EPI Focus

Newsletter of the IBE European Regional Committee

Issue 2-2013

Dear Friends

After a few busy months since we met in Ljubljana, I am delighted to send a short message in this, the first issue of EPIfocus prepared by our new committee. There are reports from Ljubljana and from the congress in Montreal last June; Michael Alexa writes about the WHO Regional Committee meeting he attended in Izmir in October; and we begin to prepare for European Epilepsy Day in February 2014.

I am delighted to see that so many members have provided us with very interesting reports on a huge range of activities being carried out in Europe. I want to thank you for taking the time to send us your news and wish you well with these fantastic initiatives.

In closing, since this will be the last EPIfocus of 2013, I will take the opportunity to send you good wishes for 2014 for you, your family and your association. EREC looks forward to working with you next year!

With best wishes to all
Anastasia Vassou
Chair - European Regional Executive Committee.

Meet Lipko - mascot of Eurobasket 2013 - the European basketball championships, which took place in Ljubljana immediately after the Epilepsy & Society conference. You'll find a report and more photos on page 4.

IN THIS ISSUE

EREC Officers

Chair:	Anastasia Vassou, Greece
Vice chair:	Michael Alexa, Austria
Secretary:	Ljubica Vrba, Slovenia
Members:	Margaretha Andersen, Sweden Shirley Maxwell, Scotland

Ex officio: Janet Mifsud, VP Europe, Athanasios Covanis, President; Sari Tervonen, Secretary General; Robert Cole, Treasurer.

Material for EPIfocus should be sent to Ljubica Vrba: ljubica.vrba@hotmail.com

Getting ready for European Epilepsy Day 2014

Associations across Europe are preparing activities to celebrate European Epilepsy Day 2014 on Monday 10th February.

EED will be launched in the European Parliament in Strasbourg a week earlier, on Tuesday 4th February, when the Joint Task Force - Epilepsy Advocacy Europe - is organising an evening reception. EU Health Commissioner Tonio Borg has been invited to speak at the reception and has accepted the invitation. We are keeping our fingers crossed that an official duty or meeting, requiring his attendance, will not change things at the last moment. Gay Mitchell MEP has also agreed to host the event once again.

The Joint Task Force is arranging a poster display and the EREC members will also travel to Strasbourg to attend the event and to have private meetings with MEPs. This is a great oppportunity to alert MEPS to the need for improved treatment and information on epilepsy.

We know that, since its launch in 2011, EED has been marked by a number of very interesting initiatives across Europe. The IBE office has already gathered information on some past events and several have been reported on in the IE News. However, EREC plans to survey members to get the full picture so that we can collate these into a Users Manual that we will provide to all members. We believe this will provide a great source of inspiration to members for future events!

In the meantime, you will all have seen the logo for EED 2014 and the poster that has been drafted to mark the theme ‘Epilepsy is more than Seizures’. The logo is now available in most European languages and the poster has also been translated on request.

If you would like to have the poster in your language, please send the translated text to Ann Little at the IBE Office ibedublin@eircom.net who will prepare the translated poster within a few days. In the meantime, you will find all of the logos together with a number of posters on the website of the Joint Task Force www.epilepsyadvocacyeurope.org.

As plans for EED are progressed, the Joint Task Force will be circulating up to date information. This will be the 4th EED and we believe it is now a successfully established event, which is celebrated, not only by IBE and ILAE member associations across Europe but, also, by epilepsy centres and support groups and by the pharmaceutical industry.

With Horizon 2020 now, literally, on the horizon, any means of raising awareness on the problems faced by people with epilepsy and the need for increased funding to address these problems, is important. So, let’s all celebrate EED 2014 as widely and as loudly as possible!

IBE rejoins the European Federation of Neurological Assocations

EFNA
European Federation of Neurological Associations
Empowering Patient Neurology Groups

IBE has rejoined the European Federation of Neurological Associations - EFNA - as a full voting member. The ratification announcement was made at the EFNA General Assembly in Vienna on 18th September, with Ann Little, IBE Executive Director, representing the Bureau.

Following a lapse in membership, IBE is pleased to be once again involved. FNA is a federation of European patient associations working in the field of neurology and currently has twenty voting members, which includes Stroke Alliance for Europe, the Motor Neurone Disease Association, International Brain Tumour Alliance, European Multiple Sclerosis Platform, and the European Headache Alliance. The current President of the association is Mrs Audrey Craven.

EFNA is represented on a number of European bodies, including the European Brain Council - EBC. The EBC is a powerful force in Europe and this connection is valuable.

EFNA plans for 2014 include:

- A campaign in the lead up to, during and after the European Parliament elections to bring to the attention of election candidates the need for increased funding and programmes for neurological diseases;
- Efforts to identify and develop a network of national contact points (NCPs) in EU Member States.

A final activity for 2014 relates to ongoing effort for a European Year of the Brain. While the EU had designated the month of May this year as the European Month of the Brain, there was disappointment that the designation was not for a full twelve months. However, without the endorsement of the EU, it is still planned by the EBC to have 2014 as the European Year of the Brain.

The next assembly of EFNA will take place in the first months of 2014.

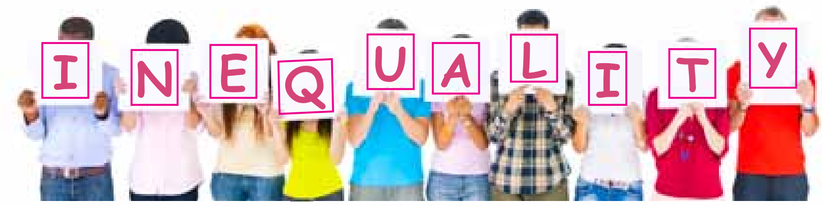
10 FEBRUARY 2014

eed

EUROPEAN EPILEPSY DAY

EPILEPSY IS MORE THAN SEIZURES

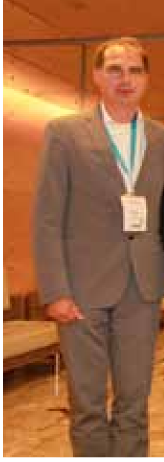
Stigma in epilepsy causes



TO IMPROVE QUALITY OF LIFE WE NEED

Epilepsy Advocacy Europe

ILAE IBE ILAE-CEA EREC



Photos (clockwise from top left):

- *Reetta Kälviäinen (Finland), Helen Cross (UK) and her daughter, Charley Cross, enjoying the Welcome Reception.*
- *Terra Folk and Symbolical orchestra players delighted delegates with their eclectic mix of traditional, jazz and blues music that keep feet tapping at the Welcome Ceremony. When they continued to play at the Welcome Reception, some delegates took the opportunity to take to the floor.*
- *Members of društvo Liga proti epilepsiji Slovenije, the IBE and ILAE member association in Slovenia, who played a big role in ensuring a great conference, from left: Matevż Krżan, Jasna Žunko, Ljublica Vrba, Svetlana Simić and Igor Ravnik.*
- *Delegates from Epilepsy Ireland: Mike Glynn (IBE Past President), Eoin Megannety (who took many of the photos shown here) Agnes Mooney, Wendy Crampton and Peter Murphy.*
- *Salla Aatsinki from Finland is interviewed for Slovenian TV about her experiences of living with epilepsy.*
- *The jubilant winning team enjoys a moment of glory at the end of the friendly basketball tournament with the Lipko joining in.*
- *Zoran Janković, Mayor of Ljubljana, welcomes guests to a special reception in the beautiful Town Hall.*
- *Guitarist Miha Ložar and singer Sanja Zupančič, both medical students, entertaining guests at the reception in the Town Hall with traditional melodies. Lipko, the mascot of the Eurobasket 2013 - the European basketball championships that took place in Ljubljana after the conference - meets with IBE President Thanos Covanis.*
- *Matevż Krżan (Slovenia), with Meir Bialer (Israel) and his wife Shoshana, and Thanos Covanis (Greece) and his wife Lynne.*

LJUBLJANA

the perfect setting for a great conference

Michael Alexa reports

13TH EUROPEAN CONFERENCE ON
Epilepsy & Society
LJUBLJANA, SLOVENIA
28TH - 30TH AUGUST 2013



BEFORE THE CONFERENCE

Before this year's conference I took a little break, as usual … I've spent some time in Koper. Koper is a small but lovely city, directly on the Adriatic Sea. My hotel was connected with the beach through a tunnel, so that the guests don't have to cross the street – very comfortable … You could also walk alongside the beach from my hotel to the city centre of Koper. It took me about half an hour and, of course, I did it during day and night. Koper is really lovely and, if I ever have time, I'll return back – that's a promise ….

THE CONFERENCE

The conference itself was the first European Conference on Epilepsy & Society in the East of Europe. All the other conferences have taken place in the West (e.g. Veldhoven, Netherlands), North (e.g. Helsinki, Finland) or South of Europe (e.g. Lloret de Mar, Spain). So it was a premiere.

From Austria Ljubljana is easily accessible – I took a train from my place, only 6½ hours one way, and I also was lucky to be able to buy a quite cheap ticket. I've heard from other delegates that they've had problems to get an easy and cheap access to Ljubljana.

On the other hand the Conference was very lucky, as a huge delegation from China appeared and registered for the conference. It was the first time that somebody from another continent attended the ECES and we were very proud about that!

The speakers presentations can be found online; the link is http://www.epilepsyandsociety.org/programme/speaker-presentations/.

Just a few highlights:

- **Michael Alexa (Austria):** The IBE and its regional committees have to work on a plan, how they can increase their funding. If you compare it e.g. with AIDS you'll find out that for AIDS a lot of money is available, although AIDS has only about half of the patients than epilepsy.
- **Marietta Remoundos (Greece):** The role of the Epilepsy support groups is very important: They give you practice in skills, encourage you to meet other people with epilepsy, they show you that a whole group of people accept their lives through sharing their experiences, they give you comfort that you're not alone and last but not least they empower you through increasing knowledge and confidence - peace. Therefore the author thinks that epilepsy support groups are very important and play a vital role in encouraging the PWE that epilepsy is only ONE part of their lives.
- **Ivan Bielen (Croatia):** In Croatia we've learned that people with epilepsy have an unemployment rate of 47.5% . This rate is, unfortunately, similar throughout Europe and something needs to be done – soon! For this reduction networking is of vital importance:
- **Henrick Peerson (Norway):** Possible partners for networking are national/European/Worldwide ILAE organisations, other epilepsy associations, organisations who address the same issue. An example is the WHO, the national governments and the European Parliament; the list goes on!

  Examples for networking are increasing the health care services, the rehabilitation and the increasing of the governmental/European wide/worldwide research funding in epilepsy!
- **Natalija Kranjc (Slovenia):** What we've also learned is the fact that Slovenia is not in the position to do epilepsy surgery in their own country – the possible surgery candidates are being sent to France or Germany to do the surgery there. All the other diagnostic procedures before and after the surgery are being done in Slovenia. The question has to be raised, whether an epilepsy surgery unit is necessary in each country or if this collaboration should be an example for other countries/regions throughout Europe – even throughout the world!
- **Peter Wolf (Denmark):** Although epilepsy is not only the most frequent serious chronic disorder of the brain and has been present through the entire history of mankind, you can find rational and superstitious explanations of epilepsy. The fundament of a scientific understanding of epilepsy was expressed 2500 years ago by Hippocrates. But superstitions (e.g. the body is seized by a "spirit" which is



being exorcised by Christ, which you can find it in the bible – Marc 9, 14-29) are, unfortunately, great survivors. We have to increase our work to get those superstitions out of the "brains" of the population!

- **Vitomira Loncar (Croatia):** Last but not least we had a wonderful presentation from a Croatian lady who has epilepsy. In Croatia she is well known as a successful actress. Between 1989 and 1997 she was a huge TV star and had her personal everyday live TV show! However, since 2003 she had problems with flashing lights! Therefore the system "forced" her to retire, as she couldn't work in the job anymore. But she said that she could work in another job! Fortunately the family supported her as the system didn't!
- In 2006 she started studying and in 2011 she finished top of her class! She also started to raise awareness about epilepsy in Croatia, beginning this work in 2005 when she came 'out of the shadows' and spoke about her epilepsy. In 2008, February 14th was proclaimed by the Croatian parliament as national epilepsy day – unanimously! But she knows that further education is needed and she will be available for that in the future! The author would wish that more public persons come out of their shadows throughout the world!

OTHER EVENTS

The conference was, as you've just learned, very interesting. But outside the conference a lot of other events took place. The most important one of them was the visit of "Lipko" – the mascot of the European Basketball Championships, which took place one week after our conference. He took some of the delegates to a basketball court.

Three teams competed and the author was, unfortunately, on the team that made only third place. But not that third place was important, it was just important that "Lipko" was there – he gave us great support!

Michael Alexa, pictured above at the conference, is Vice-chair of the IBE European Regional Executive Committee.

Music for Epilepsy Calendar

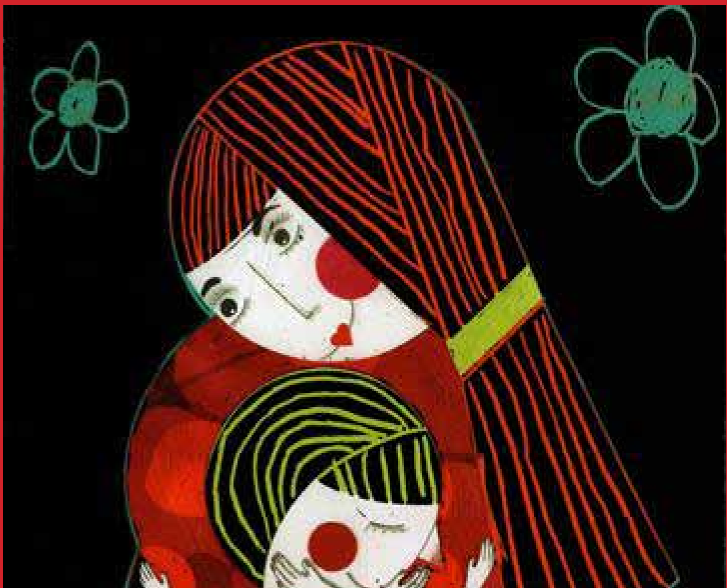
Every year a famous radio station called 'studio Brussels' organizes a major fund raising event 'Music for Life' in the week before Christmas. The idea is to motivate people to organize activities of all kinds to raise money and provide these initiatives with major media attention. This year they have chosen to support different organizations and the Flemish League against Epilepsy is one of their good causes.

The Flemish League against Epilepsy has therefor started an own initiative to raise awareness around epilepsy. We have organized a contest called 'Music for Epilepsy'. People related to epilepsy in any way were asked to make an artistic compilation. We selected nine beautiful works to be incorporated in a calendar for 2014. For this project we also worked together with a famous artist called Randall Casaer, who is known for his lovely illustrations.

The result is a very artistic calendar with some of the pictures that you can see here together with some short text about the artist in both Dutch and English. The Music for Epilepsy activity will start on Monday 2 December and our aim is to sell as many calendars as possible to support the organization. The calendar can be bought for 15 euro through our website

www.epilepsieliga.be

Thanks for all your support!



Have faith in yourself and your dreams...

Writing from Kazakhstan, Ivan's mother tells EPIfocus about her son

Ivan's pastimes of choice became the keyboard, hippotherapy and horseback riding. Vanya has been taking keyboard lessons with a tutor for more than two years, and going to hippotherapy a little over a year.

For us, hippotherapy was initially simply a therapy on horseback. Probably a lot of people think that hippotherapy is yet another amusing pastime, or a waste of time altogether, so they sit around at home.


Ivan with his biggest fan - his Mum!


With his coach, proudly displaying his awards


Ivan practicing keyboard

But as we were going through the course, we made the positive discovery that our convulsive muscle contractions immediately following seizures became less painful. It's only through careful time management that Ivan is able to continue attending regular school, take keyboard lessons, undergo hippotherapy and go swimming at the pool, which together improve both the main diagnosis and the associated conditions. Properly selecting treatment approaches for diagnoses, as well as regularly administering the prescribed medications and providing therapy catering to specific needs of the child, lead to more effective treatment, which is what we need in order to get well. Thanks to the non-profit association "SVS NEVRO", directed by Dr SV Savinov, we can use diagnostics to figure out the therapies to use next.

Over the course of treatment, we faced only two problems that we had to solve on our own. These were the fact that the subsidized drugs were repeatedly out of stock through to the end of the year (the illness requires that the medications be taken regularly) and that our main medicine (which is taken in capsule form and provides a therapeutic effect) was not available and we were provided with a replacement (pills that were ineffective).

One of the results of the work done by the equestrian coaches was a Children's Para-Equestrian Competition among children with limited physical abilities and those with impaired intellectual faculties held on 31 August 2013 in Vinnoye village in the East Kazakhstan Oblast. The children had such a wide variety of diagnoses, but were all equally driven to win.

Ivan won two first place prizes at the equestrian competition:

1. CI Division (Walk, Freestyle) in the Working Trot Event;
2. CI Division (Walk, Freestyle) Dzhimkhana Pole Bending".

We don't want to stop here; we aim to achieve our dream by claiming victory for our country, Kazakhstan. The Special Olympics is a special event for children with a compromised intellect. We, however, have faith in our dream of taking part in the Children's Paralympic Games, which are for children whose intellect is intact. And we have faith in those who will help us achieve our dream.

Conclusion: Ivan Naumik was born in 1999 with a diagnosis of residual organ encephalopathy, internal (minor) hydrocephaly, epilepsy (focal and generalized), with concurrent conditions; weak myopia, simple astigmatism, early form of optic nerve atrophy, bilateral hardness of hearing, second degree longitudinal flat foot, the left leg shorter than the other by 1.5 cm; Level 1 compensatory scoliosis of the lower thoracic spine; deformation of the rib cage - cariniform, and belonging to the Childhood Disability Group, has completed a rehabilitation course of lessons using the hippotherapy method, organized by the non-profit association 'AQ TAI Support Fund for Children with Disabilities' based at the equestrian complex at PKF TITAN LLP, over a period from 1 June 2012 through 31 August 2013.

As a result of the completed course: At the first stage (during the hippotherapy sessions themselves) substantial changes occurred in the child's physical condition: joint mobility and coordination improved, and muscle strength increased. Vanya's ability to bear physical and mental loads improved as well. Beginning in September the lessons started to include horseback riding skills training. His social circle grew substantially, which had a positive effect on his people-meeting and rapport-building skills. Vanya became more liberated, emotionally speaking, he became less self-conscious and his self-esteem grew.

During the sessions, an exercise was used for improving overall muscle tone, building the pectoral swing, for developing motor coordination, reducing the pain caused by convulsive muscle spasms, restoring metabolism and improving blood flow.

RARE DISEASES ON THE EU AGENDA

Opportunities for IBE member associations

Report: Sari Tervonen, Executive Director Finnish Epilepsy Assocation

In 2009, the Council of the European Union (EU) recommended that each EU member state should establish a national programme for the development of care, support and research of rare diseases by the end of 2013.

The programme will guideline the development of diagnostic, rehabilitation and social support for people with rare diseases. From the patient's perspective, an important aspect of the recommendation is equality and inclusion of people with rare diseases.

A disease is considered as being rare when there are fewer than 5 in every 10,000 of the population with the disease. The disease must also be chronic and/or life threatening. Many epilepsy syndromes are rare, including Dravet syndrome and Lennaux-Gastaut syndrome.

The Finnish Epilepsy Association (FEA) has been involved in planning the Finnish rare disease programme as a member of a Finnish network of rare diseases. The Finnish programme, which is ready to be launched in 2014 by the Ministry of Health and Social Affairs, gives an essential role to patient organizations on advocacy, information production and peer support activities.

All epilepsy associations throughout the EU should actively search for co-operation with medical and other professionals, as well with the other patient organisations that work for people with rare diseases. Many smaller groups of rare disease, also with rare epilepsies, have their own groups or even associations. If we have them as a part of the epilepsy organisation, together we are stronger as a part of civil society.

In addition, there will be both EU and national resources available for support services for people with rare diseases.

If the national epilepsy associations are not there lobbying their case, for sure there will be other organizations working on behalf of their members, and epilepsy could lose out.

FEA has organized events for people with rare diseases and their family members for many years. There are many subgroups, within the main group, which have needs to obtain special information, not only about epilepsies, but also, about the cause of their rare epilepsies. These rare syndromes lead often to learning (intellectual) and other severe disabilities. These people, with their parents and family members, need the advocacy support of the epilepsy associations.

For further information about rare diseases in the EU

http://ec.europa.eu/health/rare_diseases/portal/
www.ema-europa.eu
www.eurodis.org

***Photos by** Kalle Lydman*

***Left:** Children with Dravet syndrome enjoy social activities during the event organised for people with rare epilepsies and their family members by the Finnish Epilepsy Association*

***Below:** Parents of children with Dravet syndrome need peer support from each other. Peer support groups are led by a social worker or therapist during rehabilitation courses organized by the Finnish Epilepsy Association*

Epilepsy Connections' Weekend Break for Families

Families affected by childhood epilepsy spent an exciting September holiday weekend at Ardentinny Outdoor Education Centre on the shores of Loch Long in Argyll. Perfect autumn weather and dramatic Scottish scenery were the ideal backdrop for a fabulous, fun-filled couple of days of canoeing, sailing, orienteering, archery, abseiling and gorge-walking.

Epilepsy Connections Executive Director Shirley Maxwell said, "For all sorts of reasons children with epilepsy often find themselves excluded from challenging activities but this trip, supported by the Scottish Government's Short Breaks Fund and UCB Pharma, showed that adventure needn't be off-limits. And it was a great chance for parents, brothers and sisters to take a break from their usual busy caring routine, relax and enjoy family time together".

Families had a great time, and took full advantage of the activities on offer. One parent said, "It was so good to relax and not have you or your child judged and to be in an environment where you are supported and understood. It was a great weekend. I felt I was stress free for the first time in 10 years, and the whole family benefited tremendously."

CONTACT DETAILS

Epilepsy Connections provides a range of information, advice and support services to people of all ages affected by epilepsy and their families.

Epilepsy Connections
info@epilepsyconnections.org.uk
www.epilepsyconnections.org.uk

Ardentinny Outdoor Education Centre
www.ardentinnycentre.org.uk

Before the conference

As Janet Mifsud, IBE Vice President Europe, did not have the time to attend the annual meeting of the WHO Regional Committee for Europe, I had the honour to represent the IBE this year. But the work started, as usual, long before the conference was due to start. I had to register, as it turned out, twice; once on the homepage and the second time at the WHO regional office in Copenhagen. The second registration was very important as the WHO office organised a transfer from Izmir airport to Çeşme. This transfer was very important as Çeşme is about one hour drive from the airport in Izmir. When I arrived at the airport I wasn't the only one delegate who was being picked up – a small bus was full and the first connections were made during the transfer.

Introduction to the conference

Before the conference an introduction to the representatives of the NGO's was made. My plane landed at 17:10 and, as the transfer took longer than one hour, we arrived at 18:30 half an hour after the introduction started at the Sheraton. So, I only heard the last half hour.

I learned that I was only allowed to speak in the conference when the written statement, which has been submitted by the IBE to WHO, was on the agenda. During the rest of the conference I was obliged to listen to what the different countries did concerning all the different items on the agenda.

After this brief introduction, I had the possibility to record a written statement. It turned out that it was quite long – perhaps next time we should shorten it a little. After a check-in at the hotel, which was 10 walking minutes away from the Sheraton, I went back to the Sheraton for the first reception, which was hosted by the Health Minister of Turkey.

During the conference

During the conference all the NGOs had to remain silent, only the health ministers from the WHO Europe region were allowed to speak. They were seated in a U-shape formation – and they were not alone – each minister, or representative, had at least one of their leading health minister employees with them and they sat behind the ministers in the second row.

All the speeches and all the requests to speak were simultaneously translated into all the WHO Europe region official languages: English, German, French and Russian. In addition, it was also translated into Turkish. For each session all the papers were made available in English and in Russian and sometimes in the other official languages also.

Speaking requests were usually made in English and therefore the translation was not really necessary, at least for me. There were two women seated next to me and it turned out that one was from the International Nurses Federation while the other one was from the Turkish Nurses Federation. Both were very friendly and it would be great if we could intensify our work with them. Also I'd wish that we could intensify work with the International Federation of Medical Students Association – they were present with five members and had a lot of requests to speak - and some of them will become the future neurologists …!

One important issue on the agenda, and which was handled during the technical briefings, was the budget reform of WHO. Don't send a controller there, when the budget is an issue …. I could fill another page with all the problems which WHO had – and still has! Just a few highlights:

- In the past, WHO was donor driven – with donors giving funds to WHO and directing WHO on how it should be spent!
- In the past, the World Health Assembly (WHA) did not approve the secretariat budget but now it does!

63RD SESSION OF THE WHO REGIONAL COMMITTEE FOR EUROPE

16th-19th September 2013, Çeşme Izmir, Turkey

Report by Michael Alexa

- In the past, there were no targets for the secretariat; now the WHA sets targets! Any changes in targets have to be approved by the WHA!
- In the past, the budget of the secretariat was an internal matter; now it's a matter of the WHA! And the secretariat is accountable to the WHA for any changes!
- As just highlighted – money was given by the states and by the donors. Those two existing budgets (the assessed contributions (AC) from the member states and the voluntary contributions (VC) from donors) were merged to one, which has to be approved by the WHA! This has a huge impact, as through this action, WHO is not donor driven anymore – it will be state driven in the future! In addition the WHA has become very important – all changes, all the budgets and everything else has to be accepted by it.
- Last but not least, I learned that WHO doesn't have active controlling; it doesn't even have cost accounting! In future they plan to introduce a kind of process costing. Results: work plan ->team ->individual. All those can be measured and are usually shown in processes!

During the first two days, unfortunately, ***no*** NGO had the opportunity to ask to speak. The problem was that some of the county representatives spoke so long that the time for the NGOs ran out – indeed, from the first day the conference was already running behind schedule!

Why do I mention that? The IBE was scheduled for its written declaration during the Health 2020 session, which was scheduled for Tuesday morning. As we were running late, I couldn't speak in front of all the delegates. But as a result WHO reacted: Tuesday evening, before the closing the session, it was announced that the Regional Director of WHO, Mrs Zsuzsanna Jakab, would spend some of her spare time on Wednesday morning talking to the NGOs on how the partnership could be improved.

Mrs Jakab, who is from Hungary, arrived accompanied by the new meeting president Dr Daniel Reynders, from Malta. The Turkish health minister was represented by the Secretary of the meeting Mrs Dagmar Reitenbach, from Germany, and a member of the board Dr Busuttil, from Malta. All four stated that they were happy that so many NGOs were present and that they would like to have a statement on what the NGOs would like to see done in order to be able to act on wishes.

I made therefore the proposal that we could use the time on Wednesday afternoon, when the private meeting was taking place when some internal matters would be discussed, to talk about the possibilities of future collaboration between WHO and NGOs. The WHO Europe board was happy that this proposal came from the NGOs themselves. And we really managed to agree on a document.

If I would continue to go into detail on every item which has been dealt with, but then I'd need about 10 pages …

Every night another reception took place, giving a great opportunity to make new connections. I made many new contacts, especially with the Spanish delegation – don't ask me how … They stayed in the same hotel as me and I showed them how to walk to the Sheraton along the beach.

Although the wake up calls in my hotel didn't really work well, I didn't need them at all … The muezzin was calling 10 minutes to six each and every morning … so loud that you couldn't sleep anyway …

To summarize – it was a nice conference and in her last speech Mrs Zsuzsanna Jakab, Regional Director of WHO Europe, mentioned the NGOs three times and the collaboration between civil society and the WHO another two times. She also said that after this statement, which was read in front of all the ministers on Thursday afternoon before the end of the conference, if they haven't left already because of their obligations, WHO will have to think about a new way to intensify the collaboration between WHO and NGOs. But that's another story … which only time will tell!

NEWS FROM LITHUANIA

2013 has been both significant and successful for LESIA (Lithuanian Association of Integration of People with Epilepsy).

Implementing the recommendations given by WHO (World Health Organization) in 2010 and the EU (European Union) Written Declaration on Epilepsy (2011) LESIA has received increased attention.

The 20th June, 2013 marked the establishment of the Advocacy Group for Epilepsy in the Lithuanian Parliament, with members from fifteen different political parties joining the group. LESIA is very proud and happy about this event.

On the 15th October, 2013 LESIA welcomed two guests, IBE Executive Director Ann Little and Hanneke de Boer from SEIN, Netherlands, who came to learn about the work and achievements of LESIA. On the 18th October a meeting took place in the Lithuanian Parliament, during which Mrs Little and Mrs de Boer met with the Lithuanian Parliament Health Affairs chairman Dangutė Mikutienė, Members of Parliament and representatives of ministries. During the meeting IBE future plans and EU regulations for Member States were discussed, taking into account the needs of people with epilepsy in social, educational, medical and cultural areas.

LESIA, in concordance with the chairman of the Health Committee of the Lithuanian Parliament, Mrs Dangutė Mikutienė, announced a new campaign “Focus on Epilepsy 2013-2014”. This campaign is devoted to the training of Lithuanian police officers so that they will recognize seizures when they occur in public places in all major cities of Lithuania. Such training was already conducted in Vilnius and Kaunas. LESIA and the police officers are very pleased at the success of this training.

A very important task was conducted in 2013, when LESIA drafted the National People with Epilepsy document for its 2014-2018 programme, which shall be approved by the Lithuanian Government. A task group was created, consisting of representatives of Social Protection and Labour, Health, Education and Science ministries and LESIA representatives. The group is led by the undersecretary of Social Protection and Labour.

We would like to interact with other European countries, public organizations, in order to find out about their activities and to see if there are areas where we could cooperate together. Contact us at: epi@lesia.lt www.lesia.lt,

Meeting in the Lithuanian Parliament

Meeting of the Advocacy Group for Epilepsy: V Lukošaitis, V Zuzevičiūtė, D Murauskaitė, D Mikutienė, V Filipovičienė, S. Greičius

Meeting with Police Officers

Report from Montreal

Submitted by Michael Alexa

2013 MONTREAL 23rd - 27th JUNE, 2013
30th INTERNATIONAL EPILEPSY CONGRESS

Photos, from top:

- *New York Harbour boat trip*
- *The Capitol, Washington DC*
- *The Mall, Washington DC*
- *Outside the White House*

BEFORE THE CONFERENCE

As you might know from previous reports, I'm always combining congresses with some holidays. This time it was quite easy to choose the destination – it was the East of the USA – New York and Washington. One reason was the fact that there are direct flights from Vienna to New York and from Montreal via Toronto another direct flight back to Vienna. So I also needed one connection flight from Washington to Montreal, as I took a train from New York to Washington – they are just a 3 hour train journey apart …

NEW YORK

New York is a "crazy" city – but also lovely at the same time. My hotel wasn't in Manhattan; – it was in Brooklyn. This meant, which I hadn't foreseen, a one hour journey on the Subway system to get to the city centre. It was a funny experience. Everyone tells you that the underground in New York is unsafe – I don't know why, but I haven't experienced anything bad during my stay there. The only sight I couldn't visit was the Statue of Liberty – it was under reconstruction when I was there. But, more or less, everything else I've visited: boat trip around the harbour, walking down 5th Avenue, Times Square, Central Park, Grand Central Station, UNO, the Cable Car to the island and Ground Zero. Ground Zero was very interesting: they checked me completely – it felt like an airport with security controls. Security Controls will have another part later on in the story. Of course I also "visited" New York by night: Times Square is full of people. One funny thing was: on the second evening at Times Square I found a "Karaoke Bar". And if that is not weird enough, I met some Austrians in the bar and we performed together "Rock me Amadeus" from FALCO – and the whole audience joined us … Another funny part of the story is that the "R tunnel" was under reconstruction during my stay, but just at night. This meant that the underground line couldn't cross it so I had to change trains in the middle of the night … But fortunately I managed …

WASHINGTON

Washington is, contrary to New York, NOT a "crazy" city. You sometimes even have the feeling that Washington is sleeping, even during the day … But there's lots to see: The White House, Lincoln Memorial, Korean War Memorial, Martin Luther King Jr. Memorial, Franklin Delano Roosevelt Memorial, George Mason Memorial, Thomas Jefferson Memorial, the Bureau of Engraving and Printing (BEP), the Constitutional Gardens, the National Mall, the Washington Monument, lots of museums and last – but not least – Capitol Hill. And it's the Capitol that brings me back to security controls. The not so funny part of this story is that I'd bought a bottle of mineral water the night before. And the security guards wouldn't let me enter with a bottle of mineral water unopened! They thought that it could be a bomb! So it was very easy for me – I didn't enter the Capitol at all! My hotel in Washington was more or less in the city centre. And it had a pool – very convenient when you're walking all day long …

THE CONFERENCE

I arrived the day before the conference in Montreal. My friend from Ecuador, Dr Guadalupe (Lupita) Bonilla, was very happy that I accompanied her through the city. The conference itself was, as far as I know, one of the conferences with the least number of attendees, as I haven't seen too many Europeans. Please don't ask me why – I don't know.

Some of the speakers presentations can be found online – the link is http://www.epilepsymontreal2013.org/congress-highlights/presentations.974.html.

SOME HIGHLIGHTS

SUNDAY

IBE organised a symposium on international advocacy. During the session, the PAHO initiative, European Epilepsy Day, Chinese Epilepsy Day, and the National Walk for Epilepsy on the Mall in Washington DC were highlighted. A very important message was that a global epilepsy day is needed. But as the representative from the Autism Organisation said: “A World Day is only the first step. An integrated global strategy for a change is needed: Community engagement and mobilization is of vital importance.

- We need our own brand
- We need to organise global awareness events (a “life ball” like AIDS has)
- We need UN partnership / Member state support
- Community resource development
- Data collection and research
- Policy advocacy, development and implementation.

The workshop about international advocacy was followed by another interesting workshop: Act Local – think Global! Some important research facts are still missing:

- How many people have epilepsy? (Use population based studies?)
- What is the impact of epilepsy on those who have a diagnosis and family members who provide support?
- We need to “highlight figures” for policy makers – e.g. number of voters.
- We need to determine equitable research allocation.
- How many specialists per 100,000 population treat epilepsy in your country? – e.g. in Ireland you can find 24 specialists, although 42 would be needed!
- Which AED’s are already available in your country? How much do they cost?
- How much does the treatment of epilepsy cost in your country/region/ worldwide?

Philip Lee (UK): We need to identify the problem, do the research, get the evidence, communicate the evidence, make the change and measure the improvement!

Sarah Wilson (Australia): they created new software in Australia – Living with Epilepsy. It shows the personal views of patients and caregivers. The software can evaluate different numbers – e.g. mean age, mean education, living arrangements, employment situation and marital status – and of course compare it between patients and caregivers. Can we enlarge it for a worldwide database?

Last part of the Sunday was the Welcome Ceremony. It was, as usual, very nice.

MONDAY

During the Presidential Symposium an important question was raised: Who really has epilepsy? There are two problems: those people diagnosed with epilepsy, although they don’t have it, and those who are currently not diagnosed with epilepsy, but who have the disease. As a result: we need to have the “correct” figures for epilepsy. We can only influence politics, if the numbers are accurate!

Robert Cole (Australia) invited us to a meeting of the Editors Network. It’s of vital importance to share the problems and success which have been achieved!

Platform Session in the afternoon – Social issues: During this session a lot of questions were raised. One of them: could epilepsy affect patients’ marital status, which is a source of social support and a predictor of health status? The answer, which has been found in Chinese patients is – unfortunately – yes, as the divorce rate and the unemployment rate are higher than in the control group and the rate of not having a child is lower than in the control group. A lot of studies have been executed throughout the world to measure the stigma which accompanies epilepsy. The ILAE Stigma Task Force is working on synthesizing all of the evidence regarding stigma in epilepsy and will be making recommendations regarding “where to next?”.

Carlos Acevedo, as retiring IE News Editor, cuts the celebration birthday cake marking 50 years of IE News

Controversies Session – Costs and consequences of AEDs: At first it was shown to us that new medications are superior to old medications. But are they really? Do they have a greater efficacy? Are they better tolerated by patients? Do they have fewer chronic problems? All those questions can’t be answered – yet. For some of the new medications the time is too short, as they have just been introduced to the market. Another important issue is that about 80 % of people with epilepsy live in resource poor countries (e.g. China, India). In those countries the old medication is still of vital importance, as the people with epilepsy can’t afford the new AEDs.

TUESDAY

The discussion on stigma, which had begun already on Sunday, continued on Tuesday. Gretchen Birbeck (USA, Zambia) showed us that better measures of stigma on epilepsy are needed. She also said that knowledge, attitude and practice (KAP) data needs to be validated – does this data really reflect how people behave? There is a need to develop quality indicators for epilepsy care in low income countries. Long term studies should be focussing on areas such as:

- Does stigma reduction improve care setting? Yes/No? Why/Why not? Reasons?
- Are improved KAP scores accompanied by better care? More appropriate behaviour by power entities?

Another important discussion was on the cost of epilepsy. There are different methods to do this:

- Top down
- Incidence / prevalence based
- Longitudinal (collecting data for a specific period of time) / cross sectorial studies (they form a class of research method that involves observation of a population, or a representative subset, at one specific point in time.)

Another aspect is, which costs do we include in the studies

- Direct costs only (e.g. medication, hospital)
- Direct + indirect costs (e.g. early retirement, unemployment costs)

One more aspect that needs to be addressed is the language issue. Some of the studies, such as in Austria, are being published in German and not in English. Therefore those studies, although they exist, are not being included in the global survey. This needs to change fast!

Last but not least, the burden of epilepsy is greatest in low income countries (e.g. Kenya), the treatment gap is highest in those countries, the cost of widely available AEDs near the limit of average expenditure of health in low income countries, the cost of hospital visits is about twice the costs of clinic costs and the costs of traditional treatment is undetermined in those countries.

The cost of illness studies vary – even throughout Europe. There needs to be a global set up for the studies to make the numbers comparable throughout the world. Otherwise we'll never have a "worldwide" cost of epilepsy!

The platform session epilepsy in the developing world showed some interesting facts:

- A study from China showed that a moderate correlation was found between the changes in AED adherence and seizure control and a weaker correlation was found between lifestyle and seizure control. AED adherence has been studied in industrial nations for decades, but in developing countries reports were relatively limited.
- In Pakistan a poor compliance rate exists, which is being caused by inconsistent availability of AEDs, lack of awareness, erroneous socio-cultural beliefs, costs, spurious drugs and poor counselling doctor patient ratio.

The next session was very important: the controversies session about guidelines:- PRO: there are different kinds of studies being performed throughout the world. The most important, as well as most expensive, is a randomised, controlled, clinical trial (RCT) which lasts at least 48 weeks and its primary outcome is efficacy or effectiveness. The study must be double blind, superiority must be demonstrated, the study exit is not forced by a predetermined number and an appropriate statistical analysis must take place. Only if ALL those criteria are met, can you call it a Class I study. Studies which are lasting between 24 and 48 weeks are being called Class II studies. It can be called a Class III study when none of the criteria of the Class I or Class II studies are met. You are referring to a Class IV study when only expert reports can be found. The problem is that only a limited number of well designed, properly conducted epilepsy clinical trials can be found! When selecting a patient's AED, all variables and not just efficacy and effectiveness, should be considered!

WEDNESDAY

Classification of epilepsies continued:

- Immune mediated epilepsies may account for 15% to 23% of epilepsies with unknown causes. Not every antibody may be disease relevant but there may be cases with abnormal standard CSF studies. They might form a separate group within the organisations of epilepsies.
- Another important issue, which has been raised, was the influence of the animal models – how should the ILAE organization of the human epilepsies influence our thinking about animal models? The goal would be to create an animal model for each of the human epilepsies, and include every possible feature for each of the human epilepsies. This goal is – probably – not feasible.

Photos, from top:

- *Athanasios Covanis, as incoming IBE President, addresses delegates at the Opening Ceremony*
- *Gay Mitchell MEP is presented with the Ambassador for Epilepsy Award by Mike Glynn and Nico Moshé, outgoing IBE and ILAE Presidents*
- *Karen Harvey from the IBE office mans the IBE stand in the Exhibition Hall*

Lupita Bonilla and friends take time out in Montreal

Political advocacy: raising awareness and funding for epilepsy.

One important message, for me at least, is the fact that they had to find a “new name” for epilepsy in South Korea. The reason is simple: the former Korean characters which symbolise epilepsy, had a negative effect, the new name for epilepsy “noi-jeon-jeug” doesn’t. It automatically created awareness, as people were “forced” to talk about epilepsy. But the process of renaming epilepsy in Korea is just the beginning of a long journey against epilepsy.

Another important message was related by Sandy Finucane (USA). Her key actions to change the public health policy are:

- Have a plan, message and agenda – a public blue print for action is needed.
- Establish partners among epilepsy organisations with similar goals, other organisations with similar goals and partners in delivery services.
- Build relationships and agree actions, such as research activities, with these partners.
- Utilize a variety of advocacy tools – lobbyists, advocacy networks, hearings, congressional meetings - to create awareness, and events to mobilize advocates.
- Use committees and circles for advocacy, e.g. WHO, EU, government agencies.
- And, last but not least, don’t give up.

The afternoon was filled with general assemblies – IBE and ILAE. I attended the IBE general assembly. I met many old friends there … It was interesting to hear what was going on in the world during the last two years – and Europe played a leading role in it through developing the EED, the written declaration on epilepsy, the Epilepsy Advocacy Europe task force and the European Forum on Epilepsy Research. After the reports, the results of the elections for the next four years of the different committees were announced – including the new president: Dr Athanasios “Thanos” Covanis – Greece.

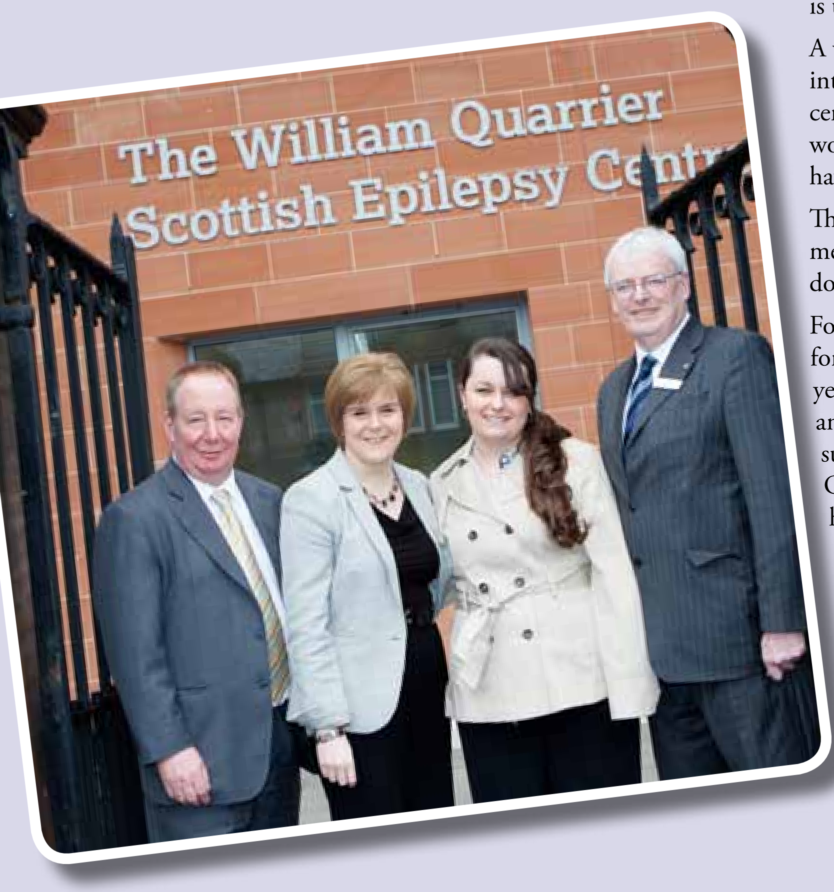
THURSDAY

The highlight of Thursday was the “Epi-Quiz: Mission impossible”. Doctors tried to answer difficult questions – sometimes they failed – but still it was a lot of fun – and everyone learned a lot.

BESIDES THE CONFERENCE

As usual, I spent a few more days in Montreal. It’s a nice city and a lot to see – from the Olympic Park and the cathedral of Montreal to the city centre and the shopping streets – above ground (shopping centres) and below ground (a passage way is connecting all the shopping centres). You can spend a lot of time there – especially if you have such a lovely companion by your side like Dr Guadalupe (Lupita) Bonilla!

STATE OF THE ART EPILEPSY CENTRE OPENS IN SCOTLAND



Deputy First Minister of Scotland, Nicola Sturgeon *(second from left)* joined former patient Kelsey Durham *(third from left)* to unveil a plaque to mark the opening recently of a new epilepsy centre in Glasgow. The William Quarrier Scottish Epilepsy Centre is the only one of its kind in Scotland, offering assessment for people with complex epilepsy and diagnosis where the condition is uncertain. Around 100 patients will be admitted each year.

A wireless enabled video telemetry system, which has built-in integrated observation and alerts has been installed in the new centre with technology never before used anywhere else in the world. This allows patients to freely roam the centre while still have integrated video and EEG monitoring.

The majority of Scotland’s trainee neurologists will have placements at the centre, which will also deliver training for family doctors, nurses and conduct cutting-edge research into epilepsy.

Former patient Kelsey Durham, said that Quarriers had transformed her life. She said:“When I first came to Quarriers four years ago I was a prisoner to epilepsy, and I couldn’t take part in any of the usual activities teenagers do with their friends. It was such a relief when I was given a clear diagnosis of my epilepsy at Quarriers. My condition is now managed by medication and I have got my life back.

Chief Executive, Paul Moore *(fourth from left)* said: “This marks the start of a new chapter in the history of the charity’s services for people with epilepsy which have been going for more than a century. “The vision of the charity’s founder, William Quarrier, is very much embodied in this new state-of-the-art centre which will truly transform lives.” Also in the photo: Mr Bill Scott, Chair of Fundraisers. Quarriers is an Associate Member of IBE.

4TH SEIN COURSE ON CLINICAL EPILEPTOLOGY

The 4th SEIN Course on Clinical Epileptology was held in Heemstede, the Netherlands from 9th to 20th September 2013.

Although Autumn seemed to make an early entrance, the students received a warm welcome from everyone at SEIN. On Sunday evening, 8th September, a small, informal welcome reception was organised at the hotel where the students were staying, to break the ice and to give everyone the opportunity to meet course organisers and fellow course participants.

The course lasted two weeks (10 working days), with nine days at SEIN – Epilepsy Institute in the Netherlands - in Heemstede and one day at the Free University in Amsterdam. After these intense weeks the participants returned to their own countries, tired but fulfilled. The students found the course to be of great use and exhilarating.

SEIN is a tertiary epilepsy centre in the Netherlands, founded in 1882, which provides specialised multi-disciplinary care to people with complex forms of epilepsy. The mission of SEIN is to improve the quality of life of people with epilepsy worldwide. This course aims to contribute to this mission.

The students gained a great deal of knowledge during their stay at SEIN and they have now taken this knowledge home to apply it in their own clinical settings, as well as to share their new insights with their colleagues.

This year's participants came from Europe (Albania, Bosnia & Herzegovina, Georgia, Montenegro, Portugal, Turkey), Africa (D.R. Congo, Ghana and Namibia), South East Asia (Indonesia, Myanmar) and the Western Pacific (China). A total of 16 young doctors, with varied medical backgrounds but all with a common interest in epilepsy, participated in the course, .

A number of Dutch fellows currently working at SEIN also participated in the course, either in full, or for selected topics. One of the Dutch students commented that she felt it was a highly informative course in which all aspects of epilepsy were presented in an interactive manner. Besides this, it was also a unique experience to hear from the participants about the (social) consequences of epilepsy for people with the disease in other countries.

A number of well-known speakers contributed their expertise and time to the programme. In total, 28 national and four international speakers participated. The programme consisted of didactic sessions, interactive group discussions, workshops and site visits.

Social activities included the already mentioned welcome reception, a group outing and a closing dinner.

A new topic to this year's programme was: Epilepsy Care in Student's Own Countries. This interactive session was added to the programme to stimulate the students to think about epilepsy care in their own settings, and how they could improve this.

At the end of each day there were feedback sessions during which the students had the opportunity to discuss the topics that were covered during that day or any other issues which came up.

The World Health Organization, African Regional Office, funded two participants from the African Region: D.R. Congo and Namibia. These participants are involved in epilepsy projects in their own countries and the course was a perfect opportunity to contribute to capacity building there. Furthermore, participants from Ghana and Myanmar were partially sponsored through WHO demonstration projects in their respective countries.

This year we were also able to receive funding from NUFFIC for two students: one from Bosnia & Herzegovina and one from Myanmar. Funding covered the costs for their participation, travel and accommodation. Unfortunately, because of budgetary restrictions, due to the ongoing financial crisis, NUFFIC was not able to sponsor additional students.

NUFFIC is the Netherlands' organisation for international cooperation in higher education. As an independent, non-profit organisation based in The Hague, the Netherlands, NUFFIC supports internationalisation in higher education, research and professional education in the Netherlands and abroad, and helps improve access to higher education worldwide.

FUTURE CONGRESSES

2nd AFRICAN EPILEPSY CONGRESS
CAPE TOWN, SOUTH AFRICA
22nd – 24th May 2014

11th European Congress on Epileptology
STOCKHOLM
29th June - 3rd July 2014
ILAE-CEA

10TH ASIAN & OCEANIAN
Epilepsy
CONGRESS
SINGAPORE 2014
7 - 10 AUGUST

17-20 Setiembre 2014
BUENOS·AIRES
VIII CONGRESO LATINOAMERICANO DE EPILEPSIA

31st International
Epilepsy Congress
06-10 September 2015
Istanbul 2015

www.epilepsycongress.org