EPI Focus

Newsletter of the IBE European Regional Committee
Issue 1-2013

Dear Friends

As the current European Regional Executive Committee comes to the end of its term of office, this is an opportunity to review activities in the Europe that have taken place during the second half of our term. We can see how much as been achieved since the beginning of 2012 but, of course, there is still much to do. In this issue, you can also read the interesting reports from Members in Europe and hear about Michael Alexa's adventures in recent months.

As we elect the next committee, I would encourage all Full Members in Europe to play an active role in this important task. In closing, I would like to thank all those who supported the committee over the past four years and I look forward to working with you, in my capacity as IBE President-elect for the coming term.

With best wishes to all - *Athanasios Covanis*

One of the main preoccupations of EREC in 2012 was the preparation of the programme for the **Epilepsy & Society Conference** taking place in Ljubljana in August 2013. We also had a set back when the original dates had to be changed due to a major international sporting event that was moved to Ljubljana and was due to clash with the congress.

Major progress was made when the committee met in Dublin in August. Two representatives from the IBE member association, the Slovenian League Against Epilepsy, also travelled to Ireland and this enabled us to bring the programme to near completion.

Once the structure of the conference was outlined, the committee then began to identify speakers. Letters of invitation have since been circulated. The theme of the conference is: **Break Down the Barriers and Stand Up for Epilepsy**

Session topics include:

- What's next after the European Declaration?
- What are the alternatives when drugs don't work?
- Beyond seizures and medication
- Epilepsy and cognition
- The role of epilepsy support groups?
- Social media
- Women and epilepsy
- Switching brands: what are the issues?
- Epilepsy care in Europe.

Special Workshop

At a meeting held in October last, the idea for an addition to the programme began to emerge. Following careful analysis, it was decided to add a full-day Advocates for Epilepsy workshop to the congress programme. This innovative event will be held on Wednesday 28th August. The topics that the workshop will address include:

- Epilepsy networks
- Seizure observation
- Case reports
- Acute management of seizures
- Risk of seizures and safety measures
- Comprehensive epilepsy care
- Epilepsy everyday activities (sports, driving, work and travel)
- Risk factor of pre-disposing to seizures
- Raising awareness and contributing to better epilepsy research
- Conclusion – How can I be a better advocate? Take home messages

Support for the workshop has been received from the ILAE Commission on European Affairs and we are confident that this event will be very popular.

For Ljubljana, special emphasis is also being placed on posters at the conference.

The online submission system will open in February 2013. Registration will also open in February.

A number of conference bursaries will be available, funded by the Jonina Gudmundsdottir fund.

We hope that as many IBE members in Europe as possible will be represented at the conference, during which the first meeting of the new European Regional Committee will be held.

IN THIS ISSUE

EREC Officers

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

Material for the magazine should be sent to Michael Alexa:
Email: michi19691@yahoo.de

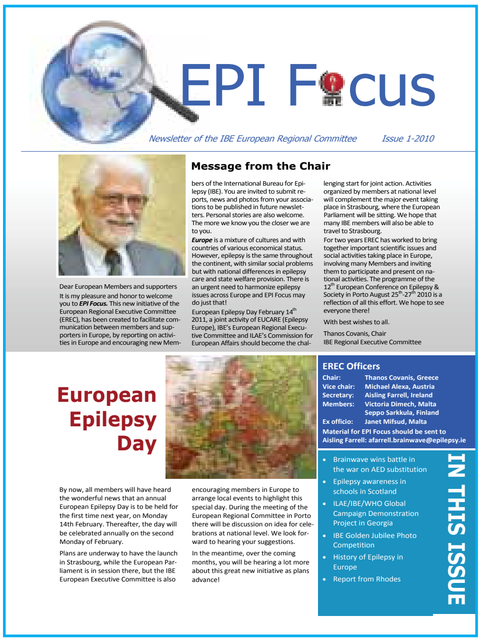
EPIFocus-European Regional Committee newsletter

First introduced in 2011, as a means of sharing news, reports and experiences between members in Europe, a total of five newsletters will have been printed since then.

Since it was first introduced, the number of members in submitting material for the magazine has gradually increased and we hope that the new committee will decide to continue with this initiative and develop it even further.

Responsibility for gathering information for the magazine has been with Michael Alexa, who has played an important role in ensuring that there was always lots of content available. The design and layout of the magazine has been provided by Ann Little and the magazine has also been circulated through the IBE office by email. Each issue has also been made available on the IBE website, where you can browse through all of the issues.

Hard copies of the third issue were printed for the International Epilepsy Congress, Rome 2011 and the last issue was available to delegates at the European Congress on Epileptology, which took place in London in early October 2012.



EPI Focus

Newsletter of the IBE European Regional Committee Issue 1-2010

Message from the Chair

Dear European Members and supporters

It is my pleasure and honor to welcome you to ***EPI Focus.*** This new initiative of the European Regional Executive Committee (EREC), has been created to facilitate communication between members and supporters in Europe, by reporting on activities in Europe and encouraging new Members of the International Bureau for Epilepsy (IBE). You are invited to submit reports, news and photos from your associations to be published in future newsletters. Personal stories are also welcome. The more we know you the closer we are to you.

Europe is a mixture of cultures and with countries of various economical status. However, epilepsy is the same throughout the continent, with similar social problems but with national differences in epilepsy care and state welfare provision. There is an urgent need to harmonize epilepsy issues across Europe and EPI Focus may do just that!

European Epilepsy Day February 14th 2011, a joint activity of EUCARE (Epilepsy Europe), IBE's European Regional Executive Committee and ILAE's Commission for European Affairs should become the challenging start for joint action. Activities organized by members at national level will complement the major event taking place in Strasbourg, where the European Parliament will be sitting. We hope that many IBE members will also be able to travel to Strasbourg.

For two years EREC has worked to bring together important scientific issues and social activities taking place in Europe, involving many Members and inviting them to participate and present on national activities. The programme of the 12th European Conference on Epilepsy & Society in Porto August 25th-27th 2010 is a reflection of all this effort. We hope to see everyone there!

With best wishes to all.

Thanos Covanis, Chair
IBE Regional Executive Committee

European Epilepsy Day

By now, all members will have heard the wonderful news that an annual European Epilepsy Day is to be held for the first time next year, on Monday 14th February. Thereafter, the day will be celebrated annually on the second Monday of February.

Plans are underway to have the launch in Strasbourg, while the European Parliament is in session there, but the IBE European Executive Committee is also encouraging members in Europe to arrange local events to highlight this special day. During the meeting of the European Regional Committee in Porto there will be discussion on idea for celebrations at national level. We look forward to hearing your suggestions.

In the meantime, over the coming months, you will be hearing a lot more about this great new initiative as plans advance!

EREC Officers

Chair: Thanos Covanis, Greece
Vice chair: Michael Alexa, Austria
Secretary: Aisling Farrell, Ireland
Members: Victoria Dimech, Malta
Seppo Sarkkula, Finland
Ex officio: Janet Mifsud, Malta

Material for EPI Focus should be sent to Aisling Farrell: afarrell.brainwave@epilepsy.ie

IN THIS ISSUE

- Brainwave wins battle in the war on AED substitution
- Epilepsy awareness in schools in Scotland
- ILAE/IBE/WHO Global Campaign Demonstration Project in Georgia
- IBE Golden Jubilee Photo Competition
- History of Epilepsy in Europe
- Report from Rhodes

EPI Focus

Celebrating European Epilepsy Day in Strasbourg

IN THIS ISSUE

EREC Officers

EPI Focus

Newsletter of the IBE European Regional Committee Issue 2-2011

Celebrating IBE's Golden Jubilee Year

The 29th International Epilepsy Congress, which was held in Rome, the city where the IBE was founded by the motion of Dr Abraham Moscovich in 1961, was the high point of 50 years of achievements and developments.

Earlier in 2011, the IBE launched a photography competition "Epilepsy Without Words", as part of its Golden Jubilee celebrations, which attracted in excess of 300 artistic entries. One of the main criteria for the award was to express epilepsy through a photographic image and during the congress an exhibition of the best 60 photographs was displayed.

An international panel of judges had the very difficult task of choosing the winners from the excellent diversity of submissions. All photographs submitted to the competition are now available in a special gallery on the IBE website, where each image has information on the photographer and the individual photograph.

A focal point of previous congresses has been the IBE Poster Displays, which provide IBE members with a unique opportunity to promote their activities, initiatives and achievements. In recognition of our Jubilee celebrations over 100 IBE members submitted posters which formed an impressive display.

While the event celebrated the past 50 years, the posters served as a reminder of the present and future of the IBE.

To commemorate the celebration, a special keepsake publication "50 years Focussed on Epilepsy" was launched. Compiled by Hanneke de Boer this excellent booklet provides a condensed history of the first 50 years of the IBE and is available for download from the IBE website.

During the congress, all attendees had the

Symphonia 5 by Douglas Capron, Canada. A seasonal choice from the IBE Golden Jubilee photo exhibition Epilepsy Without Words.

IN THIS ISSUE

1. IBE's Golden Jubilee Year
2. IE News Jubilee Award
3. EREC Meetings in Rome
4. News from Germany and Greece
5. Danes take to the streets
6. European Declaration
7. UK Take action campaign
8. Legislation in Italy
9. Services in Norway
10. Michael's Roman Diary
12. Busy Hungarian association

EREC Officers

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

Material for the magazine should be sent to Michael Alexa:
Email: michi19691@yahoo.de

1

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

1. Letter from the Chair
2. Summer Camp in Croatia
   Epilepsy Action launches magazine on Kindle
3. National Conference in Malta
   Gravesend Network celebrates 30 years
4. Report from AOEC, Manila
6. News from Greece
   New Member in Serbia
7. EED in Russia
8. Epilepsy & Society 2013

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

Material for the magazine should be sent to Michael Alexa: michi19691@yahoo.de

1

Welcome to New Members

The European Regional Executive Committee was very pleased to welcome two new members during 2012:

- **Albanian Association of Epilepsy (Full Member)**
- **Epilepsy Association Doctors for Support - Serbia (Associate Member)**

At the end of February 2013, a new IBE Full Member in France was ratified:

- **CNE France (Full Member)**

We also hope to welcome a new Associate Member from Russia in the coming weeks. The new members will be officially welcomed as IBE member associations at the time of the General Assembly meeting in Montreal at the end of June.

We look forward to working with these new members in the future.

DUBLIN 2013
European Forum on Epilepsy Research

Dublin 25th -27th May 2013

Irish EU Presidency

European Forum on Epilepsy Research

The leading voices in the epilepsy community around one table

There is much excitement about the future of epilepsy research in Europe following the recent signing of the European Written Declaration on Epilepsy.

To build on this new atmosphere, the **European Forum on Epilepsy Research 2013** will take place in Dublin, Ireland from 25th to 27th May 2013. The forum is a collaborative research conference co-funded by the 7th Framework Programme of the European Commission in conjunction with the Irish Presidency of the European Union in 2013 and the European Month of the Brain - May, 2013.

As the 8th Framework Programme ***Horizon2020*** will be launched in 2014, this conference aims to bring together European epilepsy researchers, care providers and policy makers to discuss a strategy for increasing funding for epilepsy research.

The forum is a ground breaking initiative and has come into being to facilitate discussion, debate and strategy in the field of epilepsy research ahead of ***Horizon2020***, due to launch on 1st January 2014.

The aims of the forum are to achieve more focused research to improve diagnosis and treatment; to raise public awareness and reduce stigma associated with epilepsy; and to improve access to optimal standards of care across Europe for people with epilepsy.

To achieve the goal of improved research support, the epilepsy community must speak with one voice when the European Union formulates the future strategies to improve healthcare and health research across the EU.

For this reason it is important that as many IBE and ILAE associations in Europe as possible are represented at the forum.

A number of IBE and ILAE member associations are already fully engaged with the forum's goals and are informing and encouraging European Union National Contact Points (NCPs), Ministries of Health Officials and Members of the European Parliament (MEP) to attend. There are also a number of bursaries available to support IBE members in Europe to attend.

Epilepsy Advocacy Europe - the joint task force of IBE and ILAE, which is organising the event, is also asking members in European Union member states to make contact with National Government representatives and NCPs to encourage them to attend the forum.

To assist in the development of research proposals there will be a pre-conference workshop dealing with the new features of the ***Horizon2020*** applications, time schedules and the decision-making process, which will be of interest to many delegates. There will also be a reception with EU Health Research National Contact Points from European Union Member States.

The two-and-a-half day meeting has six Main Sessions:

- Epilepsy Stigma Across Europe
- Standards of Care
- Epilepsy in the Developing Brain
- New Targets for Innovative Diagnostics and Treatment
- What is Required for Prevention and Cure of Epilepsy?
- Epilepsy and Co-Morbidities - Special Focus on Ageing and Mental Health

To present on these topics an Advisory Committee has identified internationally recognised speakers, including Christian Elger, Germany; Ley Sander, UK; Renzo Guerrini, Italy; Torbjörn Tomson, Sweden; and Bert Aldenkamp, The Netherlands.

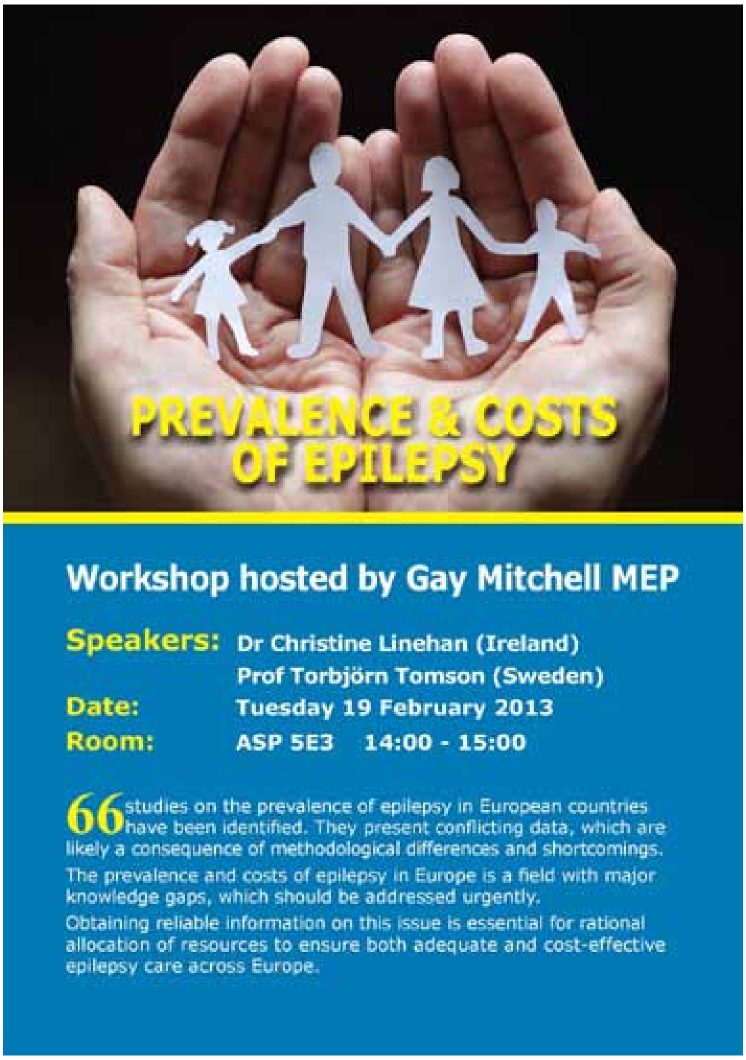
The European Forum on Epilepsy Research 2013 will be held at the new Convention Centre Dublin, a world class international conference and event venue situated in the centre of the city and within walking distance of several hotels. IBE and ILAE member associations are being encouraged to send at least one delegate to the meeting. In addition, ILAE chapters are being asked to sponsor a member from a less affluent member state, where funds permit. There will also be a limited amount of bursary support for IBE members where association finances would prevent attendance.

With Dr Tonio Borg, EU Commissioner for Health and Consumer Policy and Mrs Máire Geoghegan-Quinn, EU Commissioner for Research, Innovation and Science invited to address the forum, and with a number of MEPs and NCPs due to attend, this is an excellent opportunity for associations across Europe to highlight the urgent need for more focused research in epilepsy in order to improve diagnosis and treatment. It is also the chance to focus on the need for greater public awareness in order to reduce stigma associated with epilepsy and to call for improved access to optimal standards of care across Europe for people with epilepsy.

We hope to welcome many of you to Dublin in May, for what promises to be a great occasion!

EUROPEAN EPILEPSY DAY 2013

PHOTOGRAPHED AT EED 2013 IN THE EUROPEAN PARLIAMENT (left-right): Jim Higgins MEP, Francisco José Millán Mon MEP, Filip Kaczmarek MEP, Gay Mitchell MEP, Anna Záborská MEP, Veronika Mitykó, Pat The Cope Gallagher MEP, Sean Kelly MEP, , Kristzina Danczik, Dr. Judit Jerney M.D., President of the Hungarian Epilepsy League (Hungarian Chapter of the International League Against Epilepsy) and Ann Little Executive Director IBE (International Bureau for Epilepsy)



PREVALENCE & COSTS OF EPILEPSY

Workshop hosted by Gay Mitchell MEP

Speakers: Dr Christine Linehan (Ireland)
Prof Torbjörn Tomson (Sweden)
Date: Tuesday 19 February 2013
Room: ASP 5E3 14:00 - 15:00

66 studies on the prevalence of epilepsy in European countries have been identified. They present conflicting data, which are likely a consequence of methodological differences and shortcomings.

The prevalence and costs of epilepsy in Europe is a field with major knowledge gaps, which should be addressed urgently.

Obtaining reliable information on this issue is essential for rational allocation of resources to ensure both adequate and cost-effective epilepsy care across Europe.

11 FEBRUARY 2013

eed

EUROPEAN EPILEPSY DAY

The 3rd European Epilepsy Day was celebrated throughout Europe on 12th February, the second Monday of the month. As the week commencing 12th February was Constituency Week in the European Parliament, i.e. the week in which a large number of MEPs remain in their home countries to address national issues, celebration of the event in the European Parliament in Brussels was delayed by a week.

As in previous years, EED 2013 was hosted by Irish MEP Gay Mitchell, with three major activities:

- Workshop on the Prevalence and Costs of Epilepsy, with speakers Dr Christine Linehan (Ireland) and Prof Torbjőrn Tomson (Sweden)
- Reception to launch EED week in Brussels with a display by Hungarian gymnast Veronika Mitykó. Eleven year old Veronika has well-controlled epilepsy but is still prevented from national competition in her country.
- Display of the Stand Up for Epilepsy exhibition of international sports people pictured with people with epilepsy, which was first displayed during the European Congress on Epileptology in London in October 2012.

At national level, events to mark EED have been growing in number and stature and you can read about many national events on the IBE website.

http://www.ibe-epilepsy.org/european-epilepsy-day-in-the-eu-parliament/

A New Name - Epilepsy Ireland

Brainwave – The Irish Epilepsy Association will be changing our name to Epilepsy Ireland early next year. The official launch of the new name will be part of the 2013 European Epilepsy Day campaign in February.

The word "Brainwave" was added to the original "Irish Epilepsy Association" over 20 years ago in response to members' needs at the time. It is a positive word, closely associated with epilepsy and had the advantage that the word "epilepsy" did not have to be used by staff when leaving messages in the pre-mobile era. It is important to remember that at the time, people with epilepsy were more likely to keep their diagnosis hidden compared to today.

It is clear that these reasons are not as relevant as they once were. Firstly, the word "epilepsy" should not be hidden in the title of our organisation. By making it more prevalent, the name itself can be used to highlight epilepsy and raise awareness. At a time when people are encouraged to speak openly about epilepsy to reduce stigma, we need to lead the way with a name that doesn't hide the condition we represent.

Secondly, name recognition of Brainwave is very poor. Recent research conducted by the Amarach research agency found that 53% of over 1,000 people questioned were unable to state a cause or condition associated with Brainwave. Of those that offered an answer, more people (19%) associated us with acquired brain injury than with epilepsy (15%). This confusion can have a negative impact in a number of areas. For example:

- When newly diagnosed, unless directly referred to Brainwave by a doctor, where does a person with epilepsy go for information and support?
- When campaigning and raising awareness, does the name Brainwave confuse the message? Considering over half of the people surveyed didn't make the connection of the name with epilepsy, the answer must be yes.
- When fundraising, do donors fully understand the condition they are supporting? Again, probably not.

Changing our name to Epilepsy Ireland provides an opportunity to improve public understanding of what we do and of epilepsy itself. In marketing and branding terms, the name Epilepsy Ireland does exactly what it says on the tin!

While the name will change, the vision, mission, objectives and work of the organisation will not. Epilepsy Ireland's vision will continue to be "to achieve a society where no person's life is limited by epilepsy" and our mission will remain "committed to working for, and to meeting the needs of everyone with epilepsy in Ireland and their families and carers".

The image shown will become Epilepsy Ireland's new logo. As you can see, the light bulb image and the blue/ yellow identity both remain. The light bulb represents the idea of "shedding a light on epilepsy", a theme that is used by many epilepsy organisations around the world.

We hope you like the new changes. Please let us know your thoughts at info@epilepsy.ie.

URGENT CALL FOR HELP FROM GEORGIA

Dear friends,

Recently I received a proposal from the Ministry of Health of Georgia to take part in an elaboration of pediatric epilepsy care standards in Georgia. The ministry also asked me to provide them with reports and information from other countries. Therefore I am asking you to send me information on standards and annual costs, if possible as soon as possible. Forgive me for addressing you so directly, however, I believe this is important and I hope you will understand and support my request. I believe that the interest of the Ministry to epilepsy care problems could be very important for the development of a National Program on Epilepsy in Georgia.

The letter from the Health Ministray points out that the social and medical care and treatment of children with epilepsy is connected to a number of difficulties. The main difficulty is – the letter states – to find the correct, optimal, comprehensive diagnostic process, which is impossible in general outpatient clinics. In addition, there are only a few special institutions in Georgia.

At the same time the poor economic-financial condition of this social group, is also obvious and must be taken into consideration. The Ministry of Health wants to find the most cost effective, and at the same time, medically effective standard of diagnostic procedures in order to achieve correct diagnosis. In this respect, the experiences of other countries would be of special interest for us and it is for this reason that we in Georgia are seeking suggestions about this issues.

Another important point for the Ministry of Health of Georgia is information on annual costs for anti-epileptic drugs (AED) treatment for children with epilepsy. Any information you can provide on this aspect would also be appreciated.

If you are based in Europe and can provide information on the issues raised by the Ministry of Health of Georgia, please send any details you can either to me (Natela Ojujava) directly - email natelaokujava@yahoo.com - or through the IBE office - email ibedublin@eircom.net - I would be very grateful.

Thanks a lot in advance!

Best wishes

Natela Okujava

Deutsche Epilepsievereinigung e.V. – Germany German Epilepsy Association

Activities 2012 and what we've planned for 2013!

Activities in 2012 included:

Bielefeld, Germany

- **Celebration of EED** on the 14th February in Bielefeld, with a focus on "Epilepsy and Work", in collaboration with the Epilepsy Centre Bethel Bielefeld. Neurologists and social workers spoke on issues such as how to avoid unemployment (medical, social and legal requirements as well as job-creating measures).
- **Workshop on "Memory practice for people with epilepsy"** - 22nd to 24th April (Berlin).
- **Workshop on Epilepsy & depression** - 18th to 20th May (Berlin).
- **Annual Conference** "New ways for epilepsy treatment" - 22nd to 24th June (Berlin).
- **Workshop for self-help group leaders** to discuss topics such as conflict solving, funding, awareness, establishing a new group - 31th August to 2nd September (Jelna).
- **Workshop "Epilepsy & Self-Control"** - 21st to 23rd September (Bielefeld).
- **National Day of Epilepsy:** 5th October with the theme "Epilepsy in Childhood": Since 1996 Austria, Switzerland and Germany celebrate a joint National Day of Epilepsy. From umbrella organisations to small self-help groups, during the months of October there were plenty of activities on public awareness on epilepsy arranged in these countries. The German Epilepsy Association hosted a national conference in collaboration with regional epilepsy organisations and the Frankfurter Rundschau. Neurologists informed the audience about epilepsy in childhood – diagnosis, treatment, problems, i.e. Parents reported on their experiences. Parents, neurologists and social workers offered advice and information.
- **Workshop for families with children epilepsy and special needs:** During the weekend of 31st August to 2nd September we organised a recreation workshop at the Teutoburger Forest Resort near Bielefeld. Children cared for separately, allowing parents time to be free from their usual responsibility and able to enjoy the beautiful scenery and old city of Bielefeld.

Overview of upcoming activities in 2013:

- **Seizure self-control courses:**

  Basic Course: 19th to 21st April 2013
  Berlin, Haus Morgenland

  Advanced Course: 20th to 22nd September,
  Bielefeld, Hotel Lindenhof
- **Self-help groups:** 21st to 23rd June, Walsrode, Ver.di Bildungszentrum
- **Workshop on "Epilepsy and psyche" in conjunction with the German Annual Meeting:** 7th to 9th June, Walsrode, Ver.di Bildungszentrum
- **Workshop on "Epilepsy & depression":** 27th to 29th September, Jena, Thüringer Sozialakademie
- **National Epilepsy Day:** "Epilepsy & Mobility" 28th September, Ökomenisches Forum HafenCity, Hamburg

ANNUAL DUES 2013

Member associations are reminded that annual dues payments for 2013 are now due. Payment can now be made securely online on the IBE website using Paypal. You are encouraged to use this method of payment to keep bank charges as low as possible both for the association making payment and for IBE.

When arranging payment, please also consider making a donation to the Solidarity Fund. Funds donated are used to support members in developing countries, both by supporting their dues payments and by providing funds for Promising Strategies Projects.

NEWS FROM HUNGARY!

Zsolt Szabo tells us about some of the successes enjoyed and problems faced by the Association for Future of People with Epilepsy in Hungary

Although the situation in Hungary is not easy those days and having a diagnosis of epilepsy becomes more difficult, the Hungarian Epilepsy Association has enjoyed some achievements:

The association's members and their families were able to produce a brochure and delivered it to secondary schools and to medical institutions. This allowed us to make several presentations to high schools. As a result, we won our first state aid, which allowed us to produce 1,000 copies of the brochure!

Our members and supporters of the booklet, which include neurological groups, are helping us to improve the contents of the brochure for the next issue. Unfortunately, there is great apathy and despair among the people living with epilepsy, because of the difficult economic situation which led to the financial problems.

In the summer, we organized a five-day camp, which took place close to the Balaton. It was a great success for its participants. During the five day camp the participants had the possibility to swim, to enjoy some picnics and a lot of ballgames were played. In addition psychological training was held twice during those five days, where the participants were able to tell the trainers their most important problems. Unfortunately only 15 participants took part – for the coming year a sponsor would be more than welcome!

We are trying to help a young gymnast living with epilepsy – Veronika Mitykó – to allow her to complete internationally. This is an ongoing situation which has yet to be resolved. Veronika's predicament was hightlighted on a video, which won first prize in a competition run by Team Epilepsy.

Co-operation agreements were signed with two industrial centers because one of the biggest problems is the lack of job opportunities. Unfortunately, they were unable to provide an efficient means of finding employment for people with epilepsy and this is something that our association continues to work on.

Photo Captions:

Pictured above, members of the Association for Future of People with Epilepsy in Hungary enjoy a 5-day summer holiday camp.

Veronika Mitykó pictured with Katalin Makray, Silver medalist in Uneven Bar at the 1964 Olympics and wife of former President of Hungary Pál Schmitt.

A busy time in Slovenia!

Ljubica Vrba writes about activities in 2012 and looks forward to hosting the European Conference on Epilepsy & Society in August

The League against Epilepsy Association of Slovenia combines both Slovenian ILAE and IBE board committee members. This means that both work united in the care for professional development of epileptology in Slovenia, as well as to improve the quality of life of people with epilepsy, their families and friends.

Some campaigns, carried out by the association in 2012, were organized by pulling together lay people and experts in the field of epileptology:

In February 2012, we successfully organized the 2nd European Epilepsy Day. A press conference was held, which was attended by journalists from various television and radio stations as well as newspaper and magazine journalists. A lot of information on epilepsy was presented to the public.

One of our self-help groups – the Maribor branch – celebrated 20 years of continuous work and to celebrate this occasion a meeting for all self-help groups and other members of the society was organized. A lecture on the topic of juvenile myoclonic epilepsy was followed by a cultural and social program.

In previous years, we organized 16 lectures and discussions about epilepsy in kindergartens, schools and other institutions. Two public forums were held in the more isolated areas of Slovenia. Local media were involved with interviews for local radio, which resulted in the publication of more than 80 reports on TV and in newpaper articles.

A group of people with epilepsy who had undergone surgical treatment met for the third time. Since surgery is carried out abroad, our association has a program for escort interpreters, usually medical students. People with epilepsy, who went through this program, exchanged their experience in dealing with foreign hospital environments and problems after surgery. This helps us in preparing people who will have epilepsy surgery in the future, so that they know what to expect when they travel abroad for their treatment.

Each year we publish 4 association newsletters, which are sent to all members and include both short professional articles as well as contributions from groups and individuals.

Once a week an afternoon telephone counselling line EPITEL, is open to anyone interested in psychosocial aspects of life with epilepsy. The helpline runs each Thursdays from 4pm to 7pm.

The Association's website contains all relevant information with regard to our activities and is updated daily.

The next European Conference on Epilepsy & Society will be held in Ljubljana, Slovenia and is the main focus of this year's work. We look forward to this event and hope that it will be very successful and that all participants will take home good memories of their stay in Ljubljana and Slovenia.

Photo caption: *Ljubica (in green top) and colleagues enjoy traditional Slovenian dancing performed by young children as part of the 20 year celebrations in Maribor branch of the association.*

IBE General Assembly

Date and time: Wednesday 27th June 2013
Time: 13:00 to 17:00 including lunch reception
Venue: Hall 7, Palais des Congrès de Montréal

10th European Conference on Epileptology - LONDON 2012

Michael Alexa, Vice Chair EREC, sent EPIfocus this report

10th European Congress on Epileptology
LONDON ILAE-CEA
COMMISSION ON EUROPEAN AFFAIRS
The year of the Olympics and the European Epileptology Congress
September 30th - October 4th 2012

Sunday – 30th September

1st Day of the Congress

The first session I attended was: ***"Epilepsy Surgery in Childhood – what can be achieved?"*** Delegates were told that brain surgery can be fatal, but epilepsy can be fatal as well if the epilepsy is complicated. Neurodevelopmental outcomes were also part of the session. Those are – like behavioural improvement - secondary outcome aims. The primary outcome aim is – of course – seizure freedom/reduction.

Satellite Symposium: ***"What happens when a child has a prolonged acute convulsive seizure in the community?"*** This symposium introduced us to the **PERFECT** (the **P**ractices in **E**mergency and **R**escue medication **F**or **E**pilepsy managed with **C**ommunity administered **T**herapy) initiative. PERFECT is needed to fill the gaps to optimal management of epilepsy in the community setting.

Monday – 1st October

2nd Day of the Congress

The second day started with a Satellite Symposium: ***"Managing Seizures, managing mood?"*** This symposium raised the question whether or not seizures and mood are connected to each other.

I attended the ECE Forum: ***"Trans-border Epilepsy program in the EU – How and why to apply?"*** It's important to collaborate together – a good example is the collaboration between Kork (GER) and Strasbourg (FRA). While Kork is specializing on the MRI-scan before and after surgery, Strasbourg specializes on the surgery itself.

During the ***Chairs Symposium: "The borderland of epilepsy in 2012"*** the argument that an AED is being used no only to treat epilepsy was backed up the sales revenues of different AED's**: whereas 91% of Leviteracetam sales was for use in epilepsy treatment, 40% of sales of Topiramate was for treating migraine!**

During the ***Platform Session: "Genetics 1"*** the speakers introduced new findings about the different genes they are working on.

An important issue was dealt with in the ***Session: "Addressing treatment gaps in North America and Europe".*** The treatment gap can not only be found in Africa/Asia/Latin America – it is found worldwide.

During the Satellite Symposium: ***"Making evidence-based decisions in partial epilepsy treatment"***, the burden of epilepsy was addressed. Although epilepsy is one of the most common neurological diseases, only 4 AED's have dominated the German market. Another big finding is that the direct costs (AED, admission) are SMALLER than the indirect costs (early retirement, which is of huge importance in Germany!).

Tuesday – 2nd October

3rd Day of the Congress

The day was started off with another Satellite Symposium: ***"Advances in clinical application of Magnetoencephalography***

(MEG) for refractory epilepsy in paediatric and adult patients", which told us that the MEG can be used in addition to the Video-EEG and provide the doctors with additional information before the surgery is being executed.

During the ***Platform Session: "Genetics 2"*** the speakers introduced new findings about the different genes they are working on.

In the session: ***"What the professionals need to know to improve healthcare and research",*** a UK member of the European Parliament told us that we have to do more advocacy work and should NOT stop with the EED – it can only be a start!

The EU provides opportunities for researchers under the auspices of FP7, which will be followed by the Horizon 2020 (2014 to 2020) program. There is NO European-wide study available regarding the direct and indirect costs of epilepsy – some studies were conducted, but they had different results, due to the different methods used.

The last session of that day was another Satellite Symposium: ***"Managing Epilepsy: Learning from today to inform tomorrow"***. This session pointed out that the ***communication gap*** between doctors and patients

- regarding expectations and perspectives on the one hand
- regarding perceptions of out-patients on the other hand ***has to be reduced***.

A reduction can take place

- if patients are empowered by promoting knowledge and
- if a systematic pre-visit tool is established.

Wednesday – 3rd October

4th Day of the Congress

The main Session: ***"Recent trends in AED clinical pharmacology"*** made it clear to me that not only genes are a target but also the ***transporters*** – a lot of them can be found in a human body. But it'll take some more time until those transporters can be used for creating new AEDs!

Another trend is the ***pregnancy registers*** which are available all over the world. Parallel to the recent trends in the AED's, ***a new classification possibility of status epilepticus*** was presented, which consists of 4 axes: Semiology, Sex, Etiology and Age. **This was a very popular session, with every seat taken and some delegates standing!**

As London has been the host for the 2012 Summer Olympics, the ILAE organized an Olympiad epilepsy quiz – and the final was won by Ireland – against Portugal.

Thursday – 4th October

5th Day of the Congress

The last day of the conference – for me – started with the ECE Forum: ***"Perspectives of brain stimulation therapy in epilepsy".*** It seems to me that a lot of questions are still under discussion and therefore a German-Austrian protocol for independent safety assessment might also be useful for other countries. The safety of the patient should always be on top of the list!

I continued my day with the "***Medical causes of epilepsy".*** In this session you learned that alcohol and even recreational drugs can have an anticonvulsant phenomenon. For real use as a medication, a lot more of additional research would have to be undertaken. Also discussed were the drug interactions between HIV and epilepsy drugs.

Travel and days after the Conference

This time it was different. Not only that I didn't have any time for visiting the city or the country, I also had to buy my presents at the airport – but that's another story ….

7TH LATIN AMERICAN CONFERENCE QUITO, ECUADOR

Michael Alexa, Vice Chair EREC, presents an intersting report

IBE Member Association office in Quito

Getting there

I flew from Vienna via London and Miami to Quito, arriving late at night. The next morning I was able to get up early and started my holidays with a walk through the city. I didn't expect so many old cathedrals but when you start thinking about it, all South America was once either a Spanish or Portuguese colony.

I continued my journey the same evening to Cuenca, where I visited a good friend of mine – Dr Guadalupe "Lupita" Bonilla. My friend showed me around Cuenca – the nice museums, a good view point, and we drove to a mountain which is about 4,000 me-

La Mitad del Mundo

ters high. It was cold up there! As she has been born and raised in Cuenca, she showed me "her personal" Cuenca, a wonderful small city nobody should miss. The next morning I returned to Quito.

2.) 7th Latin American Congress about Epilepsy

Wednesday – 14th November

1st Day of the Congress

Instead of attending the classes for the doctors, I turned my attention to the symposium ***School & Epilepsy.*** At first the different types of seizures in children were dealt with. This was followed by brain maturation and epilepsy. During the first years of life the brain is still changing until it's fully developed. After the break the conference continued with epilepsy, autism and attention deficit. Epilepsy is estimated to affect 25% of the children with autism. On the other hand seizures are a possible risk factor for autistic regression. The learning difficulties of children with epilepsy can have several causes: the seizure itself, the cause of the epilepsy, other abnormalities, which are shown at the EEG, cerebral dysfunction site, side effects of the AED, the attitude of parents, teachers and the general society as well as emotional factors and personality management.

At the presidential symposium the presidents of the IBE and ILAE reported on the IBE-ILAE-PAHO initiative. This initiative started in December 2009 and a task force was created in 2010 during the previous Latin American conference in Cartagena. In September 2011 – after a lot of discussion – the strategic plan was unanimously approved by all PAHO member states – Epilepsy will not be invisible anymore!

After this symposium the opening ceremony took place. We reception afterwards with great food and music was most enjoyable.

Thursday – 15th November

2nd Day of the Congress

The session ***"Diagnosis of non-refractory epilepsy in adults"*** started with a prevalence of epilepsy in adults in Ecuador. It turned out that there is no difference to the numbers we've already heard – about 72,000 persons with epilepsy can be found in Ecuador.

In Colombia law 1414 was signed in November 2010 - The object of this law is to guarantee the protection and integral attention of the people with epilepsy, what is a HUGE step forward! Let's hope that Colombia is an example for other countries!

Satellite Symposium: ***"Rational polytherapy, evidence vs. experience"*** The symposium told us a lot about the effects, side effects, and possible interactions of Lacosamid (Vimpat) – so far no interactions are known – great!

After the lunch the ***"Treatment of epilepsy in Adults"*** was the topic. Several studies showed that none of the newer AEDs surpass Carbamazepin in efficacy for focal epilepsies. For primarily generalized seizures, Valproaic acid remains the most effective drug.

Another important issue, which had been raised was: "Stop Saying Epileptic". A study – also from Brazil – showed it impressively: Another item which has been discussed was the lesional epilepsy surgery.

After the interesting Satellite Symposium: ***"Status Epilepticus"*** the whole conference went to a concert at the Casa del la Música. It was really wonderful. We heard Argentinian and Ecuadorian music – played by the national symphonic orchestra of Ecuador, conducted by Jorge Oviedo. After so much information, all the participants were happy to listen to the wonderful music – a real highlight of the conference!

Friday – 16th November

3rd Day of the Congress

This day started with an ALADE Course ***"Genetics of epilepsy"***. In the past years – since the human genome has been identified – huge advantages have been achieved in identifying the genes (e.g. SCN1A, SCN9A, PCAH19, KCNQ1, KCNH2, SCN5A, GLUT1, 1q43, 2p16.1, 2q22.3, 17q21.32 – the list is not complete!!!), which are responsible for causing epileptic seizures. Although those advantages have achieved, up till now – as far as the author knows – no AED has been developed which can "cure" the gene – but they are the target! Genetic testing will become more and more important in the future but, of course, potential harm – such as genetic discrimination – should also be considered!

The next session was called ***"Epilepsy in the elderly"***. One interesting fact was that in the 62 year period between 1942 and 2004 about 750 articles on EEG/MRI concerning epilepsy in the elderly were published – while in the 7 year period from 2005 to 2012 the number was 800!

The day continued with a Satellite Symposium: ***"Key controversies in epilepsy management"***. The symposium was divided into two parts. Firstly two well know doctors presented – one PRO and the other one CONTRA – and afterword there was time for discussion.

During the discussion I raised two points:

- The "new" AEDs are only available for 10 years – or less – compared to the "old" AEDs which are on the market for 100 years and more. I know of some side effects, which showed up 30 years after introduction to the market – can I – therefore - really compare the "old" and the "new" AEDs when the "new" AEDs are so young? -Am I not comparing apples with oranges?

- The "new" AEDs are so expensive compared to the "old" AEDs. I don't know which numbers they compared, but can I really compare an AED which has been 100 years ago? At that time there have been other regulations, other sizes of the companies, other law which have had to be fulfilled etc. – and don't forget the inflation rate – if you want to compare money from 100 years ago, you have to add at least the inflation rate, otherwise you're – again – comparing apples with oranges!

After my statements I received a lot of positive remarks from different delegates that they liked my statements very much – don't ask me why.

Another important item is ***"Epilepsy Surgery"***. The presenters pointed out that the Quality of Life of the epilepsy patient it the most important factor. Therefore you have to think carefully if you are doing epilepsy surgery, callosotomy, vagus nerve stimulation or treatment with medications. Each of them has advantages and disadvantages.

The last session of the day was co-hosted by Dr Guadalupe "Lupita" Bonilla – ***"Epilepsy and Sleep"***. It was presented that sleep has an effect on seizures; the more and the deeper you sleep, the fewer seizures you have. On the other hand sleep deprivation increases the likelihood of seizures!

After a long day at the conference, Dr Guadalupe "Lupita" Bonilla (Ecuador), Dr Celia Trujillo (Mexico), Dr Garcia Cuevas (Mexico) and I went for a nice dinner in a restaurant overlooking the city.

Saturday – 17th November

4th Day of the Congress

After visiting the WHO and PAHO initiative, Dr Bonilla, Dr Trujillo, Dr Cuevas and I went to the "Mitad del Mundo – middle of the world"! It was fascinating. You were able to walk on the Equator line. The sun was standing right over you and if you didn't have a hat – like me – you get a headache easily.

After the Conference

I had about one week holidays after the conference. On Sunday I started by walking to the Parque La Carolina. After listening to a concert in the park, I visited "El Panecillo" with its huge statue of the Blessed Mary overlooking the city; you have a wonderful view from up there.

On Monday I planned to take the highest cable car in the world – about 4,000 metres up. On my way to the station I saw, by accident, the building of the IBE association in Quito. Of course I had to stop and take a few quick pictures!

Tuesday 20th to Friday 23rd November

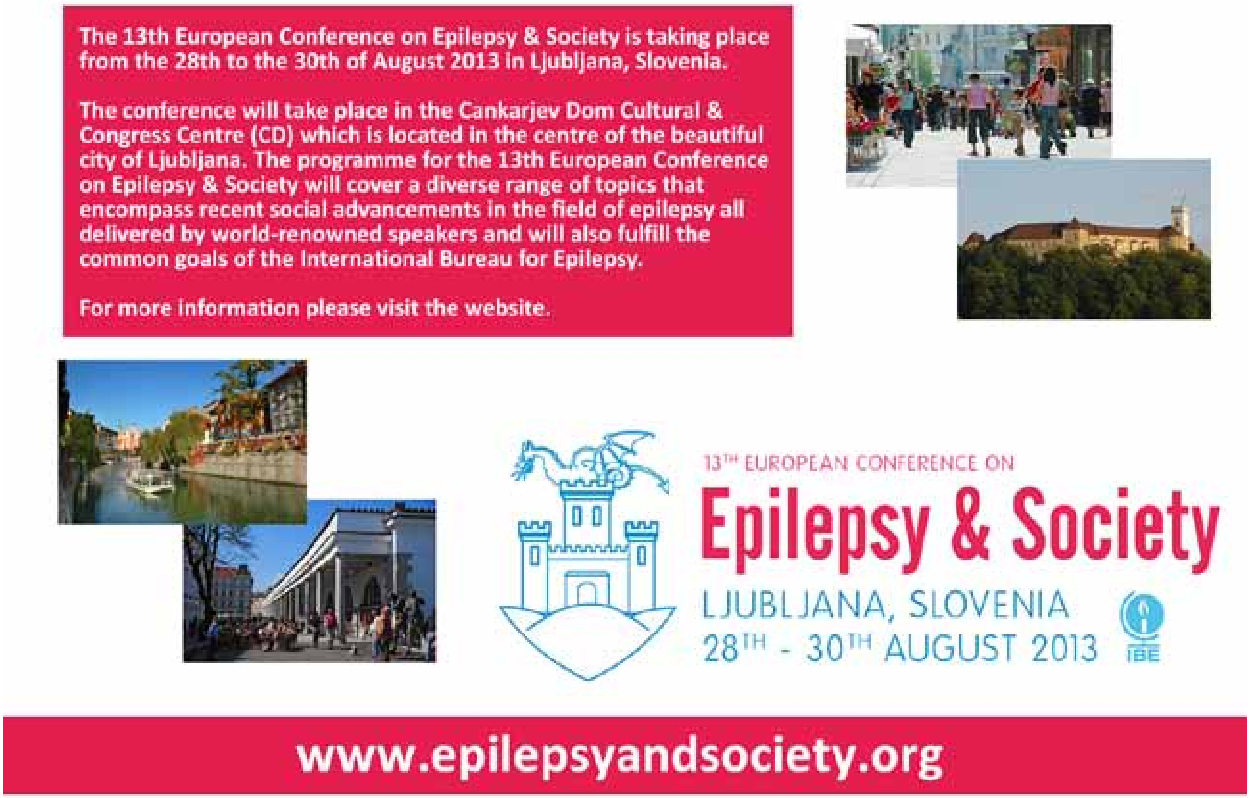
The coming days were wonderful – I took the opportunity to visit the Galapagos Islands for a few days.

I visited a giant turtle farm and walked on foot to Tortuga Bay. You have to register before you start walking on the pathway – it takes about 45 minutes one way – but the result was wonderful. I saw a lot of different birds, plants, iguanas, and sea-lions.

The next day I took a boat to Isola Santa Isabella. On the island I saw pink flamingos and a breeding station for giant turtles. I saw sea-lions lying on boats resting in the shadows, went to islands where we saw penguins, sharks and iguanas! We had half an hour for snorkeling in the Pacific Ocean.

The next day I went back to Quito and I was able to meet Dr Guadalupe "Lupita" Bonilla again for a nice dinner before flying back home to Austria.

What a wonderful holiday!



The 13th European Conference on Epilepsy & Society is taking place from the 28th to the 30th of August 2013 in Ljubljana, Slovenia.

The conference will take place in the Cankarjev Dom Cultural & Congress Centre (CD) which is located in the centre of the beautiful city of Ljubljana. The programme for the 13th European Conference on Epilepsy & Society will cover a diverse range of topics that encompass recent social advancements in the field of epilepsy all delivered by world-renowned speakers and will also fulfill the common goals of the International Bureau for Epilepsy.

For more information please visit the website.

13TH EUROPEAN CONFERENCE ON

Epilepsy & Society

LJUBLJANA, SLOVENIA

28TH - 30TH AUGUST 2013

www.epilepsyandsociety.org