity for integration into society.

The project is a joint initiative with the Finnish Epilepsy Association. It is funded by the Ministry of Foreign Affairs of Finland and by donations from Finnish people.

The project is taking place in four districts: Chikhwawa, Mulanje, Kalonga and Mchinji. In the project children and young people with epilepsy get together, and their families also have the chance to meet each other and share experiences.

In addition to this, school and village authorities are also trained about epilepsy. The teachers are mostly people with epilepsy and their family members who have been trained to tell about epilepsy; but there are also health care professionals involved in the project.

The project raises epilepsy awareness through story telling, dancing, drama and choral singing. The methods used are linked to aspects of Malawian culture. The most important thing is to find the children and young people with epilepsy in their homes in order to be able to assist them in going to school. In this work you need to start with a positive 'can do' attitude, knowing that epilepsy is not a reason to marginalize people.

The project is not directly involved in making AEDs available, but rather, through empowering people with epilepsy and their family members, it promotes advocacy for adequate epilepsy treatment.

Malawi is one of the poorest nations in the world and is located in sub Saharan Africa. The country became independent in 1964 and is a former British colony. The population is 17 million of which 85% live in rural areas. The healthcare structure is weak and there is lack of professionals. The biggest problem is availability and continuity of AEDs. It is estimated that 80% of people with epilepsy do not have access to AEDs.

Photo captions

Opposite page, main image: Traditional village in rural Malawi. Photo: Sari Tervonen

Opposit page: Martha Chilewe and her mother. Photo: Anna Tapanainen

Below: Busy market in Blantyre, Malawi's second largest city. Photo: Anna Tapanainen

My Epilepsy Story

Serene Low has an extraordinary artistic talent. She also has epilepsy and received an Outstanding Person with Epilepsy Award recently at the 10th Asian & Oceanian Epilepsy Congress in Singapore. Here she tells her story of life with epilepsy.

Pictured on the cover is *Tonic Clonic Electrical Brainstorm*. The painting above is called *White Roses* and below is a section of *Gloriously Stained*. Opposite: Serene attending the congress in Singapore.

I never knew what epilepsy was until, at the age of 18, my mom first told me a little bit about my epilepsy history. I was born a healthy baby. Still an infant I had my first seizure as a result of an extremely high fever. Thereafter I started to have more seizures that were always associated with a fever. Because of my parents' lack of knowledge about epilepsy, I never received treatment for my febrile seizures. Fortunately, I outgrew those febrile seizures at the age of seven.

Schooling years were great until I was in college. It was midterm break. My parents drove the family to a beach resort for a short stay. While there, one morning I was playing with my sisters in knee-deep water when a seizure knocked me down unconscious. My brother's friend sensed something was amiss when he saw me floating face down in the water for too long. He approached me and discovered I was motionless.

A group of friends quickly pulled

me out of the water and I was brought to a health clinic where I was resuscitated back to life. I was eventually told that I had narrowly escaped death from drowning.

After having gone through a series of EEG, CAT Scan and X-ray examinations, I was eventually diagnosed as suffering from generalized tonic-clonic seizures. With only some very vague ideas about epilepsy, life with epilepsy was a great torment. A lengthy and tedious trial period to find the right types of medication and correct dosages only made life much more unnerving and bitter.

My world had crumbled beyond repair. I lost all sense of direction in my life. "Epilepsy was a killer monster. A prowling monster that had preyed and devoured me for a hearty meal."

My personality changed drastically due to my epilepsy. My thoughts, emotions and behavior were mostly negative. I cried more than I smiled. I had suicidal thoughts. I became quieter than my usual quiet self. I became very withdrawn and lost all hope for further studies. My world was pitch black until I could not see anything left that was still worth living for.

I resented hospital visits. Without my parents' knowledge I threw away my medication. My seizures became more frequent. Even before old injuries could fully recover new injuries kept setting in. Each time I pulled out of a seizure I never failed to see distorted and blurry images of pairs of eyes staring at me. They were either medical people in a hospital or my parents and siblings or strangers.

"Oh, how I hated this thing called epilepsy. Why me? How come my other siblings didn't have it? It's just too unfair! My life was just starting to kick off and this thing is so crippling and a constant pain in the neck. My hopes and ambitions were dashed and wrecked. How on earth could I ever live normally again?"

Time passed and eventually I became tired of balking and wasting my life away. At 19 years of age, a lot of my school friends had made it into universities and that made me extremely sour about myself. "Wake up and move on or else it will be too late. I will be out of the race for good. Fight off epilepsy, Serene, fight! I know you can do it."

It was my fighting spirit that soon got me out of my epilepsy doldrums. Hospital visits became less daunting and my medication intake was strictly adhered to. My quest for a better understanding of epilepsy was made possible by my neurologist and I soon learned to accept my condition as an illness that can be well controlled with proper treatment.

I have come a long way with epilepsy. I have lived with it now for 36 years and this itself, in itself, is already testimony enough of a miraculous achievement, considering the times that I had cheated death as a result of seizures.

Wallowing in my own self pity and hiding in a cocoon will not make things any better for me and it was this simple reasoning that spurred me to stand out courageously in the open.

In order that others can know better about my condition and accept me for what I am, I decided to create an epilepsy blog. "Serene's Epilepsy Legacy" was officially formed in 2002. In April 2003, it was unanimously agreed that the Malaysia Association for Epilepsy (MSE) should form an epilepsy support group for its members. I was appointed the support group coordinator for up to five years. Up to now, I have remained active in creating epilepsy awareness, as it has already become as second nature to me.

My life with epilepsy has its colorful sides as well. On 28th of July 2014, I attended a book launch ceremony that was organized by The University of Melbourne, Australia. One of my paintings appeared in the book titled "Epilepsy - Perception, Imagination and Change." I am a self-taught artist and these few recent years have seen some of my art pieces being selected for art exhibitions.

I am an avid reader and I enjoy writing a lot. Some of my articles about epilepsy awareness have appeared in our English, Chinese and Bahasa Malaysia newspapers. I also enjoy writing poems and quotes.

Community work and fund raising activities are things that I have a passion for. I started initiating fund raising events at the age of 35. To name a few, I have raised funds for the National Kidney Foundation, The Salvation Army, Ci-Hang Old Folks Home, Society for the Severely Mentally Retarded, Mercy Malaysia, WWF, Asian Tsunami 2004, etc.

To sum up my life living with epilepsy, I would describe it as a life with no less happiness, joy, excitement, contentment and meaningful achievements. Our lives are really what we make them to be and one philosophy that I hold dear to my heart is written in my quote. "Be joyful in hope and patient in sufferings. Life with epilepsy is not without hope. Joyous hopes come about when we strive for positive changes."

10th Asian & Oceanian Epilepsy Congress, Singapore

Dr Derrick Chan, Scientific Organising Committee reports


Prof Lim Shih Hui, congress co-chair, addresses the Opening Ceremony

The 10th Asian Oceanian Epilepsy Congress was held in Singapore from 7th to 10th August 2014. The Congress was attended by 1,306 delegates from 48 countries.

The programme covered a broad range of topics selected from recommendations across the region and featured eminent speakers from the region and around the world. A total of 400 abstracts were submitted from centres from across Asia and Oceania and from as far as Russia and USA. The subjects ranged from cutting edge basic science to critical community and epidemiological work.

The opening ceremony was framed by videos highlighting the uniqueness of Singapore culture and diversity. An entertaining explanation of the conference logo by the Co-chair Prof Lim Shih Hui was followed by remarks by CAOA Chair Dr Lee Byung-In, Co-Chair IBE Dr Vinod Saxena, the ILAE President, Prof Emilio Perucca, IBE President Dr Athanasios Covanis and IBE Treasurer Mr Robert Cole. The Asian and Oceanian Outstanding Achievement Epilepsy Awards and the Outstanding Persons with Epilepsy Awards were handed out to recipients from across the region.

ASEPA didactic lectures led off each day, underlining the educational mission component. Two excellent symposia on neuro imaging and structural and metabolic causes of epilepsy were followed by the Chairman's session on anticonvulsant tolerance and resistance. The Seino memorial lecture was delivered by Prof Samuel Berkovic, who shared his insights into the impact and future of genetics in epilepsy.

Main sessions ranged from the burden of epilepsy and neurostimulation in epilepsy to neurophysiological markers of the epileptogenic zone. The post-main and parallel sessions covered anticonvulsant cost, side effects and generics, psychiatry and mortality in epilepsy, epilepsy surgery in Asia, epilepsy in the elderly and children, seizures and epilepsy due to inflammation and infections and prospective therapies for epilepsy.

The Tournament of Brainwaves quiz was engaging and pitted teams from across the region against each other in friendly rivalry. Amongst the audience, unofficial groups also vied for the correct answers. The debate sessions on relevance of AED mechanism in epilepsy treatment and epilepsy surgery in non-lesional epilepsy were cordial and spirited.

A total of 5 satellite symposia were held, ranging from MEG to newer anticonvulsants to community initiatives in developing countries in the region. Many business meetings were held, notably those of the IBE Western Pacific and South East Asian regions of the IBE and the ILAE Commission of Asian and Oceanian Affairs. The IBE Editors Network also had the opportunity to meet up and exchange news and experiences.

From Singapore, Ming Ying Goi, who spoke with great positivity about living with epilepsy at the Epilepsy & Society Forum, with Diana Koh and Sherman Goh

Meeting of the IBE Western Pacific Regional Committee

Delegates attending the Epilepsy & Society Symposium enjoy playing the IBE Action Zone Game during the Mini Fair held at the end of the symposium

Shenaz Haveliwala, India and Robert Wierzbicki, Australia, who both received Outstanding Person with Epilepsy Awards at the congress in Singapore

Platform sessions were of good quality with many countries represented. The posters filled the exhibition rooms to capacity and a wide range of topics were on display. From such a field of important and quality work, it was necessary to choose recipients for the Takadoro prize, which was awarded to two platforms and two posters.

The Epilepsy & Society Symposium saw 190 attendees from Singapore and across the region. Recognizing that epilepsy is a condition that impacts the entire family, a family rate was introduced to facilitate attendance of the entire family unit.

Topics ranged from anticonvulsants to stigma at work and school, and the truth about reflexology and stem cell therapy for epilepsy, as well as heartfelt sharing from people with epilepsy and caregivers. The symposium was rounded off with a Minifair. Booths showcased seizure first aid guidance, educational games stations, cognitive and behavioural strategies in epilepsy and videos from IBE groups around the region.

Fun was also to be had, with balloon animals, a lucky dip, exercise station, street artist and back massage stations, funded by a generous grant from the Singapore Epilepsy Society and gifts from the Singapore Epilepsy Foundation.

Volunteers from the Singapore General Hospital, KK Women's and Children's Hospital, Tan Tock Seng Hospital and Singapore Epilepsy Foundation generously donated their time and effort to make it an enriching experience for all.

Many opportunities for discussion and networking were made, friendships renewed and new acquaintances made.

A highlight of the meeting was the evening of the 9th August. Delegates venturing to the quayside were treated to the fireworks display crowning Singapore's National Day celebrations.

Ann Little, IBE Executive Director, Dr Derrick Chan, a Member of the Congress Scientific Committee, and Denise Chapman, Chair of the IBE Western Pacific Regional Committee

Delegates from Indonesia, Malaysia and the Philippines, enjoy the Boat Ride to Clarke Quay to watch the fireworks display for Singapore's National Day

Joint purchasing of vaccines and medicines becomes a reality in the EU

Paola Testori-Coggi, European Union Director General for Health and Consumers announces important new agreement

The signing by European Health Ministers of the Joint Procurement Agreement for Medical Countermeasures, at the Council meeting on 20th June in Luxembourg, marks a new achievement in the work of the European Council to protect European citizens from cross-border health threats such as communicable diseases.

The Joint Procurement Agreement defines the framework for common purchases and enables European Union (EU) countries to procure pandemic vaccines and other medical countermeasures as a group, rather than individually. Through the united strength of the signatories, Joint Procurements make it possible for Member States to ensure that pandemic vaccines and medicines are available in sufficient quantities - and at fair prices - should a cross border health threat emerge.

Mrs Testori-Coggi reported that "the mechanism will benefit all EU countries, in particular those which encountered difficulties in purchasing vaccines developed for the H1N1 pandemic in 2009. Indeed, it was this pandemic, and the lessons learned from it, which prompted the European Commission to take action on this front."

Mrs Testori-Coggi went on to say that the Agreement would reach well beyond vaccines for pandemics and that Member States could benefit from extending the agreement to cover the purchase of medical countermeasures for other diseases. While the original intention is for the Agreement to cover infectious diseases, it would greatly benefit people with epilepsy if this could also be extended to chronic diseases, especially for those people who must pay for their medication and in situations where there are regular shortages of prescribed medication.

The Agreement is strictly voluntary and, while there is no compulsion for Member States to sign up, to date 14 EU countries have committed to this ground-breaking measure. An additional eight countries have agreed to sign a letter of intent with a view to signing the Joint Procurement Agreement in the future.

Mission to Madagascar

Edycs Epilepsy Group Mauritus pays a visit to Tsiry Signe de Foi, an ONG (NGO) association in Madagascar

Report: Youssouf Noormamode, Edycs President and Chair, IBE African Regional Executive Committee

Youssouf Noormamode, President Edycs Epilepsy Group Mauritius and Chair of the IBE African Regional Committee was on official mission to Madagascar in Antananarivo to establish links and collaboration with a local based NGO, known as Tsiry Signe de Foi, located in Anosibe West, with a view to expanding the scope of epilepsy promotion within the region and the creation of an 'Epilepsy Core Unit' in line with the International Bureau for Epilepsy African Regional Committee mandate.

This initiative is also embraced by the European Union Decentralised Cooperation Programme (DCP), following the DCP 2014 Non-State Actors (NSA) Regional Networking Conference, held on March 2014, at Le Preskil Hotel, Mahebourg, Mauritius.

All those attending the conference, including Edycs Epilepsy Group, pledged to network with NSAs from the Union of Comores, Madagascar, Reunion Island, Seychelles, Mauritius and Rodrigues in the Disabilities/Community Health sector.

On Friday 5th September, a first meeting was held at the seat of Tsiry Signe de Foi, attended by Youssouf Noormamode; Mrs Raholisoanirina Jeanne Marie Monique, Project Coordinator; Rakotoarisoa Rina, Technical Assistant; and Rakotomalala Andriantsoa, Trainer at Tsiry Signe de Foi; at which the basis for collaboration and action based programmes in epilepsy was outlined.

On Monday 8th September, a second meeting took place in the same venue with the President of Tsiry Signe de Foi, Andriamanehoarivoivy Philibert Philippe Ignace, at which time a memorandum of understanding was mutually agreed and signed covering the following areas of intervention:

- Opening of an Epilepsy Office within the Tsiry Signe de Foi Headquarters to coordinate and implement epilepsy actions and programs with support funding from funders through Edycs Epilepsy Group;
- Recruitment and appointment of a full time Program Facilitator to implement and monitor epilepsy action based programs through Edycs Epilepsy Group;
- Research in epilepsy through registration call of patients in Anosibe West;
- Training of Staff and Non-Staff in Epilepsy Management;
- Local sensitization programs in epilepsy – street marches, exhibitions, radio programs;
- Production of epilepsy promotional materials (brochures, pamphlets, etc.)

IBE hopes to welcome Tsiry Signe de Goi as a new member in the not too distant future and is grateful to Mr Noormamode for his support and encouragement to the Madagasy association.

Malagasy people crossing the river by the wooden bridge near Maroantsetra in eastern Madagascar. Photo: iStockphoto

Amendment to Road Traffic Act and criminal law in Japan

Report by Dr Hidemoto Kubota

Tokyo city traffic
Photo: Ann Little

In April 2011, a driver who was not fit to drive caused a traffic accident and killed six elementary school children. The driver, who had epilepsy, had a seizure while driving a crane truck on the road.

After the accident, national sentiment towards traffic accidents caused by people with such diseases as epilepsy worsened. Many people with epilepsy felt uncomfortable about the sentiment, but observed it quietly because that they were afraid of rejection by society.

The existing driver's license system evoked a sense of distrust of people with epilepsy as drivers, because some drivers do not report their illness when applying for, or renewing, licenses and the law sets no punishment for such violations.

Then a Diet committee began discussing a toughening of Road Traffic Laws for people suffering from such diseases as epilepsy, schizophrenia, sleep disorders, dementia, and alcohol and drug addiction.

The discussions are described below:

- People who make false reports about their illness will be jailed for up to one year or fined up to ¥300,000.
- Allow doctors to voluntarily report to public safety commissions on drivers who continue driving in spite of advice not to drive.
- If a driver who is not fit to drive causes a traffic accident, due to his or her illness, the accident shall be deemed to be intentional and not accidental. The driver will then be imposed a penalty as severe as that for a drunk driver.

Japan Epilepsy Association (JEA) has been given an opportunity to make a presentation to the party's Policy Committee and to present to a panel of experts set up by the NPA. Also, JEA has provided information through the media as necessary. Statements are described below:

- The likelihood of drivers with epilepsy or other disease causing traffic accidents is less than that for healthy people. However, reducing to zero the number of accidents caused only by people with disease must be seen as discrimination. Furthermore, it is also discrimination that the Road Traffic Law has designated such diseases as epilepsy, schizophrenia, sleep disorders, dementia, and alcohol and drug addiction without medical basis.
- Since 70% of people with epilepsy don't know the driver's license system in which illness is reported when applying for or renewing a license, it is necessary to provide information before making such new rules that involve severe penalties.
- Voluntary reporting on patients by doctors may destroy trustful relationship between doctors and patients. Or, patients may stop visiting doctors and may make false reports about their medical condition. The system must be adopted with highest caution.
- Special treatment for those who are not eligible for driving, including deductions or exemptions on public transport fares, not only for people with epilepsy but for elderly or other persons who have difficulty in mobility, and developing automated vehicles, are needed.

In order to understand the above claims, JEA has held a joint symposium with Japan Epilepsy Society (JES,) and has collected more than 20,000 signatures, in the space of a few weeks, from disability organisations that are against the new law under discussion. As JEA had

If a driver, who is not fit to drive, causes a traffic accident due to his or her illness, the accident shall be deemed to be intentional and not accidental. The driver will then be imposed a penalty as severe as that for a drunk driver.

provided accurate information on people with epilepsy to lawmakers who show understanding about epilepsy, JEA had an opportunity to express its opinion in a Diet. A survey on public attitude on epilepsy has been conducted. The last such survey was conducted in 1998.

Finally, new laws have been passed in draft with these additional resolutions.

Additional resolutions are described below:

- To prevent discrimination because of the disease;
- Medical questionnaire should be changed to be more clear;
- Consultation office should be well prepared;
- Support for education, employment and social life should be promoted for persons whose rights to drive are restricted;
- Protect the right of these persons
- Promote research on the disease and guidelines should follow the progress of medicine;
- Re-evaluate the guideline every five years.

Unfortunately, the bills have been passed in the Diet. However, the understanding of epilepsy is growing step by step among Diet members.

Right now JEA is conducting research on means of mobility for people with epilepsy who are not fit to drive and on the influence which the revised Road Traffic Law has made to the lives of people with epilepsy.

Final call for dues payments 2014!

Has your association arranged payment of annual dues for 2014? If not, then time is running out to remain in good standing with your IBE membership. Failure to pay annual dues on time could jeopardise membership. And making a payment could not be easier. Just go to www.ibe-epilepsy.org/

Please also consider making a donation to the Solidarity Fund so that we can expand the support we provide to members in developing nations. Even small donations can make a difference.

Effects of Ebola on projects of the Epilepsy Association Sierra Leone

While the world watches with both horror and sorrow as the Ebola pandemic takes greater hold on Guinea, Liberia and Sierra Leone, in particular, and with new cases now being reported in Europe and the USA, Epilepsy Association of Sierra Leone reports on how the devastating virus is causing serious disruption to the treatment and care of people with epilepsy.

Max Bangura, National Coordinator, Epilepsy Association of Sierra Leone (EASL) sent IE News this report

Background

In March 2014, a rapidly growing outbreak of Ebola started in forested areas of south eastern Guinea, Liberia and Sierra Leone. Ebola virus disease (also known as Ebola hemorrhagic fever) is a rare and deadly disease that is spread by direct contact with a sick person's blood or body fluids. It is also spread by contact with contaminated objects or infected animals.

Symptoms of Ebola include fever, headache, joint and muscle aches, sore throat, and weakness, followed by diarrhoea, vomiting, and stomach pain. Skin rash, red eyes, and internal and external bleeding may be seen in some patients.

Current situation

As of October 8th, the cumulative number of cases in Guinea, Sierra Leone, Liberia, Senegal and Nigeria stands at 8,032 with 3,864 deaths. Distribution and classification are as follows:

- Guinea - 1,298 cases
  - 1,044 confirmed cases
  - 180 probable cases
  - 74 suspected cases
  - 768 deaths in total;
- Liberia - 3,924 cases
  - 941 confirmed
  - 1,795 probable,
  - 1,188 suspected
  - 2,210 deaths; in total
- Nigeria - 20 cases
  - 19 confirmed,
  - 1 probable
  - 8 deaths in total;
- Sierra Leone - 2,789 cases
  - 2,455 confirmed
  - 37 probable
  - 297 suspected)
  - 879 deaths in total.

(Note: this report was submitted in mid-August but the statistics have been updated by the Editor from figures included in the most recent WHO Ebola Response Roadmap dated 8th October 2014. http://apps.who.int/iris/bitstream/10665/136020/1/roadmapsitrep_8Oct2014_eng.pdf?ua=1.

The government of Sierra Leone has recently instituted better measures to combat the spread of Ebola, some of which will likely impact on the implementation of many projects in the country. These include:

- Instituted restrictions on public and other mass gatherings,
- Instituted quarantine measures for communities affected by Ebola - travel in and out of those communities is restricted until a medical team clears them.

Nevertheless, 296 Volunteers have been trained to conduct contact tracing and ensure immediate evacuation of suspected cases of Ebola from the communities.

Effect on EASL projects

Epilepsy Association of Sierra Leone (EASL) trained and positioned 13 Epilepsy Support Workers in all districts in Sierra Leone to advise and support families and persons with epilepsy and to carry out awareness raising campaigns to debunk the myth associated with the disease, alongside increased access to clinical treatment to those affected.

The death of a prominent nurse in the hospital, who died of Ebola, caused more panic

All trained health workers in the districts, who are involved as focal persons for the distribution of anti-epileptic medication, are in place, with the exception of two health workers (Mr Moray Belewa attached to the peripheral health unit at Malema Cheifdom in Kailahun district and Mr Alex G. Mogboi attached to the Kenema Government Hospital) both of whom died in July 2014 as a result of their contact with the disease. A Community Health Worker to replace Alex has already been identified but she has not received training for epilepsy work while the replacement for the Public Health Unit at Malema chiefdom has not been identified.

15 patients came for the July 19th AED distribution, where often we would see hundreds

The Community Health Officers (CHO) involved in our Comic Relief supported project continue with their outreach work to all the districts with the exception of Kailahun and Kenema District whose travel in and out is currently quarantined as an epicentre of the Ebola outbreak.

With Kenema, the International Committee of the Red Cross (ICRC) is in the process of relocating the Ebola isolation unit from the Kenema Government Hospital to another location outside the town. This may result in Kenema being cleared for right of entry.

The District Epilepsy Support Workers currently remain in their respective districts to advise and support patients and their families. Of the 13 DESWs, only the one based in Bombali District reported receiving training on Ebola awareness-raising.

The training was conducted by Caritas and by the Primary Health Care unit of the Ministry of Health and Sanitation team in the District.

EASL operates in Government owned health facilities countrywide to sensitise and dispense antiepileptic medication to persons with epilepsy. It is reported that, generally, people tend to avoid all health facilities known to have had Ebola cases whether suspected or confirmed.

The Ebola crisis has made persons with epilepsy afraid to come to the Kenema Government Hospital to receive their medications. As a result, it is reported that only 15 patients came for the 19th July antiepileptic drug distribution where we often see hundreds. The death of a prominent nurse working in the hospital, who died of Ebola, caused more panic and outrage from the Kenema inhabitants, who demanded that the Ebola units be removed from Kenema.

The news spread to other areas prompting the distribution of antiepileptic drugs to be postponed, which eventually affected our supply schedule. There is great difficulty in getting the anti-epileptic drugs from Freetown, the capital city, as a result of the cautionary restriction of movements to these districts by our CHOs.

Challenges

As a result of the cautionary restriction to the quarantined areas where Ebola has been identified, particularly the epicentre of the outbreak (Kailahun and Kenema) in Sierra Leone, movement of staff, drugs and reporting activities are not recommended. Patients in Kenema and Kailahun are at risk of getting recurrent seizures, which should be avoided at a time of an Ebola crisis.

With the exception of the District Epilepsy Support Workers (DESW) in Bombali, who received some training, the DESWs in the other districts feel inadequate to respond to questions being asked by their patients regarding Ebola.

For EASL staff operating from government facilities, where the risk of contracting Ebola is higher, the lack of personal protection equipment and materials is a major worry.

Conclusion and EASL Recommendations

As at this point, the only major hit operational areas in Sierra Leone are Kailahun and Kenema. However, the following actions can be put in place:

- A link with ICRC, for example, can be explored to get the drugs to Kailahun and Kenema as an interim measure until the restriction on travels to these communities is lifted. It is hoped that this linkage can be facilitated abroad.
- Basic personal protection equipment and materials provided for all EASL staff, office and clients.
- Basic training on Ebola prevention and response to be given to all EASL staff.

SHARE YOUR NEWS

Do you have news from your association that you would like to share with IE News readers? Please submit your news articles, reports and photos for future publication. All material is welcome and should be sent to ibeexecdir@eircom.net. Please send any photos in high resolution and as separate image files.

Happiness Laughter Fellowship and Solidarity!

Susanne Lund writes about a successful Swedish summer camp

Young people with epilepsy are of major focus within the Swedish Epilepsy Association. For a 15th year the Swedish Epilepsy Association organised a well-attended summer camp - or "Summercramp" as the youngsters themselves call it - for young people with epilepsy.

Due to external funding of one million Swedish krona, received annually for a period of three years, the association was able to welcome an increased number of participants this year.

- We are happy not to have to refuse anyone who needs to get away, to share experiences and to meet other young people who have seizures, says Margaretha Andersson, Vice President of the Swedish Epilepsy Association.

As many of the young people have severe epilepsy, the plans and preparations are worked on very carefully by the youth section in Sweden, with Mrs Anna Eksell having chief responsibility for this. It is about being a step forward - to have everything under control, to offer nice challenges with a lot of activities and with staff on hand to ensure safety.

A vital part of the camp is to have fun, to be safe and relaxed with no fear of having seizures. If seizures occur, and they do, they will be taken care of by experienced leaders. The parents need to be at ease knowing that their young people will be in good hands. No parents are allowed at the camp, but the leaders stay in contact, if needed. The underlying aim is to encourage the young people to be independent and to rely in their own abilities.

A colourful bouquet of activities was offered, both indoors and outdoors; for example team activities to increase self-esteem and build confidence, painting, playing ball, conversations, games, disco and dance, etc.

A wonderful part of the camp is that every participant has to write something positive about each person in the group. At the end of the camp every individual will have a heavy pile of notes in their bag, as they head back home, with appreciative words written about them.

- That is really a boost for self-confidence! Why don't we use this very nice simple way of sharing positive images, in the family, at work, in the epilepsy movement and elsewhere in life?, says Susanne Lund, Chief Executive of the Swedish Epilepsy Association.

MEP Group Revived

When the term of the previous European Parliament ended earlier this year, with its last meeting having taken place on 1st April, membership of the European Advocates for Epilepsy Group stood at just under 50 MEPs. Membership had been built up gradually since the group was first created by former MEP, Gay Mitchell in early 2011.

Since the formation of the advocates group, epilepsy has enjoyed greatly increased exposure in the heart of Europe, with annual events to celebrate European Epilepsy Day; with the successful passing of the European Written Declaration on Epilepsy; and with important meetings with the EU Commissioners for Health and for Research.

The group also helped in highlighting the urgent need for increased funding in epilepsy, which saw an increase of 36 million euro for epilepsy-related research programmes in the final round of the EU 7th Framework Programme.

When the results of the elections were announced across Europe, it showed that just 50% of standing MEPs had been successfully re-elected - although, in some countries, due to public unrest at austerity measures put in place to address recessions, this figure was much lower. In line with election results, it became clear that just 50% of the members of the Advocates Group would be returning to Brussels. In addition, prior to the elections themselves, Gay Mitchell had announced his decision to retire from politics.

The good news is that we now have a new President of the Advocates Group - Brian Hayes MEP, from Ireland. Mr Hayes was elected at the first meeting of the new group, which was called by Heinz Becker MEP on 10th September. On assuming the chair, Mr Hayes paid tribute to the work undertaken by the previous group under the chairmanship of Gay Mitchell and added that efforts would now get underway to build up membership to at least its former size or, better still, to exceed that number.

In increasing membership of the Advocates Group, IBE's greatest asset is its membership in EU Member States, those very people who have voted the MEPs into power. IBE is now calling on all of its Members based in EU Member States to contact their local MEPs to encourage them to join, or support, the Advocates Group.

The IBE office is happy to provide MEP lists by country with contact details and can also assist in drafting emails and messages. If you know of any MEP willing to join the group, please send the details to the IBE office ibeexecdir@eircom.net or directly to the office of Brian Hayes MEP brain.hayes@europarl.europa.eu.

In the meantime, plans are in being put in place to celebrate the 1st International Epilepsy Day in the parliament in Strasbourg, starting on Monday 9th February and running throughout the week. A highlight event and reception will take place on Tuesday 10th February and it is hoped that the event will be at least as successful as in previous years. The events will be hosted by the European Advocates for Epilepsy Group.

Pictured above at the first meeting of the new Advocates Group in Brussels are, from left:

Chantal Depondt (Belgium), member of the ILAE/IBE Joint Task Force in Europe; Philippe Ryvlin (France) and Thanos Covanis (Greece), co-chairs of the ILAE/IBE Joint Task Force; Marian Harkin MEP (Ireland) and Seán Kelly MEP (Ireland), both members of the Advocates group; Brian Hayes MEP (Ireland), President of the Advocates group; and Ann Little, IBE Executive Director and Secretariat to the Joint Task Force and the Advocates Group.

Myths and Perceptions in Rural Zimbabwe

As part of his academic study at Bindura University in Zimbabwe, Jacob Mugumbate, together with Jane Mushonga (a Rehabilitation Technician at Murambinda Mission Hospital, Buhera), carried out a study of villagers in Buhera District to measure myths, perceptions and incorrect knowledge on epilepsy. The study was published in full in the journal Epilepsy & Behavior. Jacob Mugumbate explains.

In 2012, we carried out a study on epilepsy. The aim of this study was to assess the myths, perceptions and incorrect knowledge that people in Buhera Rural District harbour about epilepsy. It supported Epilepsy Support Foundation of Zimbabwe's attempt to reach out to rural communities.

The study was a follow up to Epilepsy Support Foundation's (ESF) first Promising Strategy Project that focused on rural awareness in Buhera.

It was conducted amongst people living with epilepsy (n=100) using a standardised questionnaire that was developed after two focus group discussions with village health workers (n=20) and interviews with key informants. Each respondent was interviewed during his or her monthly visit to Murambinda Mission Hospital.

Focus group discussions and interviews identified 32 types of myths, perceptions and incorrect knowledge relating to causes, prevention, treatment and effects of epilepsy.

Most of the respondents agreed that epilepsy is a misunderstood condition that has stigmatising myths, perceptions and incorrect knowledge surrounding it.

The study concludes that these myths, perceptions and incorrect knowledge are a hindrance to the aim of reducing the treatment gap in Buhera, Zimbabwe and that desired quality of life for people with epilepsy can only be achieved after imparting accurate understanding of epilepsy in rural communities.

The table opposite summarises the results. It shows the type of MPIK and the number of people who confirmed it existed. This number is also confirmed as a percentage.

Reference:

Epilepsy & Behavior 27 (2013) 144–147

Form of myth, perception and incorrect knowledge	*No. of respondents who confirmed existence*		*Total (%)*
	Males (n)	*Females (n)*	
Cause of epilepsy			
1. *Epilepsy is from ancestors*	*30*	*50*	*80*
2. *Epilepsy is hereditary*	*31*	*58*	*89*
3. *Epilepsy is contagious or infectious*	*33*	*55*	*88*
4. *PLWE are cursed or punished for their sins or those of others.*	*35*	*45*	*80*
5. *Body fluids can transmit epilepsy*	*34*	*50*	*84*
6. *Body smells can transmit epilepsy*	*34*	*52*	*86*
7. *Body contact can transmit epilepsy*	*34*	*52*	*86*
8. *Sexual conduct can transmit epilepsy*	*33*	*50*	*83*
Prevention of epilepsy or seizures			
9. *PLWE should not eat beans or cow beans*	*38*	*46*	*84*
10. *PLWE should not eat chicken*	*33*	*47*	*80*
11. *PLWE should not eat liver*	*2*	*5*	*7*
Treatment of epilepsy and control			
12. *Epilepsy is not treatable*	*40*	*56*	*96*
13. *If PLWE is burnt by a fire, it is no longer possible to treat them*	*30*	*50*	*80*
14. *Tanganda (popular local tea) treats epilepsy*	*3*	*1*	*4*
15. *Surf (washing powder) treats epilepsy*	*2*	*1*	*3*
16. *Vomiting stops epilepsy*	*0*	*1*	*1*
17. *A root found beneath a fallen 'damba'* (local fruit) *treats epilepsy*	*0*	*1*	*1*
18. *Epilepsy is caused by witches*	*34*	*50*	*84*
19. *If PLWE eats eggs, treatment will not work*	*1*	*4*	*5*
20. *Don't move the person in a fit even if they are in danger because they will die*	*33*	*45*	*78*
21. *If PLWE defecates/urinates on self they will not be cured*	*37*	*55*	*92*
22. *Epilepsy medicines resultantly kill PLWE*	*30*	*43*	*73*
23. *You cannot combine epilepsy medicines with alternative treatment*	*34*	*56*	*90*
24. *Epilepsy can only be managed traditionally*	*37*	*56*	*83*
Effects of epilepsy			
25. *A PLWE will bear children with epilepsy*	*20*	*20*	*40*
26. *A PLWE will not bear children*	*23*	*23*	*46*
27. *PLWE can't watch TV*	*0*	*1*	*1*
28. *PLWE should not marry*	*30*	*56*	*86*
29. *PLWE should not go to school*	*5*	*13*	*18*
30. *People with epilepsy are lazy*	*10*	*23*	*33*
31. *People with epilepsy are mad*	*35*	*55*	*90*
32. *People with epilepsy will not succeed in life*	*30*	*50*	*80*

PLWE: People living with epilepsy

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