EPI Focus

Newsletter of the IBE European Regional Committee

Issue 1-2014

Dear Friends

As I write to you, we are preparing for a meeting of the European Regional Executive Committee (EREC), which will take place in Athens in early June. I look forward to welcoming the members of the committee to my home town!

In Athens we will be spending a lot of time considering future plans for EREC, and the responses provided by IBE Members in Europe to the recent survey will be carefully considered in this task. I would like to thank those of who who took the time to respond.

I would also like to welcome two new members to the IBE European Region - in Italy and Moldova - and you will find out more about them in the pages of this issue.

You will also see reports on how associations celebrated European Epilepsy Day in February. It is great to see that this annual event is gaining in momentum as a good opportunity to highlight epilepsy across Europe.

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

THIS TIME IT'S DIFFERENT

European Elections 2014

By the time you read this, we will likely know if there was, indeed, any difference in the European elections that took place across the 28 EU Member States between 22nd and 25th May.

Hopefully you will have played your part in voting for the candidates you believe will best serve you and your family, and work hardest to support the cause of epilepsy over the next five years. This was your chance to influence our future political course in Europe.

By now, it is likely that the full list of 751 elected MEPs for 2014-2019 is known. These MEPs will represent the more than 500 million citizens living in the EU community.

The next task will be for the parliament to select the Commissioners. A major new development introduced by the Lisbon Treaty is that, when the EU member states nominate the next president of the European Commission, to succeed José Manuel Barroso, in autumn 2014, they will - for the first time - have to take account of the European election results.

Continued on page 2

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

Continued from page 1

Voters now have a clear say in who takes over at the helm of the EU goverment

The new Parliament must endorse this candidate: it ‘elects’ the Commission president, in the words of the Treaty. This means voters now have a clear say in who takes over at the helm of EU government. Of the 13 European political parties, five have already nominated a candidate to succeed the current Commission President:

- The EPP has nominated Jean-Claude Juncker, former Luxembourg prime minister,
- The PES candidate is Martin Schulz, current president of the European Parliament,
- The Liberals and Democrats (ALDE) have opted for Guy Verhofstadt, former Belgian Prime Minister and current Liberal group leader in the European Parliament,
- The Greens have nominated two current MEPs, José Bové (France) and Ska Keller (Germany),
- The European Left have put forward Alexis Tsipras, leader of the Greek SYRIZA party.

The new political majority that emerges from the elections will also shape European legislation over the next five years. The Parliament - the only directly elected EU institution - is now a linchpin of the European decision-making system and has an equal say with national governments on nearly all EU laws.

Epilepsy Manifesto for MEPs

In advance of the European Parliament Elections in May, the ILAE-IBE Joint Task Force on Epilepsy created a short manifesto highlighting some of the problems that people with epilepsy in Europe face. The aim of the manifesto was to bring the issue of epilepsy to the forefront of the nominated candidates standing for election.

Now that the elections are completed, there is still the opportunity to encourage the newly elected MEPs to support the cause of epilepsy in Brussels.

The IBE office invited IBE members in Europe to translate the original English text and prepared the manifesto in a number of languages (some of which you can see here) for use at national level. To date there are translations in German, Dutch, Flemish, Portuguese, Slovenian, Greek, Czech and Turkish - as well as in English.

If you would like to have the manifesto available in your national language, please send the translated text to Ann Little at **ibedublin@eircom.net.**

You may like to provide your association’s web address and logo and these can also be placed on the document.

Citizens have the right to choose and be reimbursed for treatment, either public health care or private health care, anywhere within the EU.

New European Cross-border Healthcare Directive comes into force

Paola Testori Coggi, Director General for Health and Consumers, European Commission explains

European citizens, no matter where they live, now have the right to choose where to receive medical treatment across the EU, and to be reimbursed for it. This right is now spelled out in the Directive on Cross-Border Healthcare, which entered into force throughout the European Union in October 2013.

Under previous EU laws, European citizens benefitted from their own countries national social security scheme if they became ill while travelling in another Member State. However, for planned cross-border care, a Member State could require that patients first applied for prior authorisation and the Member State was only compelled to grant the authorisation, if patients could be treated at home within a time limit considered medically justified.

The new Directive introduces three major changes focusing on patients' rights:

- Firstly, citizens have the right to choose and be reimbursed for treatment, either public health care or private health care, anywhere within the EU.
- Secondly, prior authorisations for cross-border healthcare will become the exception rather than the rule.
- Finally, citizens will now have the right to make informed decisions about treatment options. They are, therefore, entitled to receive any relevant information from EU National Contact Points, established under the new Directive, and information from health care and treatment providers directly.

In order to increase transparency on quality and safety standards across the EU, the Directive advocates mutual assistance and cooperation between Member States, in particular on inter-operability of eHealth tools and the use of health technology assessment. It also facilitates recognition of prescriptions for medical products in every Member State.

Eventually, the Directive will provide for the development of European reference networks, to encourage the pooling of knowledge and thereby maximise the cost effective use of resources in highly specialized healthcare, such as diagnosis and treatment of rare diseases.

This new law marks a real breakthrough for European citizens: not only will European citizens be able to take more control over their own health care, this will in turn help patients associations promote higher quality and safety of care. This can only have a beneficial effect on our healthcare systems.

Link to the full text of the Directive:
http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF

North American Regional Committee
Canada
Jamaica
USA

Latin American Regional Committee
Argentina
Brazil
Chile
Colombia
Cuba
Dominican Republic
Ecuador
Guatemala
Honduras
Mexico
Panama
Peru
Uruguay
Venezuela

Where we are in the World

As IBE welcomes two new Members to the European Region, it’s a good time to stand back and look at IBE’s representation, both in Europe and worldwide.

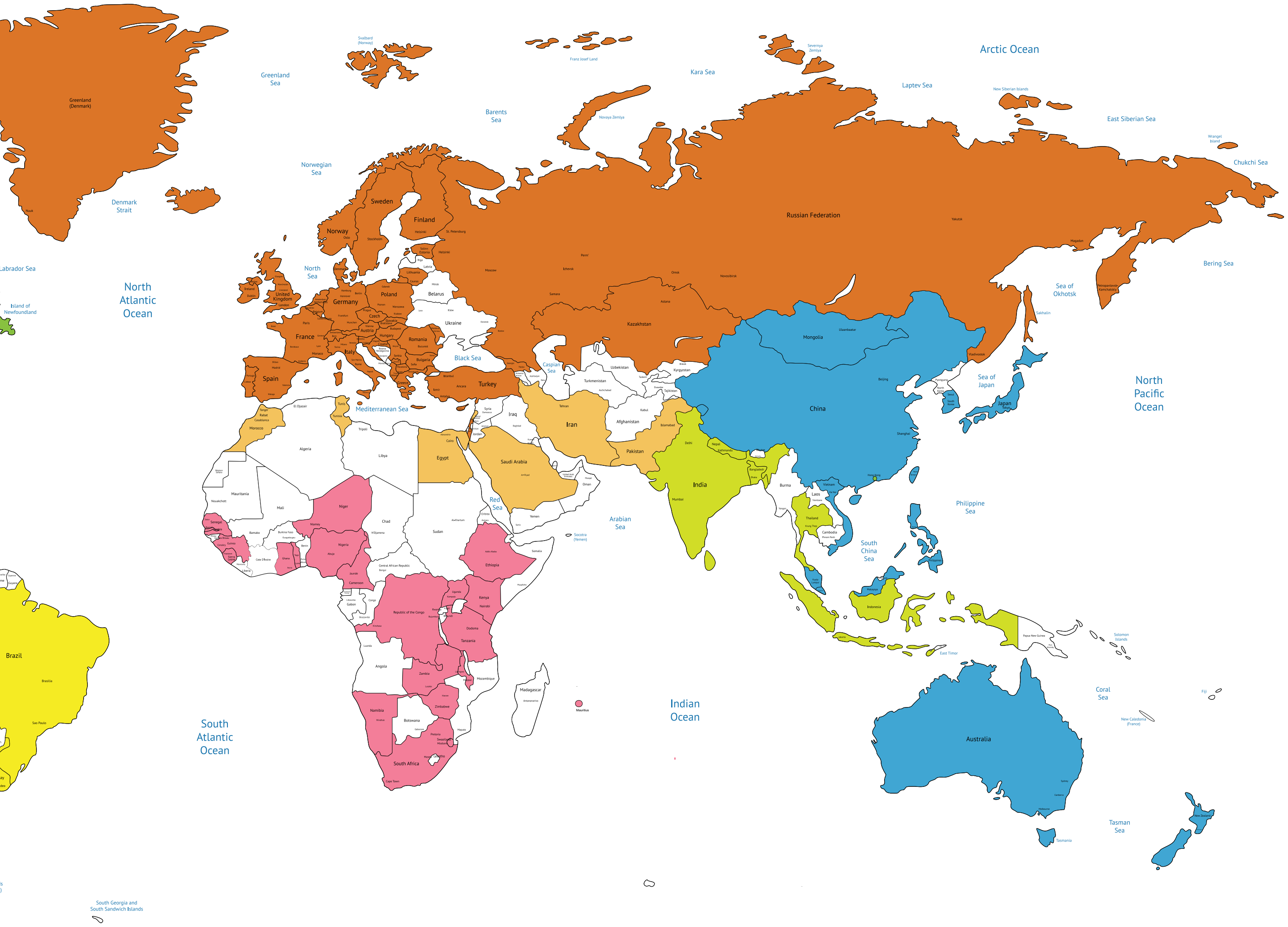
In the last 14 years, since the start of the 21st century, the Bureau has grown significantly and now has 137 members in 100 countries across the globe.

Of course, some areas have grown more quickly than others. Europe is the prime example of a region that continues to welcome new members as new epilepsy associations are created in some of the newer European states. There has also been growth in the number of Associate Members - associations who would like to be involved in the work of the Bureau but who are based in countries where IBE already has a Full Member.

Membership in the European Region is now almost three times higher than in any other of the seven regional committees. There are currently 39 Full Members in Europe and 20 Associate Members and, even as I write, a further application for Associate Membership is being processed.

Next nearest is Africa with 18 Full Members and 3 Associate Members.

Of course, Europe should not rest on its laurels as long as there are countries in the region where IBE does not yet have a Member. So, which countries are



European Regional Committee

Albania
Austria
Belgium
Bulgaria
Croatia
Cyprus
Czech Republic
Denmark
Estonia
Finland
FYR Macedonia
France
Georgia
Germany
Greece
Hungary
Iceland
Ireland
Israel
Italy
Kazakhstan
Lithuania
Malta
Moldova
Netherlands
Norway
Poland
Portugal
Romania
Russian Federation
Scotland
Serbia
Slovakia
Slovenia
Spain
Sweden
Switzerland
Turkey
UK

African Regional Committee

Cameroon
Congo, DR
Ethiopia
Gambia
Ghana
Kenya
Malawi
Mauritius
Namibia
Niger
Nigeria
Senegal
Sierra Leone
South Africa
Swaziland
Tanzania
Togo
Uganda
Zambia
Zimbabwe

Eastern Mediterranean Regional Committee

Egypt
Iran
Lebanon
Morocco
Pakistan
Saudi Arabia
Tunisia

South East Asian Regional Committee

Bangladesh
Hong Kong
India
Indonesia
Nepal
Sri Lanka
Thailand

Western Pacific Regional Committee

Australia
China
Japan
Korea
Malaysia
Mongolia
New Zealand
Philippines
Singapore
Taiwan

missing from the Membership Map? Based on the WHO regional boundaries, which IBE uses when determining the region in which a Member belongs, they are as follows:

1. Andorra
2. Armenia
3. Azerbaijan
4. Belarus
5. Bosnia and Herzegovina
6. Kyrgyzstan
7. Latvia
8. Luxembourg
9. Monaco
10. Montenegro
11. San Marino
12. Tajikistan
13. Turkmenistan
14. Ukraine
15. Uzbekistan

If you have a contact in an epilepsy association in any of these countries, please let us know. The bigger we are, the better we are, and the more powerful we become!

Which brings us back to the start of the story, introducing IBE's two new members. I am sure you will all join in welcoming:

- **The Association Of Supporting Children With Special Needs** - Moldova (Full Member)
- **FIE - Federazione Italiana Epilessie** - Italy (Associate Member)

as members of the IBE European Region. Congratulations to both organisations!

EU tells the pharmaceutical industry to "lobby better" in Member States

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

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

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

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

European Academy of Neurology becomes a reality

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

Since then, an EFNS/ENS Transitional Task Force has been busy preparing for the change by formulating new bylaws and resolving technical issues in order to pave the way for a smooth official founding, which will take place in June during a joint EFNS-ENS meeting in Istanbul. Thereafter, both ENS and EFNS will cease to exist.

EFNA
European Federation of Neurological Associations
Empowering Patient Neurology Groups

General Assembly of European Federation of Neurological Assocations - EFNA

Anastasia (Tata) Vassou, Chair of the IBE European Regional Executive Committee, has been invited to attend the annual General Assembly of EFNA, which takes place in Istanbul, Turkey on 1st June, directly in advance of the EFNA-ENS Joint Congress on Neurology.

This will be the opportunity to meet with other members of EFNA following IBE's renewed membership of the association last year.

It will also be the chance to hear more about the plans for European Year of the Brain which is now underway.

JUST THE TICKET!

Members of the Scottish Parliament (MSP) SIGN up to the latest gold standard for managing epilepsy in adults.

Allana Parker, Public Affairs Officer, Epilepsy Scotland provides a snapshop report on a range of activities held during Epilepsy Week

Wow – what a few days in the Scottish Parliament during National Epilepsy Week!

- The Epilepsy Consortium Scotland exhibition in the Parliament attracted more than 120 visitors, mostly MSPs
- 17 more MSPs signed the Consortium's pledge boards for equal access to epilepsy care across Scotland. These were first taken to recent political party conferences. We now we have 71 MSPs supporting this aim
- Tuesday night: 5 MSPs spoke at an epilepsy debate, on the theme was tackling the stigma of epilepsy through education. The Minister for Public Health Michael Matheson responded and there were another dozen MSPs staying on to listen to the 30 minutes session, which is held in their own time
- Wednesday evening: There were 35 MSPs at a photocall. These included party leaders Willie Rennie (Liberal Democrat) and Patrick Harvie (Green Party)
- Politicians were very supportive of the forthcoming Stamp Out Stigma campaign. They were also in favour of the Consortium's call for local councils to include epilepsy awareness as an essential part of first aid training for teaching staff
- Two thirds of MSPs (83 of 129) have signed up to support forthcoming SIGN guidelines for managing epilepsy in adults due to be launched this autumn. They will be inviting local health boards to adopt this new gold standard of care
- Finally, Gil Martin MSP has agreed to join the Cross-Party Group on Epilepsy. His constituent Brian Rocks is working to raise epilepsy awareness in the media including an Evening Times feature during National Epilepsy Week.
- Our current mapping exercise of epilepsy services in Scotland will afford another opportunity shortly to engage with policy makers with the aim that people with epilepsy benefit from future decision making.

EUROPEAN REGIONAL EXECUTIVE COMMITTEE TO MEET

EREC is planning an important 2-day meeting in Athens in early June with a busy agenda for discussion. One of the issues for discussion willl be future direction for Europe and we look forward to reporting back in the next issue of EPIfocus.

ECS the voice and vision for change

Report by Alanna Parker, ECS Chair

The Epilepsy Consortium Scotland (ECS) is a collaborative which hit the ground running in 2013. This recent umbrella body aims to bring issues concerning the 54,000 people living in the country with epilepsy to the attention of policy makers and the Scottish Government. It also offers an important channel for comprehensive feedback on what is happening in the field of epilepsy at a local and national level.

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

At a time when Scotland faces significant change, especially in how future health and social care will be delivered jointly by the NHS and local authorities, the Consortium advocates for those with epilepsy who need optimum and continued services. Representatives on the ECS forum include learning disability and epilepsy specialist nurses, clinicians, leading social care providers, voluntary organisations and individuals with epilepsy and those with associated expertise.

In the last year the Consortium has:

- Given comment on the new health legislation (Public Bodies Joint Working Act)
- Started mapping epilepsy services across Scotland (findings due June 2014)
- Contributed a response to the Scottish Government's proposed Lobbying Bill
- Asked MSPs (Members of the Scottish Parliament) to sign a pledge for equal access to epilepsy care across Scotland – 56 have already done so
- Held National Epilepsy Week exhibitions in the Scottish Parliament (2013/14)
- Undertaken a survey of first aid/ epilepsy awareness training in schools through the Cross-Party Group on Epilepsy
- Provided a briefing for MSPs taking part in the 6th epilepsy parliamentary debate on 20 May 2014. The topic is tackling the stigma of epilepsy through education
- Arranged a National Epilepsy Week photo call with MSPs to support the good standard of care and sign up to SIGN guidelines for managing epilepsy in adults.

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

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

enquiries@epilepsyconsortiumscotland.co.uk or visit our website at www.epilepsyconsortiumscotland.co.uk

Collage of MSPs signing the Consortium pledge. Photo far right: Johann Lamont, Scottish Labour Party, pictured with Alanna Parker, ECS Chair. Photo right: Alex Neil, Cabinet Secretary for Health and Wellbeing with Katherine Harvie (left), Epilepsy Connections.

At a time when Scotland faces significant change, the Consortium advocates for those with epilepsy who need optimum and continued services.

“We asked Members of the Scottish Parliament to sign a pledge for equal access to epilepsy care across Scotland – 56 have already done so”

European Epilepsy Day

Ireland

Rugby head coach Joe Schmidt lined out for epilepsy with a new TEAM at Dublin's Aviva stadium and asked for people to 'Be Seizure Aware' in advance of European Epilepsy Day.

A series of advertisements, voiced by Joe Schmidt, were broadcast on national and local radio focusing on the acronym TEAM:

T - Take care to protect the person
E - Ensure you stay with them
A - Allow the seizure run its course
M - Move the person on to their side when the seizure is over

Joe has a particular interest in epilepsy: his 10 year old son, Luke, was diagnosed with epilepsy at the age of four, and has undergone numerous brain surgeries since then.

GEORGIA

A Piece of Cake!

Nino Gzirishvili sent great photos of a very special EED cake. Nino told IBE that the Georgian association invited a pharmacology agency, which has supported the association every year with its EED celebrations, to a special Thank You event held at the Institute of Neurology and Neuropsychology in Tbilisi. Celebrations included the cake decorated with the image of the EED 2014 poster.

SEIN, Netherlands had a heart for epilepsy!

Stichting Epilepsie Instellingen Nederland (SEIN) created a special landing page for EED 2014 on its website and promoted it on Facebook and Twitter.

There was a heart-shaped badge that could be stuck to your FB profile photograph to show that you had 'a heart for epilepsy.'

There were also heart-shaped candles to promote EED 2014, to raise awareness for epilepsy and to raise awareness for SEIN.

Photo left: Nino Gzifrishvili, Georgia.
Photo above: Caroline Morton with her Hart voor epilepsie badge on Facebook.

SPAIN

Introduced by Dr Rocía Mateos Ruiz, President of Federación Española de Epilepsia, Dr Jaime Parra, a neurologist at the San Rafael Hospital in Madrid, presented a 15 minute video about epilepsy.

The video can be viewed on YouTube http://www.youtube.com/watch?v=6qjQcByEs34

across Europe

How national associations celebrated EED 2014

FINLAND

The Finnish Epilepsy Association (FEA) promotes the rights of people with epilepsy with the European Epilepsy Day (EED) theme 'Epilepsy is more than seizures' throughout the year.

EED was launched with an educational event for Human Resource Managers of large companies. A special EED 2014 website was also launched. There were personal stories and an electronic postcard that could be sent to decision-makers with messages such as "Have the courage to make good decisions".

FEA sent 2,000 emails to Finnish decision-makers, including MEPs, the Finnish Parliament; and local city councils and communities. Volunteers were asked to send electronic cards from the campaign website to their local politicians and government officials focussing, in particular, on Finnish candidates standing in the European Parliament elections. The message called for more resources for epilepsy research.

Nora Klemola, Assistant of the Supreme Court and Juha Karjula, kindergarten teacher speak openly about how their drug resistant epilepsies have affected their capacity to work in their professions. Klemola and Karjula were the faces of EED 2014 in Finland

HUNGARY

The Hungarian Chapter of the ILAE came up with an interesting event,to raise awareness about epilepsy and to mark European Epilepsy Day. On 15th February, epilepsy was in focus in Budapest Zoo, with participation of representatives of the League, the lay organizations, the president of the International Children's Safety Service and children and adults living with epilepsy. When the official programme ended, special tours of the Zoo were available, in small groups with guides who talked about the animals and their habits.

A second event, organized by the Hungarian League, was a meeting with representatives at the Ministry of Public Administration and Justice, the Ministry of Human Resources, the Presidents of the Hungarian lay organizations and the executive Board of the Hungarian Chapter of ILAE.

CZECH REPUBLIC

EpiStop decided to commemorate European Epilepsy Day by increasing knowledge on epilepsy and bringing attention to the daily obstacles with which people with epilepsy have to struggle. A Press conference was held in Thomayer´s Hospital.

Epileptologists, Jana Zárubová, MD and Klára Brožová, MD, ergotherapist Michaela Stoupová and enthusiastic advocate for epilepsy, Lucie Vávrová, brought out of the shadows the issue of coming to terms with the diagnosis of epilepsy and learning to live with it, as well as the impact that ignorant or hostile attitudes of surroundings may have on people with epilepsy.

CROATIA

EED 2014 in Croatia was organized by the Croatian Association for Epilepsy. The main event was a public conference in Zagreb, which was promoted using electronic and social media (webpage and Facebook). Both public and professionals showed great interest in the event, so there was almost not enough space for all the participants!

The conference was opened by a representative of the City Office for Health. There were presentations followed by open discussion and a small banquet, which provided the opportunity for the participants to share their personal experiences in a relaxed and enjoyable atmosphere..

FUTURE CONGRESSES

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
ILAE
Istanbul 2015

www.epilepsycongress.org