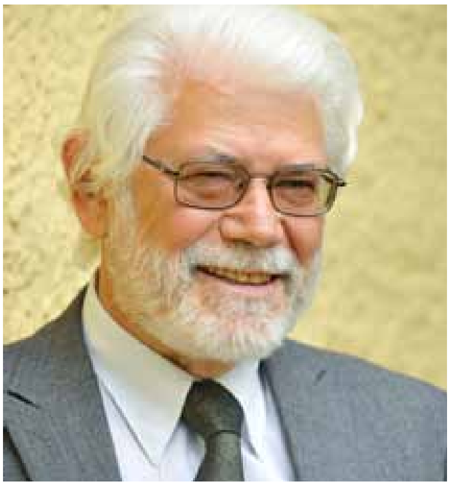
EPI Focus

Newsletter of the IBE European Regional Committee

ISSUE 4



Dear European Members

Dear friends and readers

We are about to edit the 1st EPIFocus of the current year, the 4th issue in total and you - our readers and authors - continue to be the backbone of the journal.

There are several reports on activities in the European Region in this issue. However, more reports are needed, particularly from those parts of Europe that still need to come "out of shadows" and show their presence in EPIFocus. This is your Journal, that depends on the input of your material and you should be very proud of it. Reporting your activities will act as a stimulus to other IBE/Members to become more active. EREC would like to thank you and encourage you to continue.

This year Europe celebrated a very successful 2nd European Epilepsy Day on February 14th, with the theme the Burden of Epilepsy. The co-chairs of the IBE-ILAE Joint Task Force - Epilepsy Advocacy Europe - travelled to Strasbourg to meet the MEPs from Greece, the UK, Hungary, Slovakia, Netherlands, Italy and Czech Republic. In addition, 60 wonderful photographs from the IBE Jubilee Photography Competition were on display in the parliament building to celebrate the event.

More importantly, it is very heartening to hear of the interesting and successful activities organised by IBE and ILAE associations throughout Europe to celebrate European Epilepsy Day. I hope that this great opportunity to highlight epilepsy across Europe will continue to grow and develop in the coming years.

I am delighted to announce that the dates for the next Epilepsy & Society Conference are now confirmed. The meeting will take place in the beautiful city of Ljubljana, Slovenia from the 28th to 30th August 2013. The European Regional Executive Committee met recently in Dublin to finalise the programme, together with two of our colleagues from Slovenia. It is a terrific programme, full of interesting sessions and, of course, excellent speakers. We have chosen as the congress theme: *Break Down the Barriers and Stand Up for Epilepsy*!

As I write this letter to you, Janet Mifsud, a member of the European Regional Executive Committee, is attending the annual WHO European Regional meeting in Malta at which she has been allotted two minutes for an oral presentation, in addition to a short written submission. This is a fantastic opportunity to bring epilepsy even more into focus in the WHO.

Other upcoming activities in Europe include a workshop in Brussels on the prevalence of epilepsy, organised by the Joint Task Force. Preparations are underway and we should have more information in the next few weeks. I hope that many IBE member associations will be able to send representatives to this meeting.

Already there are plans in place for 2013. European Epilepsy Day will take place on Monday 11th February and the theme has been chosen as Stand Up for Epilepsy: No seizures, No side effects. Further information will be available in the coming months on how the event will be celebrated in the European Parliament.

Also next year, during the Irish Presidency of the European Parliament, a special forum on research is being organised by the Joint Task Force. This event has received support from EU funds. The programme is almost complete and we will have more information available to us soon.

On a happy note, we are delighted to have in the family of IBE/EU Members the Albanian Association of Epilepsy, as a full Member and the Epilepsy Association "Doctors for Support", Serbia as an Associate Member. Both are welcome. We congratulate Dr Jera Kruja and Dr Biljana Kohen and all the members of their associations for their efforts and achievement.

Finally, for those IBE members who are reading this newsletter in London, I hope that you will be able to come along to the informal meeting we have arranged to take place on Tuesday 2nd October from 13:00-15:00 in Tactic Room 5. I hope to see you there!

With best wishes,

Athanasios Covanis
Chair, IBE European Regional Executive Committee
Member: Commission of European Affairs

IN THIS ISSUE

EREC Officers

Chair: Thanos Covanis, Greece
Vice chair: Michael Alexa, Austria
Members: Victoria Dimech, Malta
Seppo Sarkkula, Finland
Svetlana Simic, Slovenia
Ex officio: Janet Mifsud, Malta
Mike Glynn, Ireland

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Summer Camp for Children With Epilepsy a major success in Croatia

The Croatian Association for Epilepsy organized a Summer Camp for children with epilepsy in both 2010 and 2011, together with the University Hospital Centre Zagreb and University Hospital Centre "Sestre milosrdnice". The first camp took place at Fužine, a small settlement in the Croatian mountain area of Gorski Kotar, and the second in Selce, a popular seaside resort. The participants were children with epilepsy aged 8-18 years.

The main goal of these camps was to increase self-esteem, improve self-efficiency in disease management, facilitate adaptation to illness and to avoid development of psychological problems arising from the sense of being different from their peers. Sometimes, the camp is the only place where children meet someone who has the same illness and is a place where they don't feel different from their peers.

Daily Camp activities included different workshops (socialization, team building, creative arts), sightseeing trips, games, competitions and social program. Educational activities included medical and psychological workshops. Camp staff included pediatric neurologists, psychologists, paediatricians, registered nurses, trained volunteers and camp personnel. The Camps were reported on in the public media (TV, newspapers, electronic media) which made it possible for the general public and people coping with epilepsy to find out more about this project.

At the beginning and at the end of the Camp participants filled out epilepsy knowledge test and a questionnaire drawn up to determine psychological adjustment. Before returning home participants filled out a camp validation questionnaire.

Results showed that, during their stay, children improved their knowledge on epilepsy and showed more positive attitudes about living with epilepsy at the end of the camp. All participants found the Camp a happy place, interesting and useful and indicated that they wished to attend the camp the following year. Most camp participants stated that socializing with other children helped them to cope better with epilepsy.

All campers discovered that they are not the only ones to have epilepsy and were encouraged to reach their full potential and to live a full and active life. It gives us great pleasure to provide this notion through our Summer Camp for Children With Epilepsy 2012.

Epilepsy Action UK launches its magazine on Kindle!

Epilepsy Action has become the first UK epilepsy charity to launch its member magazine, *Epilepsy Today* on Amazon's Kindle eReader.

The publication is the only dedicated epilepsy magazine that can be downloaded and read on a Kindle. It can also be read on smartphones, tablets or computers, using the free Kindle app.

Epilepsy Today is produced six times a year and contains news on epilepsy research and treatment, inspiring features from people living with epilepsy and updates on the charity's work.

The publication is currently available to Epilepsy Action members and non-members through membership or a magazine subscription. Printed copies of Epilepsy Today are distributed to the majority of the charity's members.

Philip Lee, chief executive at Epilepsy Action, said: "This is an exciting time for Epilepsy Today and is the next step in taking the publication to new audiences. eReaders, like the Kindle, are becoming increasingly popular. By making the publication available on Amazon we hope to reach people with epilepsy across the globe."

Peter Fox, editor of Epilepsy Today says: "Epilepsy Today is the first epilepsy magazine to appear on the Kindle. It's a very exciting step!"

Epilepsy Today will be available to buy on Amazon to readers in 100 countries. It costs £3.99 for one issue or £17.88 for an annual subscription.

To find out more, visit the association's website at www.epilepsy.org.uk.

National Conference in MALTA

More than 100 delegates attended the National Epilepsy Conference organised by Caritas Malta Epilepsy Association and Dr Janet Mifsud, IBE Vice President Europe from the Dept of Clinical Pharmacology and Therapeutics, University of Malta. The meeting was opened by Monsignor Dun Victor Grech, Director, and Mr Mario Dimech, President, Caritas Malta Epilepsy Association. The European Union Health Commissioner, John Dalli spoke about the initiatives being taken by the Commission, which has recognised the importance of prioritising epilepsy as a major disease since it affects about 6 million people in Europe and 20 million family members. This follows approval of the EU Written Declaration on Epilepsy late last year.

The key note speeches were made by Prof Mike Kerr, Dept of Psychological Medicine & Neurology, University of Cardiff and Ms Hanneke de Boer, Coordinator, ILAE/IBE/WHO Global Campaign Against Epilepsy.

The conference presented an innovative way of understanding epilepsy through an interactive session which consisted of a play written by Giovanni Attard, with Bernardo Riolo and Daniela Micallef in the main roles. This was followed by a panel discussion.

The conference highlighted how epilepsy presents a global problem affecting all ages, social classes, groups and countries.

Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder “into the shadows”. The most significant problems people with epilepsy encounter in daily life often are not related to the severity of the condition, but stem from misconceptions held by the general public. The impact of epilepsy on social functioning, or the ability to participate in a broad range of social activities and interpersonal relationships, can be quite varied. People with epilepsy have a higher prevalence of social problems than those from the general population. Children and adolescents often suffer from overprotection within the families and at school. In adult life problems are reported concerning obtaining and retaining employment, which is confirmed by research findings. Older people like younger ones suffer a loss of confidence. They may lose their functional independence.

All chronic conditions have an impact on quality of life; however, the impact of epilepsy may be greater partly because of the unpredictability of the seizures and partly because of the associated stigma.

Gravesend Epilepsy Network celebrates its Big Three-O!

Lynn Savill MBE, Counsellor at the association, sent us this short report of a happy anniversary party.

Gravesend Epilepsy Network in the UK celebrated its 30th Anniversary in September with a party for over 90 Members of the charity both past and present. The party was held at a hotel in Kent, with ‘hosts’ at the entrance who directed all guests into an official photographer taking portrait photos of everyone.

A DJ played discreet background music early in the evening allowing everyone time to catch up with their news. The music was then ‘cranked up’ to get everyone dancing to end the evening on a high.

Several local dignitaries were invited, and Chris Simmons, a long time supporter, who is a well known actor from a popular UK television series called ‘The Bill’, came along and had his photo taken with a large number of guests, amid a lot of excitement.

There were also friends from other epilepsy organisations in the UK. We are now looking forward to our 40th!

9th Asian & Oceanian Epilepsy Congress,
Manila, The Philippines

Report from Michael Alexa, Secretary, IBE European Regional Executive Committee

Before the Congress

This time it was different. As there are no direct flights from Austria to the Philippines, I decided to combine the Philippines with a visit to Japan.

I visited some historical cities in Japan: Hiroshima and Osaka. Hiroshima, where the first atomic bomb was dropped, astonished me by its beauty and charm. I also visited Shukkeien garden, and another "world cultural heritage" venue in Japan – the Itsukumatsu Shrine at Miyajima – which is situated close to Hiroshima. It's really incredible what the Japanese architects did hundreds of years ago!

I continued on to Osaka. I can tell you that you've never ever seen so many shrines next to skyscrapers – it's really incredible how Japan is trying to preserve its past and at the same time make enough space for the latest developments! Osaka My personal highlight of Osaka was a visit to Grand Sumo Wrestling! I've seen Sumo Wrestling on TV and I always wanted to see it live one day! You wouldn't believe it, but the "big and fat" wrestlers don't always win against the "small and wiry" wrestlers!

The next part of my journey was Manila. Manila is a city where you find a lot of cars and taxis, too much traffic and more or less no public transport! Only two underground lines for 12 million inhabitants – Vienna has 1.7 million inhabitants and 5 underground lines! But taxis are very cheap; from my hotel to the conference center, which is about 7 km away, cost about 200 pesos, or four euro one way!

Manila is a very nice city and has a lot to offer with several historic sights, good food and the biggest shopping mall in Asia.

Day One of the Congress

My conference diary started with the editors meeting, which has been arranged by Robert Cole from Australia. I arrived a little late but I still had the opportunity to raise a question: "Why does the Manila Bulletin, one of the largest newspapers on the Philippines, write that you should hide chronic diseases when applying for a job!"

After the Chairman's Symposium, which gave us insights on the latest developments on the epileptic networks, the Masakazu Seino Memorial Lecture and its speaker Jean Gotman turned our attention to high frequency oscillations (HFO); a new marker of the epileptic region.

Afterwards I attended the session: The need to advocate for epilepsy funding: How advocacy is working around the world. The different speakers told us a lot about the developments within their regions. One interesting point is that Europe (European Declaration on Epilepsy), Latin America (Pan American Health initiative for epilepsy) and North America (the IOM report, which was the first study on epilepsy in the USA), have their kind of "Epilepsy Declaration" – while Asia and Africa, two continents with large populations, don't! It was also pointed out that similarities within those declarations should be identified and they should result in a "Global Epilepsy Declaration". Let's hope this works!

The Opening Ceremony was fantastic, with wonderful food and entertainment.

Day Two

Latest developments in research

Friday started with the main Session and it's post main Session: Epilepsy genes and beyond. This was followed by a Satellite Symposium titled Epilepsy: from diagnosis to management.

A Global Campaign Against Epilepsy (GCAE) workshop gave us an update on the most recent developments in the AOEC region under the auspices of the campaign.

We started in the Philippines with the Epilepsy Manager Project (a non-neurologist/physician who renders medical care to people with epilepsy at primary care level); continued with guidelines for the management of epilepsy in India (GEMIND); and ended in Australia with an important lesson on evaluation of research in Asia.

This was followed by the second satellite symposium of the congress: An updated view on the clinical uses of Magneto Encephalography in epilepsy.

Day Three

Epilepsy and Society Symposium

Saturday was – at least for me – reserved for the Epilepsy and Society Symposium, with the best doctors of the region presenting the latest data to people with epilepsy in the region! At the end of each session a person with epilepsy or a parent told us their experiences of epilepsy. It was a really marvelous day!

Empowering people with epilepsy: IBE President Mike Glynn gave us an overview: empowerment consists of many factors:

Photo left: Michael Alexa pictured in front of Osaka Castle
Photo below: The atomic bomb dome at Hiroshima

The Itsukumatsu Shrine at Miyajima

access to social and cultural activities, driving, education, employment, information, specialist diagnosis/treatment, supply of antiepileptic drugs and training.

The day started with a great kick off: as everyone knows, it's hard to find a job nowadays. And when you've got epilepsy it's even more difficult. But at the conference we had a nice lady who taught me an important lesson: My career is in my hands! I need skills, values, professionalism, and to overcome barriers to reach my career goal! Don't stop working on yourself; you're the product and the employer is your customer!

Dr Ding Ding updated us on the China Seahorse Club – a club which runs a successful art workshop people with epilepsy.

A similar initiative was presented by Maria Isabella Calilung from the Philippines called the Livelihood Project. People with epilepsy sold organic dishwashing and hand washing soaps with the income generated divided among the participants, thus helping with the purchase of their AEDs.

Anxiety and depression in epilepsy

Between 50% and 60% of all the people with chronic epilepsy have various mood disorders – including anxiety, while in the "normal" population the percentage is only about 20%. The message was that if you treat epilepsy, you also treat anxiety and vice versa! People with epilepsy, their parents and partners also experience anticipatory anxiety. Anticipatory anxiety occurs when people are contemplating the possibility of a negative outcome or personal catastrophe that is yet to happen - may not even happen – and this can lead to feelings of shame and stigma. If you are informed about your seizure condition, inform others about what to do when you have a seizure, take your medications regularly, etc. you gain control over the anticipatory anxiety. Depression is also being found in about 50% of the PWE!

The mom with epilepsy

The afternoon session dealt with other very important questions: should women with epilepsy have children? What about breastfeeding? Is infant stimulation for women with epilepsy possible? AEDs, seizures in the postpartum period, caring for a baby (will I drop it during a seizure?) were others. Jeanne Desiree Dumlao-Khonghun from the Philippine association showed us that having epilepsy is not a bar to successful motherhood provided precautions are taken and there is medical guidance!

Day Four

Epilepsy and the developing brain

The most important question Tomonori Ono (JPN) raised was: Do early life seizures cause cognitive decline, such as learning and memory impairments in later life? Terry O'Brien (AUS) talked about the effects of foetal exposure to AEDs on pre and post natal brain development. He told us about the Australian Pregnancy Register that is being used to gather more information about the pre and post natal effects of AEDs.

Sex and Epilepsy

Sarah Wilson (AUS) started the session off with sex after surgery. Sex starts in the brain – especially in the frontal lobe. If now a part of the brain is removed, a person with epilepsy may experience a sexual change after surgery. Christine Walker (AUS) continued with beyond the clinical: counseling someone with epilepsy to deal with their sexual problems.

Last but not least Dr Ding Ding gave a speech about sexual dysfunction of people with epilepsy in China. She told us that sexuality is an important factor in Health Related Quality of Life (HRQOL).

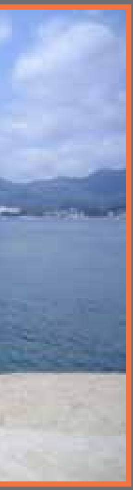
Dr Ding Ding presented the results of the first study on sexuality and epilepsy in China. Sexual dysfunction was observed, especially in women with epilepsy. The sexual dysfunction was associated with several factors including quality of life and education levels.

After the Conference

Boracay Island

After the congress I spent a few very pleasant days on the island of Boracay, which is about one hour's flight south of Manila. Boracay is a very lovely island with clear beaches and hotels everywhere! I went swimming in the Pacific Ocean and used the hotel pool … Unfortunately it was also raining – but it's such a warm rain that you can enjoy it!

I returned home with many pleasant memories.



Enjoying the Gala Evening with, from left Dr Dede Gunaman, Indonesia and Dr Ding Ding, China

Sumo Wrestling: The "big and fat" wrestlers don't always win against the "small and wiry" wrestlers!

NEWS FROM GREECE

Tata Vassou, Executive Board Member, Greek Association against Epilepsy (GrAAE) reports

Since the last EPIFocus was published, the Greek Association against Epilepsy (GRAAE) has organized two major events.

A night at the Theatre

In November 2011, the GrAAE organized a theatrical event at the Moraitis school theatre, performed by amateur actors from the Center of Art and Culture of the Municipality of Maroussi district of Athens. Amongst the actors was a Member of the Greek Association, Andriani Ioannidou. A significant play named "*Our Great Circus*" was written by Jacob Kabanellis. The plot runs through Greek history from the years Greece was under Turkish rule and other rulers, via the Asia Minor Catastrophe, to the events of the Second World War and right up to recent years. The scenes, through the representation of historical moments of Greece's past, are sometimes satirical, sometimes thoughtful, but always sharp and critical, intensifying the emotional charge with musical bridges from the whole spectrum of Greek music, between the scenes. Epilepsy nurse Panayiota Nasiopoulou with her two children, and with some people with epilepsy, together with Anastassia Vassou (Tata), ensured a smoothly run event. It was well attended: teachers and students of the Moraiti School, many members of the Greek Association and various people from the district of Maroussi came along. An enjoyable evening was had by all. The GrAAE benefitted financially from the event.

European Epilepsy Day

Unfortunately this year, due to destructive demonstrations in the centre of Athens as a result of the economical crisis and austerity measures in Greece, we were unable to celebrate European Epilepsy Day on February 14th. Instead this was done during the Greek Pan-Hellenic Epilepsy Conference from March 28th to 30th from 11:00am to 5:00pm, at a central point of Athens in Glamour Garden - Zappeion next to the Greek Parliament. Members of the Association distributed information material and answered questions on many aspects of epilepsy. The vision of the GrAAE is to change the fear, ignorance and stigma that pervades epilepsy in society. Many people showed an interest to stop at the stands and to ask questions on various epilepsy issues and to collect information leaflets.

Members of the Executive Board together with volunteers, who constitute the basic core of our Association, were present to help us implement our objectives. The establishment of European Epilepsy Day and the celebration of the event in all EU Member States is a resounding effort to address both epilepsy and ways to fight against social prejudice for people with epilepsy worldwide.

"We want to live in a world that treats people with epilepsy, based on scientific facts rather than on prejudices and myths"

IBE welcomes new Associate Member from Serbia

On the 1st June, Epilepsy Association - Doctors for Support, Serbia was approved as an Associate Member of IBE.

Epilepsy Association was founded in June, 2011. as a group of doctors and patients in Serbia who have come together to help people with epilepsy and their families by fighting epilepsy stigmatization and providing support and help. Since its founding, Epilepsy Association has initiated successes in the proclamation of the 14th of February and the 26th of March in 2012 as National Epilepsy Day and Purple Day for Epilepsy, as well as conducted a survey involving more than 250 representatives of all age groups and professions on epilepsy-related knowledge and epilepsy stigma.

On the 14th of February, the Association organized a lecture on epilepsy for its member and the general public, following the release of coloured balloons symbolizing the unity of all 6,000,000 people with epilepsy in Europe. The activities concluded with a visit to the clinic for neurology and psychiatry for children and young people where sweets and balloons were given to the hospitalized children.

Since then the Association has marked Purple Day for Epilepsy with a public gathering in downtown Belgrade where brochures on the topic "How to help a person during an epileptic seizure", flyers and lavender balloons were distributed to passerbys. In coordination with ILAE's initiative SUFE (Stand up for Epilepsy) the Association is right now in preparation of a program involving the inclusion of children with epilepsy in sports.

RUSSIA CELEBRATES EUROPEAN EPILEPSY DAY

The 14th of February is a special day for people with epilepsy, their relatives, doctors, researchers and public organizations. Through the initiative of the International Bureau for Epilepsy (IBE) and ILAE a new holiday has been established — European Epilepy Day, which was celebrated first time in 2011 and was timed to St. Valentine's Day. Saint Valentine is considered as patron of people who suffer from epilepsy. In Russia, Saint Tryphon plays the same role for people with epilepsy and the Orthodox Church celebrates the day of that saint also on 14th February.

In honor of the First European Epilepsy Day in Russia there was a charity concert held in the State Museum of the famous Russian poet Alexander Pushkin. The Youth Symphony Orchestra of Russia performed for people with epilepsy and their relatives. The members of the orchestra were young and talented musicians — prize-winners of international and Russian competitions; holders of important awards in the field of music, as well as the Big Children's Choir (*photos 2*).

This concert became the first one to be conducted especially for people with epilepsy, their doctors and relatives. In addition, a significant social advertisement campaign was organised: on the streets, in the underground and on television (*photo 4*). In the museum's grand concert hall around 400 people with epilepsy, both children and adults, gathered with their relatives, friends, as well as doctors and other professionals who are helping people with epilepsy.

Oleg Smolin, the Vice-chairman of the Education Committee of the Government of Russian Federations held a speech before the concert started. He emphasized the necessity to solve all problems connected with epilepsy at parliamentary level. There were also speeches made by Russia's leading children's neurologist — Professor Andrey Petrukhin and the President of the All-Russian Charity Foundation supporting of people with Epilepsy «Sodruzhestvo» (Commonwealth) — Marina Dorofeeva.

In 2012, European Epilepsy Day was celebrated in many European countries and for Russia it was already the second time to do so. This year European Epilepsy Day had the theme of «Burden of Epilepsy» and the symbol, which was the poster with the title «Shatter Epilepsy Stigma». This theme and poster reflected the need to liberate people with epilepsy from the burden of social stigmatization and discrimination.

A charity concert, which was dedicated to the 2nd European Epilepsy Day was organized by the All-Russian Charity Foundation «Sodruzhestvo» on the 17th of February 2012 in the Moscow House of Composers. As in the previous year, the concert was held with the financial support of the pharmaceutical companies UCB Pharma and GEROT PHARMAZEUTIKA, GmbH. The Youth Symphony Orchestra of Russia played once again for the guests (*photo 1*).

An exhibitionof drawings, the work of children with epilepsy, was mounted in the foyer of the Moscow House of Composers. (*photo 3*)

It was a great occasion for the participants not only because of the pleasure of listening to classical music, but also the possibility to communicate and spent time with other people who share the same problems.

To support European Epilepsy Days in 2011 and 2012 special issues of the Journal «Bulletin of Epileptology» were published. The main themes of these issues were the improvement of life quality and the struggle with the social discrimination, connected with the illness.

Organization of the International Day of help and support to people with epilepsy accross Europe and in Russia aims to attract attention to the problems that people face on a social level and to work to improve the situation so that they can leave happier and more fulfilled lives!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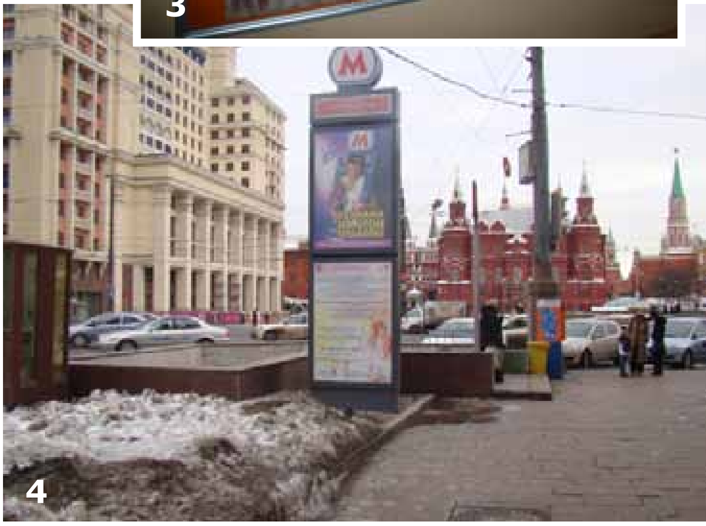

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13th European Conference on Epilepsy & Society
28 - 30 August 2013

Ljubljana, Slovenia

BREAK DOWN THE BARRIERS
&
STAND UP FOR EPILEPSY!

13TH EUROPEAN CONFERENCE ON
Epilepsy & Society
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