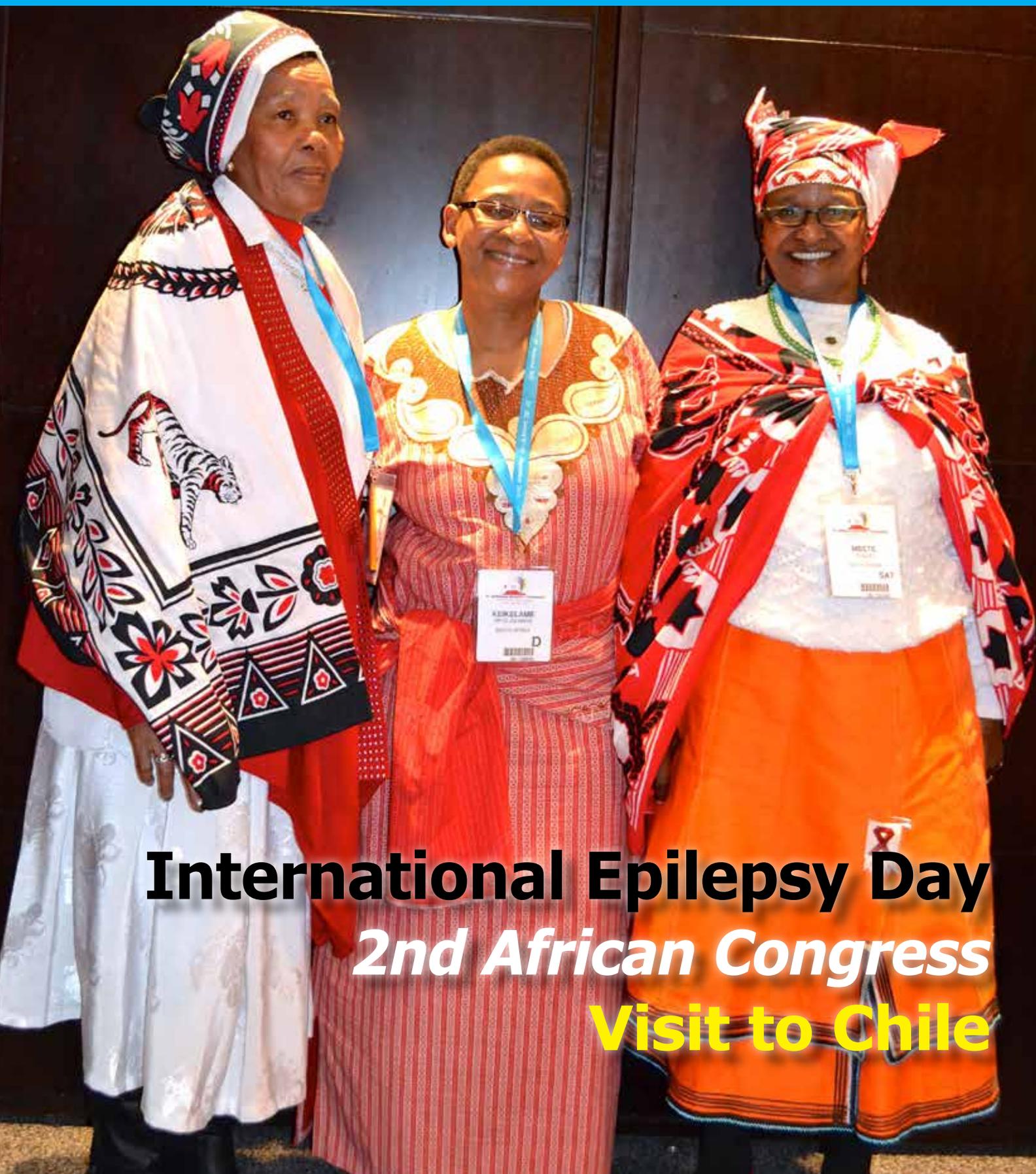


INTERNATIONAL

# Epilepsy News

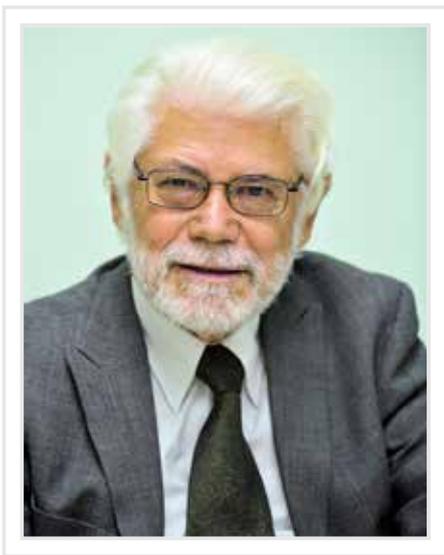
Reporting epilepsy news for 51 years

1963-2014



**International Epilepsy Day**  
**2nd African Congress**  
**Visit to Chile**

# PRESIDENT'S LETTER



Dear Friends

After years of discussion and effort, it is with great pleasure that I am able to announce the launch of an international day for epilepsy, as a new joint initiative of the International Bureau for Epilepsy with the support of the International League Against Epilepsy. As many of you will know, it has taken us a long time to reach this point. And why, you might ask? Probably the biggest single issue has been to try to find a date that will suit as many of us as possible - with the knowledge that we are never going to succeed in finding the perfect solution. Selecting a date for European Epilepsy Day was a much easier task, since our seasons are in line and school holidays happen around the same time. But when we look for a world day, this is a different matter entirely.

I am sure that some of you will struggle with the chosen date - the 2nd Monday in February - but I hope that you will be able to mark the event in some way in your country so that, together, we can raise awareness on the problems of epilepsy and the need for improved services and increased research on all aspects of epilepsy, from prevalence studies to new treatments; and from better legislation to improved care programs.

In the coming months we will be bringing you news of our plans for the launch next year and I hope that you will be as excited as we are in what we might achieve in our joint efforts.

Apart from finalising the date for International Epilepsy Day, in discussion with our partner ILAE, we have been busy on

## Bringing you good news!

a number of other epilepsy-related matters and activities.

The 2nd African Epilepsy Congress in Cape Town in May was a great success, with 300 delegates attending every single session. The African Regional Committee also had the opportunity to meet and discuss some very interesting plans for the coming three years.

Not resting on our laurels, already we are getting ready for the 10th Asian & Oceanian Epilepsy Congress, which takes place in Singapore in August. At the congress IBE will present the regional Outstanding Persons with Epilepsy Awards and there will also be the Epilepsy & Society Program on which Denise Chapman, Derrick Chan, Kathryn Hodgson and Ann Little are working hard.

The Joint Task Force, Epilepsy Advocacy Europe, is preparing for European Epilepsy Day (which will now fall in tandem with International Epilepsy Day). The theme will be *Epilepsy is more than Seizures*, which proved successful this year.

Sari Tervonen, IBE Secretary General, has been arranging the recent IBE Members Survey, the responses to which will be closely considered by the International Executive Committee when it meets in September to draft IBE's strategy for the next five years. I would like to thank Sari and the Finnish Epilepsy Association for their great help with the survey.

In closing, I wish all of you who, like me, live in the northern hemisphere, a very pleasant summer. For those of you in the southern hemisphere, I will quote Percy Bysshe Shelley: 'if winter comes, can spring be far behind?'

With best wishes to all,

Athanasios Covanis  
President



International Epilepsy News  
Issue 1 - 2014

### EDITORIAL TEAM

**Editor and Coordinator:** Ann Little  
*Email:* [ibedublin@eircom.net](mailto:ibedublin@eircom.net)

#### Regional Sub Editors:

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

#### Advisors:

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

### INTERNATIONAL RELATIONS AND PARTNERSHIPS

#### WHO

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

#### ECOSOC

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

#### CoNGO

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

#### EFNA

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

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# In this issue

## Dear Readers



It's been a very busy half year and it was difficult to squeeze in all the news in this issue. So some stories have been held back for next time.

In May we celebrated the 2nd African Epilepsy Congress in Cape Town and you will find the special magazine published to mark the occasion on the IBE website. In this issue of IE News

you can read about the congress, but make sure to visit the congress website where you will be able to find most of the presentations - [www.epilepsycapetown2014.org](http://www.epilepsycapetown2014.org).

IBEVice President Western Pacific, Dr Ding Ding, made a long journey from Shanghai, China to Santiago de Chile and shares the excitement of her visit with us.

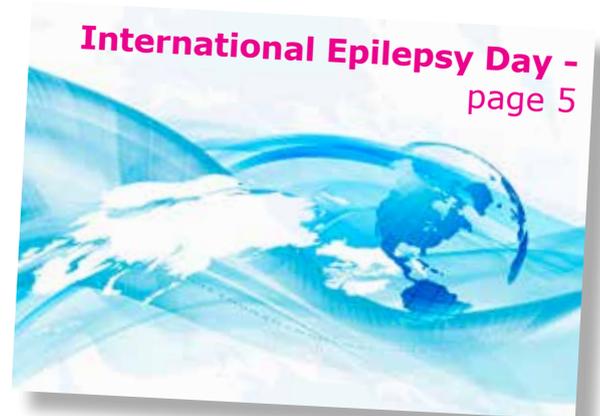
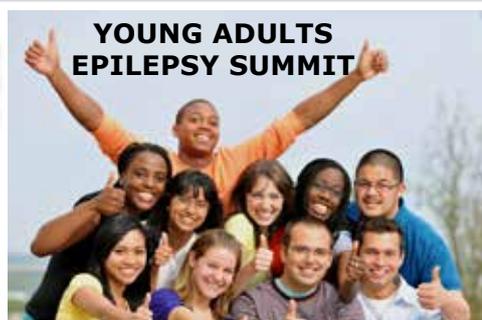
Two new seizure monitors are making life easier for parents and carers, one of which won the Epilepsy Foundation *Shark Tank Award*.

There's plenty of news from Europe, Australia, the US and Hong Kong. But the biggest news, which IBE and ILAE are delighted to announce, is the creation of International Epilepsy Day. This world day for epilepsy will be celebrated on the second Monday in February, with the first event planned for the 9th February 2015. Watch this space for ongoing news as preparations are put in place!

Until next time - happy reading.

*Ann Little*  
Editor

## Coming in the next issue



# ECS

# the voice and vision for change

## Report by Alanna Parker, ECS Chair

Created in 2013, the Epilepsy Consortium Scotland (ECS) is a collaborative umbrella body that aims to bring issues concerning the 54,000 people living with epilepsy in Scotland to the attention of policy makers and the government. It also offers an important channel for comprehensive feedback on what is happening in the field of epilepsy at a local and national level.

As well as providing the Secretariat to the Scottish Parliament's Cross-Party Group on Epilepsy, the Consortium gathers information from its membership and invites their views on a range of relevant issues. The Consortium has a role in contributing to policy consultations and commenting on epilepsy-related guidelines. Members set annual aims and work together on short term groups.

At a time when Scotland faces significant change, especially in how health and social care will be delivered in the future, the Consortium advocates for those with epilepsy who need optimum and contin-

ued services. Representatives on the ECS forum include learning disability and epilepsy specialist nurses, clinicians, leading social care providers, voluntary organisations and individuals with epilepsy and those with associated expertise.

In the last year the Consortium has:

- Commented on new health legislation
- Begun mapping epilepsy services (findings due June 2014)
- Asked MSPs (Members of the Scottish Parliament) to sign a pledge for equal access to epilepsy care across Scotland
- Held National Epilepsy Week exhibitions in the Scottish Parliament
- Undertaken a survey of first aid/epilepsy awareness training in schools
- Provided a briefing for MSPs taking part in the 6<sup>th</sup> epilepsy parliamentary debate on the issue of tackling the stigma of epilepsy through education
- Arranged a National Epilepsy Week

photo call with MSPs to support the good standard of care and sign up to SIGN guidelines for managing epilepsy in adults.

ECS members share and promote existing best practice that can assist people with epilepsy. One example was asking Police Scotland to come and present details of its new Third Party Reporting scheme. This scheme enables vulnerable individuals who experience instances of hate crime and discrimination to report these through a trained third party. Several ECS members are now registered Third Party reporters.

ECS wants to ensure that people of all ages with epilepsy will benefit from proposed policy changes especially around health and social care reform. It will also use its collective voice to put forward its vision for change and put epilepsy on the agenda.

[enquiries@epilepsyconsortiumscotland.co.uk](mailto:enquiries@epilepsyconsortiumscotland.co.uk) or visit our website at [www.epilepsyconsortiumscotland.co.uk](http://www.epilepsyconsortiumscotland.co.uk)

## Collage of MSPs signing the Consortium pledge



# INTERNATIONAL EPILEPSY DAY is announced!

**International Epilepsy Day**, a joint initiative of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) is set to be launched in 2015.

We are planning for a major event to be celebrated across the globe in the **138** countries in which IBE and ILAE have member associations.

With IBE and ILAE in official working relations with the **World Health Organization** (WHO), and with IBE having Special Consultative Status on the **United Nations** Economic and Social Council (ECOSOC), International Epilepsy Day will be the most prestigious epilepsy event in the world.

The first world day for epilepsy will take place on

**Monday, 9th February 2015**. Thereafter the date will be the second Monday in February. This is also the date on which European Epilepsy Day has been celebrated since 2011.

**International Epilepsy Day** is set to be a major step in improving epilepsy awareness in every region of the world, and will highlight the urgent need for increased research in epilepsy.

As we advance towards launch day 2015, we will keep you up to date on planned activities. We hope that your association will take advantage of this opportunity to create a special epilepsy awareness day in your country.

Please **highlight the date** in your diary for 2015!



# NEWS FROM EUROPE

## The European Union tells pharmaceutical industry to "lobby better" in Member States

Paolo Testori Coggi, Director General of DG Health and Consumers (SANCO) has told pharmaceutical companies that they need to do more to influence EU Member States to implement European Union regulations.

Dr Tesori Coggi said that health sector-related proposals that the EU Commission introduced were often weakened by the European Council and by the Member States, which was unfortunate. However, she believed that pharmaceutical companies had a role to play in using their "lobby capacity" to convince Member States of the industry's strengths. The Director General was speaking at the European Business Summit, which took place in Brussels in mid-May.

The Director General went on to say that the voice of the health minister in a

national government was often weak with the emphasis on healthcare cuts rather than an increase in healthcare provision, due in the main to the current financial crisis. This was unfortunate since the Commission was expecting to produce the highest ever number of health-related recommendations this year.

Dr Tesori Coggi said that she was not optimistic that things would significantly improve in the sector. On the contrary, she warned that, with the new Commission post-elections, the situation will become even worse. The Commission is a technical body, while the Parliament and Council are political and have already blocked many Commission proposals, she explained.



## Epilepsy Manifesto for MEPs

**EPILEPSIE znamená více než ZÁCHVATY**  
**EPILEPSIA on muutakin kuin KOHTAUKSIA**  
**ΕΠΙΛΗΨΙΑ ΔΕΝ ΕΙΝΑΙ ΜΟΝΟ ΟΙ ΣΠΑΣΜΟΙ**  
**A EPILEPSIA é mais do que TER CRISES**

www.epilepsy-greece.gr  
 www.epilepsia.pt/lpce  
 www.epilepsyadvocacy.org

In advance of the European Parliament Elections held in May, the ILAE-IBE Joint Task Force on Epilepsy created a short manifesto highlighting some of the problems that people with epilepsy in Europe face. The aim was to bring the issue of epilepsy to the forefront of the nominated candidates standing for election. Now that the elections are completed, there is still the opportunity to encourage the newly elected MEPs to support the cause of epilepsy in Brussels. The IBE office invited IBE members in Europe to translate the original English

text and prepared the manifesto in a number of languages (some of which you can see here) for use at national level. To date there are translations in German, Dutch, Flemish, Portuguese, Slovenian, Greek, Czech and Turkish - as well as in English - and you can find all on the IBE website. If you would like to have the manifesto

available in your national language, please send the translated text to Ann Little at [ibedublin@eircom.net](mailto:ibedublin@eircom.net). You may like to provide your association's web address and logo and these can also be placed on the document.



# EFNA UPDATE

## European Federation of Neurological Associations - General Assembly

Last year, IBE rejoined the European Federation of Neurological Associations - EFNA - following a break of some years. Ann Little attended last year's General Assembly at the invitation of the President Audrey Craven, at which time the membership application was ratified.

This year's assembly was held on 1st June in Istanbul at the time of the EFNS/ENS congress and Anastasia Vassou and Ann Little attended on behalf of IBE.

It's been a very busy period for EFNA and, thanks to funding it receives, the association has been able to introduce a number of activities, some ongoing and others coming to a close:

**Patient Advocate Workshops:** For the past three years training workshops to patient groups on health technology assessment (HTA) have taken place at the London School of Economics, with participant costs covered by EFNA. However, EFNA has now decided that the last of these courses will be run this year and is considering providing support to national groups to run courses in their own coun-

tries in the future.

### **European Parliament events:**

EFNA launched an MEP pledge on 7th May last year, encouraging MEPs to pledge their support for investment in neuroscience research and to protect the interest of neurology patients. On the following day, an Information Day took place where EFNA members were provided the opportunity to display leaflets and information on the conditions they address.

### **Towards Active Patients' Involvement in Healthcare:**

this conference took place in Dublin in late May 2013 at the time of the Irish EU Presidency. Marking the European Month of the Brain, the conference was organised jointly by the European Patients' Forum and EFNA.

### **IBE Joins EFNA Board**

Following the meeting of the EFNA Board in Istanbul, we are pleased to announce that Ann Little has been elected to the board for the coming two years. This is an excellent opportunity for IBE to work more closely, not only with EFNA

but, also, with other organisations, such as the European Brain Council, with whom EFNA partners.

### **Future Plans**

For the coming year, there are a number of activities being planned, including a survey of patients in Europe (the survey paper is still in draft format but, once completed, EFNA members will be asked to help with its dissemination across Europe). There is a fundraising plan still in the pipeline that will involve a high profile awards event - more details on this are expected soon. EFNA is also in discussion with one of the large Special Interest Groups of MEPs and this may result in an strategic merger. And there are a number of workshops and advocacy events being planned for Brussels.

### **New EFNA Board (pictured below):**

*From left* Maggie Alexander; Ann Little, Audrey Craven, Joke Jaarsma, Manuela Messmer-Wullen, Cathalijn Van Doorne and Bea de Schepper





# Smart Monitors help end Sleepless Nights

The impact of this on our ability to manage our son's epilepsy, and the entire family's general quality of life, cannot be overstated

*Isn't it always the way? You wait ages for a bus and then two come along together. So it is with two great stories about seizure monitors: one from the US and the other from Australia.*

I met Charles Anderson, pictured above with his wife Cynthia, when they travelled to Dublin recently to visit their elder son who is studying in Ireland. It was the perfect opportunity to learn about the SAMi, for which he had won the 2011 Epilepsy Foundation *Shark Tank* Competition.

I leave it to Charles to explain all about the SAMi - why he developed it, how it works, and the huge positive impact it has made to family life:

### **Charles' and Cynthia's Story**

There are over 37,000 children diagnosed with Recurring Seizures (RS) in the US every year with an estimated 50 million people with RS worldwide. Many caregivers either do not know when seizures occur during the night or they lose a lot of sleep trying to stay awake in case a seizure occurs. Seizures can happen at any time. Those that happen during the day can be quite

dangerous, but those that happen at night present unique challenges. Nighttime seizures are often never witnessed. In our case, Cynthia and I noticed that our son often had seizures at night when we went on family vacations. Our assumption was they were associated with the stress of travel. It turns out he was having seizures regularly at night even at home; we just never knew it.

Tracking seizure frequency is critical for assessing the efficacy of medication and other treatments. With SAMi in place, we had recordings of the nighttime seizures and could provide our doctors with accurate information.

Once we knew he was having seizures at night, we needed to not just record them, but be alerted to when they happened.

Our options were co-sleeping, a baby monitor, or a movement detector. No solutions are 100% reliable, and all involve compromises. Co-sleeping was a last resort, especially with a teenager. We tried a baby monitor but found we were waking multiple times a night on minor sounds. A movement detector can work well for



## The Shark Tank

Philip Gattone, CEO of Epilepsy Foundation and Vice President North America of IBE, pictured left, explains:

The Shark Tank Competition represents a significant component of the Epilepsy Foundation's mission – to incentivize inventors and entrepreneurs to pursue products, therapeutics or technologies with the promise of improving treatment and quality of life for people living with epilepsy. Supporting and promoting partnerships between inventors, researchers, and industry makes it possible to bring new approaches for treating and managing epilepsy in a timeframe that matters.

seizures with rhythmic movement, but our son's often looked a lot like sleepwalking. We built SAMi in 2009 and ran it on a dedicated laptop computer. SAMi silently watches, running on the nightstand next to our bed, looking like a digital clock. Minor movements such as turning over and even entering/leaving the room are ignored. If movement continues for a selectable period of time it sounds an alarm, followed by a live video. In our case, even minor motion continuing for more than 20 seconds usually indicated a seizure.

The impact of this on our ability to manage our son's epilepsy and the entire family's general quality of life cannot be overstated.

Winning the first Epilepsy Foundation *Shark Tank* Competition in 2011 allowed me to transform SAMi from an expensive custom solution for us into a refined,

much less costly tool for others. I immediately put the funds to work. Specifically, I used the award to purchase the computer and software necessary to write the iOS app. I then purchased and distributed SAMi cameras to other families for testing. Finally, the funds were used to purchase inventory, build the [www.samialert.com](http://www.samialert.com) website, and pay attorney fees for incorporation of HiPass Design Ltd and a patent application.

### How SAMi is different

- It detects movement and records video in complete darkness
- Works with all types of motion, not just rhythmic movement
- Sends live audio and video to an iPhone or iPod Touch for remote monitoring
- Analyzes live video and sounds an alarm when unusual events occur

- Saves and organizes the audio and video recordings
- Enables quick review of recordings and saves them so that they can be viewed by doctors and carers.

### SAMi Update

Fast forward three years and Charles is still hard at work on his invention. The *Shark Tank* funding allowed him to develop the SAMi 2 version of the monitor, an iPhone based model but now he is working on even greater refinement of the product. In recent months Epilepsy Foundation launched the Indiegogo campaign, to crowdfund SAMi Mark 3. If the campaign is successful, the funds raised will allow mass production of the unit, making for a more affordable version, and helping those of lesser financial means to obtain one of the monitors.

Visit [www.samialert.com](http://www.samialert.com) to find out more.

## The Generosity of Strangers



Robert Cole, CEO, Epilepsy Association of South Australia and the Northern Territory wrote to tell IE News of the generosity of people in Australia who have helped provide seizure monitors to families of lesser financial means.

"There are certain people in our lives who just make the world a better place. They give us hope and raise our spirits simply by being the kind of people they are. Some people stand up and champion a cause, or provide the spark, or defy the odds, or do the right thing simply because it's right. They don't really worry about fame or acclaim, they just think about being good friends, good neighbours, good people. We don't say it often enough, but we are grateful to have these people in our midst," enthused Cole.

Cole explains that the Epilepsy Association of South Australia and Northern Territory Call Centre, Community Link team

### There are certain people in our lives who just make the world a better place

work tirelessly to raise money for children in need of Seizure Monitors for nocturnal seizures.

Over the last year they have been able to raise enough money to purchase 23 seizure monitors for all of the children in need and they are eternally grateful to those who have donated to this cause, as are the families who have received monitors as a result of these efforts.

"We are touched by the kindness of the wonderful donors who support a family who are struggling," says Cole.

The Seizure Monitors are specifically designed for children who have nocturnal seizures. The monitors are made in Finland (EMfit) and cost AUD\$900 each. They activate a loud alarm if a child has a seizure in their sleep. This alerts the family that a seizure is occurring and is a life-saving device. More importantly the monitor allows children to sleep in their own beds whilst providing peace of mind and a more restful sleep for parents.

"The generosity of our donors to date has overwhelmed all of these children's families, as we are able to surprise them with the gift of a Seizure Monitor from the donations received," explains Cole.

A good news story indeed!

# An unforgettable visit to Chile

## Report submitted by Dr Ding Ding

*IBE Vice President Western Pacific Region,  
Vice General Secretary, China Association Against Epilepsy (CAAE), and  
Associate Professor, Institute of Neurology, Fudan University, Shanghai, China*

As the aircraft began its descent, and the Andes came into view, the fatigue of a 30-hour flight suddenly disappeared, replaced by excitement and expectation on my first trip to South America. It was in early April, the beautiful autumn season in Chile. I had been invited by Dr Tomás Mesa, President of the Chilean League Against Epilepsy (CLAE), to attend the

17th congress of the National Association of the Chilean Leagues Against Epilepsy (ANLICHE).

ANLICHE is an umbrella body of groups, institutions and clubs devoted to epilepsy throughout the country. Its main objectives are to disseminate comprehensive knowledge of the condition and exchange of information with public and private institutions; and to encourage research on epilepsy, amongst others. A national meeting is held annually, with all delegations gathering to improve communications and to share experiences and training.

On April 2nd, I visited the administration office of ANLICHE, located in downtown Santiago. Dr Mesa told me the history of the CLAE, a nonprofit non-governmental organization founded in 1953 by a prestigious neurosurgeon, Dr Alfonso Asenjo. The physician also encouraged many people to work as volunteers for people with epilepsy. Therefore, a volunteer group of women and another of physicians started to collaborate and help people with epilepsy and their families.

Nowadays the CLAE is a member of the IBE through ANLICHE. Its mission is to

improve the quality of life of people with epilepsy, their families and carers, through medical and psychosocial treatment, as well as through education, training and rehabilitation. Besides Santiago in the Metropolitan Region, the CLAE has offices in eight cities across the country: Iquique, Antofagasta, Copiapó, La Serena, Curico, Talca, Concepción and Temuco. They also have seven drugs banks and provide other benefits for people with epilepsy, such as health care services, an electroencephalography laboratory, a clinical laboratory and a social services department.

The CLAE has a special school for young people with epilepsy, aged from 16 to 24 years, who have mild to moderate cognitive impairment. I visited another center for developmental disabilities (Centre for Integral Development, CEDEI) for young children and adolescents. Ms Daniela Poblete (Secretary of the CLAE) and Ms Daniela Araya Alegría (psychologist of the CEDEI) showed me around and gave me a brief introduction to the centre. The CEDEI promotes comprehensive development of people with epilepsy and their family members in social, psychological and educational areas. The center has a multidisciplinary team with an education psychologist, psychiatrist, and behavior therapist. The objectives for the training program are to identify and respond to the specific learning difficulties of school children with epilepsy and to provide the necessary tools to promote the skills required to access formal education. Other programs have been developed, including cognitive and emotional assessments,



workshops for parents and carers, social and leisure workshops for children and adolescents, educational lectures, crisis intervention, and short term therapies.

After the visit to ANLICHE, I gave a lecture titled "Global Campaign Against Epilepsy: a Demonstration Project of Epilepsy Management at Primary Health Level in Rural China", to adult and pediatric epileptologists. I shared with them the experience of China, and we had a very good Q&A session after my lecture. Surprisingly, I felt much more excited and comfortable when I spoke at the 17th annual meeting of ANLICHE in Futrono. This was the first time I had ever spoken to so many volunteers for epilepsy care.

On the request of Dr Mesa, I spoke about epilepsy care in China and the experience of our Seahorse Club in Shanghai. At the meeting, I met many great female volunteers, who told me the history of their volunteering. The average age of these volunteers is about 60 years old. In the 1970's, the job of volunteers in the League was solely the distribution of drugs, but over the course of the last 40 years, the women's volunteer group has developed into a large organization with more than 100 volunteers all over the Chile. They carry out various fundraising activities aimed at meeting the needs of people with epilepsy and improving their quality of

life.

I was deeply impressed by the words from one lady, "I think what keeps us here is the gratification that comes from helping others. Nothing fills the soul more than that. When I see a calm face of a person who has just been diagnosed but who has had his doubts about epilepsy explained, or a happy face of someone of limited financial means after receiving free help, I feel a calmness that cannot be expressed in words."

## "what keeps us here is the gratification that comes from helping others"

Other important speakers at the meeting were: Dr Lilian Cuadra, Ministry of Health, who talked about the National Program of Epilepsy in Chile; Ms Catalina Duran, a journalist, who talked about social networks and communications in ANLICHE; Mrs Gabriela Silveti, president of the foundation of people with refractory

epilepsy, talked about the duties and rights of people with epilepsy. There was also a volunteer meeting chaired by Mrs Delfina Fuentes, a social worker. The content included: taking care of the carer: volunteer role; successful projects performed by ANLICHE in 2013; and a call for tenders to grant funds for ANLICHE'S innovative projects that will benefit patients and carers. The meeting was a great success.

Finally, I would like to thank the physicians who dedicated their time and energy to this great career of epilepsy care in Chile: to Dr Tomás Mesa, president of the CLAE, who organized this annual meeting and all other activities of the League; to Dr Carlos Acevedo, past president of the League, who is still very active; to Dr Keryma Acevedo, a pediatric epileptologist, who did a great job interpreting my English to Spanish at the meeting. Finally, thanks for the wonderful view of Futrono, which made my trip both perfect and unforgettable.

### Photos:

*Top left:* The lake at Futrono

*Bottom left:* At the Centre for Integral Development with Ms Denila Poblete (middle) and Ms Daniela Araya Alegría (right).

*Below:* Dr Ding with Dr Mesa (middle of second row) with delegates attending the 17th annual meeting of ANLICHE.





# YES for success

In Australia, the Epilepsy Centre's youth programme has been designed to realise our vision to see young people thrive in life despite living with epilepsy. The overall programme has a broad focus comprising numerous individual programmes that are founded on extensive research and together aim to meet a range of epilepsy-related physical, emotional, psychological and social needs. Two of the programmes that are seeing particular success at present are our employment programme and our leadership programme.

YES is our youth employment programme. This was launched as a grant-funded pilot programme at the beginning of the year and has seen an enormous response from young people, as well as from employment service agencies and from employers themselves.

YES stands for Youth Employment Skills, a name that describes the programme's principle aim to see young people with epilepsy learn how to develop strong epilepsy self-management skills; to understand how Australian State and Federal Law impacts them; and to understand both their own and potential employers' responsibilities. The programme has seen young people

grow in knowledge and confidence with each one leaving the programme with a firm understanding of their own epilepsy and a strong understanding of when and how to disclose their epilepsy in a way that conveys a positive message to potential employers.

YELSA which stands for Young Epilepsy Leaders of South Australia is our new leadership programme. It has been designed to help young people with epilepsy to realise their own potential and to learn how to overcome personal challenges, particularly those relating to epilepsy. The programme has a plan that over the next year will see young people attend workshops and personal development events, each designed to provide individual learning and development opportunities. The year will culminate in SUMMIT1625, a leadership summit offered to young epilepsy leaders aged between 16 and 25 years. These summits will occur annually in different locations, with the first two venues already selected.

We are very excited about the first SUMMIT1625. This is scheduled for March 2015 and will be held in Rotorua, New Zealand where young people with epilepsy

from South Australia, the Northern Territory and New Zealand will join together in a shared growth experience. The summit has provided a wonderful opportunity for The Epilepsy Centre of South Australia and the Northern Territory to partner together with Epilepsy New Zealand.

This partnership has involved visits between the two countries to plan activities, with a final trip to New Zealand in March this year ensuring that all accommodation, venues and activities both compliment our programme and convey the overall standard of excellence for which we are striving. The summit programme will see our young people engage in a range of workshops and will enable them to enjoy many of New Zealand's natural, cultural and fun tourist experiences. We believe the entire experience will be a great learning and growth experience for all our youth.

We at The Epilepsy Centre know that young people living with epilepsy face many challenges in life so we are excited about our Youth Programmes. If we can help even a few of these young people to realise their potential and become leaders, then the potential for them to influence other young people is enormous.



## Lifetime Accelerator Award

Epilepsy Foundation announces 2014 recipient

IBE sends its congratulations to Steven White, PhD, who has been announced as the recipient of the Epilepsy Foundation's Lifetime Accelerator Award 2014, in recognition of his commitment and pioneering contributions to the field of epilepsy and seizures.

Dr White is professor of pharmacology and toxicology and principal investigator of the National Institutes of Health (NIH)-sponsored Anticonvulsant Drug Development Program at the University of Utah College of Pharmacy in the US. He received his award at the 4th Biennial Epilepsy Pipeline Conference in San

Francisco in June, organised by Epilepsy Foundation, IBE's Full Member in the US. The Lifetime Accelerator Award was established in 2012 to honor physicians, scientists, industry leaders, and individuals who have demonstrated a lifelong commitment to bringing new therapies to people living with epilepsy.

Dr White's career in antiepileptic drug discovery began in 1986 as the senior scientist of the ADD Program. Over a 28 year period of Dr White's research in the field, the program has played a crucial role in the early identification and characterization of thousands of novel anticonvulsant

medications using established seizure and epilepsy models. Dr White's laboratory has identified and characterized the anticonvulsant profile and potential mechanism of action for established and new anti-epilepsy agents.

The efforts of the faculty, which Dr White has directed since 2001 have, since its establishment in 1975, contributed to the successful development of multiple new therapeutics, including felbamate, rufinamide, topiramate, retigabine and lacosamide.



## Chi Fan for Charity Award for Enlighten - Action for Epilepsy

Chi Fan for Charity (CFFC) is Hong Kong's new premiere charity dining event, which has overhauled the standard concept of a large gala charity dinner. Instead, CFFC invites some of Hong Kong's best restaurants to prepare a special menu accompanied by a selection wines or cocktails. Many of the tables at the event are hosted by some of Hong Kong's best known personalities, some by associations and others by groups of friends.

As part of the Chi Fan for Charity initiative, the public is invited to vote for one of four charities nominated to benefit from the event. Just recently, after facing strong competition from the three other nominated charities - Liberty Asia (fighting slavery and human trafficking), Morning Tears (supporting children with imprisoned parents) and Foodlink (fighting hunger & poverty); Enlighten-Action for Epilepsy - IBE's Associate Member in Hong Kong was chosen as the official beneficiary with 32% of the votes.

In receiving the award, Enlighten - Action for Epilepsy said it was extremely delighted to be part of this new concept which will help it raise epilepsy awareness in Hong Kong and also the much needed funds for the charity.

## Meeting of the IBE African Regional Committee

Organised by the Chair, Youssouf Noormamode (Mauritius); Vice Chair, Marina Clarke (South Africa); and Secretary, Harmiena Riphagen (Namibia), there was a great attendance at the meeting of the African Regional Committee. With the congress programme already bursting at the seams with a packed list of events, this meeting had a limited time slot. But, what time there was was well used with a lively exchange of views, animated discussion, and a very positive outcome with a number of suggestions for future activities.

### Fund Raising Development Strategy

There was interesting discussion on how best to raise funds for the activities of the committee around the protocol of applying for funds from international donors. It was proposed that an additional member might be co-opted to help in identifying fund raising opportunities and this is now under consideration.

Youssouf Noormamode reported that his association in Mauritius had obtained funds from a European Union budget and this was something to be looked at.

Mr A K Dube, South Africa, suggested that fund raising training to develop internal capacity to write proposals could be factored into this process. Mr Dube offered to provide the committee with sample templates for funding proposals.

### Quarterly Online Newsletters

The electronic communication planned for the region has been a little disappointing and members were urged to share information on their activities, with Karijn Aussems, Kenya, asked to assist.

### Sharing and Exchange Visits

Anthony Zimba, Zambia, suggested an allocation in the budget be used to strengthen, share and apply the knowledge of connections made by members with

other associations in the region.

### Capacity building workshops

With a serious need for capacity building in Africa, a call was made on members to share, with other members in the region and with the African Regional Executive Committee, information on projects and programmes being undertaken in order to prevent 'reinvention of the wheel'.

### Support to Young People

The African Regional Committee budget has an allowance for support for young people with epilepsy and the idea was put forward that it would be more beneficial to allocate this to one youth project than to split the money for smaller projects.

### Closing

In closing it was reiterated that this is a committee for the members in Africa therefore the call was: "Make us work!".



Delegates at the meeting of the African Regional Committee in Cape Town

# Photo Gallery from Cape Town

Clockwise from top right:

- A nurses choir gave a moving rendition of South African songs and were a big hit with delegates at the Opening Ceremony
- Shunglon Lai, former IBE Vice President Western Pacific, made the long journey from Taiwan to attend the congress
- At the IBE booth, from left, a delegate from Nepal, Robert Cole (IBE Treasurer), Kenneth Ninying Nsom (Cameroon), Sari Tervonen (IBE Secretary General) and Mbusomuni Mahlalela (Swaziland)
- Anthony Zimba (IBE Vice President Africa) is interviewed by the national TV station
- A colourful national costume at one of the sessions
- Rosemary Gathara, her young son Edward and Osman Mijanji from Kenya, with Anthony Zimba, Zambia



# Nicole's Story

**A young person with epilepsy told her inspiring story at the Epilepsy & Society Symposium**

Diagnosed with Absence seizures at the age of 9 years, has served as no impediment to Nicole's tremendous 'can do' attitude to life. Her story was an inspiration to many who attended the Epilepsy & Society Symposium in Cape Town.

During her teenage years she realized the importance of taking her medication regularly and at the correct dosages prescribed for each particular medication she was given, and which changed often during this period of her life. Of course she faced many of the problems that teenagers with epilepsy encounter - being teased, problems with medication and school days lost because of seizures.

She told delegates how she had never been discouraged by her condition and had continued to participate in school activities with her peers. Not only that; she took up drama and won the Miss South Africa Teen competition. This, says Nicole, gave her tremendous confidence to speak to large crowds and panels of judges.

From a young age, Nicole has been involved with Epilepsy South Africa and currently serves as a Youth Ambassador for the association.

Her future career looks extremely bright:

great opportunities lie ahead in terms of studying abroad at a worldclass art institution in New York. Nicole has been accepted to study an Honours programme in Design at the School of Visual Arts in New York. She is doing well at varsity and is the top student in her class. She has wonderful relationships and tremendous support from family and friends.

She has a modelling contract with Boss Models in Johannesburg and Topmodel in the UK. Drama is also a passion and Nicole is studying for her Performers Diploma through Trinity College, London.

But, let's leave the last word to Nicole:

"I hope to inspire other people living with epilepsy to see it as a challenge that will grow and mould them as an individual rather than view it as a burden.

"My contributions to society are more important than my limitations. My achievements are defined by what I can contribute and the difference that I can make. My goal is to inspire young people to never give up on their dreams."

*Read Nicole's full story on the congress website, <http://www.epilepsycapetown2014.org/speaker-presentations.1362.html>, where you will also find her mother Danica's side of the story! Danica and Nicole are pictured below at the congress.*

**"I was determined to be seen as normal by my peers and to reassure the people I came in contact with, or worked with, that my capability to perform was no less than theirs"**

**Nicole Laxton**



# EPILEPSY & SOCIETY WORKSHOP CAPE TOWN



A special half-day workshop, developed specifically for people with epilepsy, their families as well as for those caring for them, was held on the last day of the African congress. With three main sessions:

- Epilepsy and the Family
- Traditional Healers
- AEDs in Africa: availability, affordability, continuity of supply

the broaden spectrum of presentations made for an interesting and informative workshop with no shortage of interaction and participation by delegates.

On the previous page you will have read about the inspiring presentations made by Nicole and Danica Laxton during the Epilepsy and the Family session.

Other topics included "Women's issues: contraception, pregnancy and motherhood", which was presented by Gretchen Birbeck (USA). Gretchen has been working in Africa for a long period of time, in particular in Zambia.

Women's issue surrounding motherhood are of major concern but, when you live in a region where continuity of supply and availability of AEDs are already a problem, safe pregnancy and delivery and the welfare of mother and child become all the more problematic - and that is before

cultural differences are addressed.

Robert Cole, IBE Treasurer and CEO of Epilepsy Association of South Australia and the Northern Territory, spoke to the challenging topic of "Men's issues: sexual problems". This is a topic that is often 'swept under the carpet' due to people's embarrassment but epilepsy and epilepsy medication can impact hugely on men's sexual lives - an area that is often either neglected or ignored.

Harmiena Riphagen, CEO of Epilepsy Namibia talked about "Epilepsy & Schooling" -an area in which her association has been long involved through the Epilepsy Namibia Learner Awareness Program, which is supported by the IBE Promising Strategies Program. As Harmiena explained: *'the most important years of learning begin at birth'*. Anne Fredericks from Epilepsy South Africa looked at the other end of life and addressed the issue of "Epilepsy in old age", an area growing more significant as we live longer and with late on-set epilepsy becoming more prevalent.

The second session, which focused on just one aspect of epilepsy, looked at the area of "Traditional Healers". It was a truly fascinating session, presented by Johannah Keikelame from South Africa, who has been involved in this area for many years.

Delegates hung on every word making this a topic that will surely be revisited at future congresses. Johannah was accompanied by two traditional healers and our cover photo shows all three in their wonderful costume.

The last session of the workshop brought all of the speakers, from both the workshop and from the joint ILAE/IBE session held earlier in the day, back on stage for 'round the continent' look at, perhaps the biggest single problem of all, the issue of anti-epileptic drugs. Problems of affordability, availability and continuity of supply are common in all parts of the region and with little outlook for any major improvement any time soon. Add to that stigma and cultural beliefs and the future for people with epilepsy in Africa remains, for the most part, pretty bleak.

To access presentations from the congress, visit <http://www.epilepsycapetown2014.org/speaker-presentations.1362.html>.

#### Photos from below left:

- Johannah Keikelame, South Africa
- Paediatric neurologist, Sister Ornella Ciccone, Italy, who is working Zambia
- Sammy Obene, Ghana, who presented on Epilepsy in West Africa
- Rosemary Gathara, KAWWE Kenya, took part in the final session on AEDs



# Members Survey

IBE sends a big "Thank You" to all those Members who took the time to complete the recent survey paper. We realise that, for those of you for whom English is not a first language, this was quite an onerous task. However, your responses are vitally important to us in determining IBE's future strategy.

IBE would like to note its thanks also to Sari Tervonen, CEO of the Finnish Epilepsy Association, for the help that was provided by her association in crafting the survey and in collating responses.

The International Executive Committee will study the survey when it meets in September and a report is planned for the next issue of IE News.



Photo: Ann Little

Three years ago, in Budapest in 2011, the European Neurological Society (ENS), which has 900 individual members, and the European Federation of Neurological Societies (EFNS) with 45 national delegates, agreed to merge to create a single entity to be called the European Academy of Neurology (EAN).

Since then, an EFNS/ENS Transitional Task Force has been busy preparing for

the change by formulating new bylaws and resolving technical issues to pave the way for the official founding, which took place during a joint EFNS-ENS meeting in June in Istanbul. Prof Günther Deuschl, from Germany, who works in the field of Parkinson's and Movement Disorders, was elected the first President. ENS and EFNS have now ceased to exist.

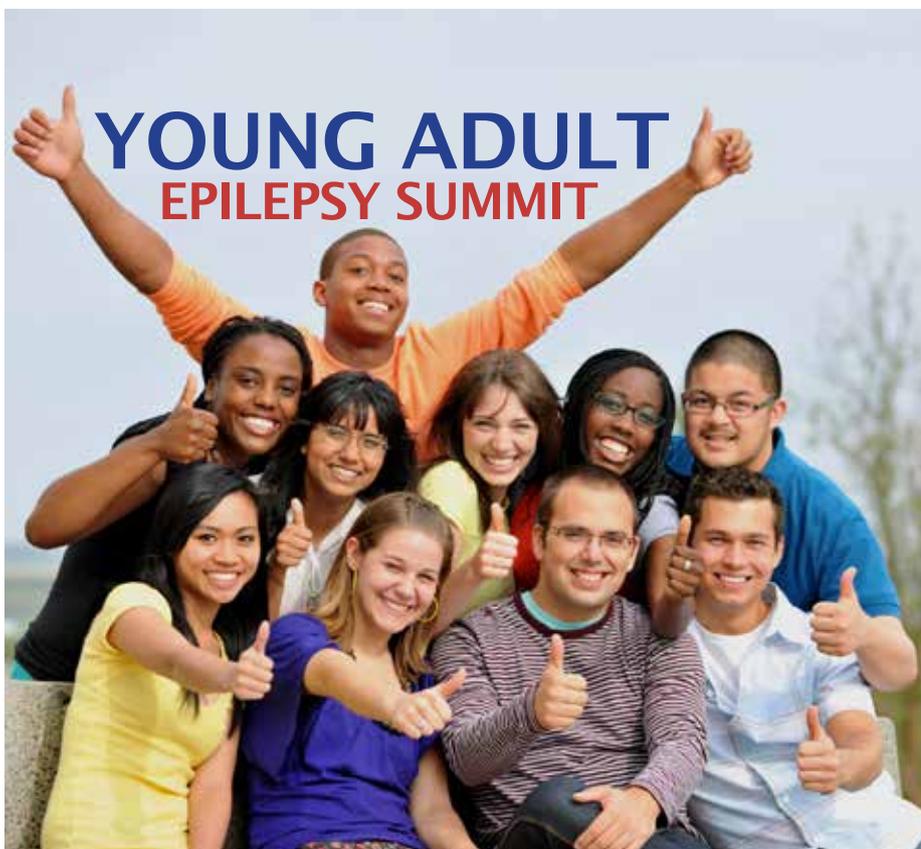
An interesting development took place in

## EUROPEAN ACADEMY OF NEUROLOGY

### becomes reality in Istanbul

the scientific sub-speciality panels within the academy, instigated following discussion between the European Federation of Neurological Associations (EFNA) and Eveline Sipido, who provided secretarial support to the EFNS Liaison Committee and now continues with EAN. The upshot was a matching of EFNA Member Groups with their corresponding EAN Groups as it was felt that the value of the patient's perspective should not be overlooked.

IBE received an invitation to attend the meeting of the EAN scientific sub-speciality group on epilepsy, which took place in Istanbul during the congress. The panel is co-chaired by Reetta Kälviäinen, Finland and Paul Boon, Belgium. IBE President Athanasios Covanis and Executive Director Ann Little attended. This collaboration marks a further recognition of the importance of the patient voice!



## July 2014 Washington, DC

Later this month, 20 young adults (aged between 21 years and 29 years) from the US, Puerto Rico, Canada and Jamaica will travel to Washington DC for a special Young Adult Epilepsy Summit. The event is being organised by the IBE North American Regional Committee and the Epilepsy Foundation in the US.

IBE would like to thank all those who helped set this great initiative underway, in particular, Mary Secco and Jan Buelow.

The event is being financed by Epilepsy Foundation and IBE and we will have a full report on the summit in the next issue of IE News.

## Concert in Kazakhstan

SVS Nevro - Movement of Physicians and Patients Against Serious Nervous System Disorders and Epilepsy, IBE's member in Kazakhstan, organised a charity performance in the Zhambyl Concert Hall to raise awareness about epilepsy. The title of the event was "Together we can do anything!"

The concert attracted an audience of 900 people and, in opening the event, Dr Savinov Sergey and Mrs Shokobaeva

Orungul from the association, highlighted the importance of the event, which was timed with the celebration of European Epilepsy Day, held for the first time in the Republic of Kazakhstan. In addition to the performance, speakers presented information about the aims and activities of the association

The Concert featured a performance by the Kurmangazy State Academic Orchestra, one of the most famous in Kazakh-

stan and whose contribution to the event was tremendous. The other performers were the Russkiye Uzory Orchestra of Folk Instruments, the vocal group "Art Vocal", the dancing group of Miras International School, and soloists from the singing studio of school 94.

The event attracted great coverage print, radio and TV media.



# FUTURE CONGRESSES

