

## 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

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Chair: Thanos Covanis, Greece  
 Vice chair: Michael Alexa, Austria  
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*Symphonia 5 by Douglas Capron, Canada. A seasonal choice from the IBE Golden Jubilee photo exhibition Epilepsy Without Words.*



Photo: Richie Stokes

opportunity to visit the Milestone Walkway a colourful exhibition highlighting the purpose and goals of the International Bureau for Epilepsy over the past 50 years. The major landmarks and achievements of the IBE were displayed in chronological order to remind attendees of the milestones that culminated in this, our Jubilee Year.

A special event to honour all those who had received an Ambassador for Epilepsy Award, since its inception in 1968, was attended by more than 150 Ambassadors.

To date, a total of 287 recipients have been presented with an Ambassador for Epilepsy pin and certificate in recognition of their efforts in both the social and medical fields to improve the quality of life of people with epilepsy. In addition, a special booklet to honour all Ambassadors for Epilepsy was produced.

The major social event of the congress was a concert in the exquisite Auditorium Conciliazione beside the Vatican, the site of the 1961 congress where the IBE was founded.

As part of the Jubilee celebrations, IBE made copies of the book "SUDEP continuing the global conversation" available free to all delegates at the conference.

One of the biggest highlights of the Rome 29th IEC was the Presidential Symposium on the theme "Avoiding epilepsy deaths". This symposium, chaired by both Presidents, Mike Glynn and Nico Moshé, was packed out in a con-

ference room holding 1,200 seats, where a large number of people had to stand.

Speakers at the session included some of the world's top experts in SUDEP - Prof Lina Nashef, Prof Dale Hesdorffer and Prof Jeffrey Noebels - but was opened with a stunning presentation by Ms Susan Axelrod, who is the mother of a daughter with very difficult epilepsy. The final speaker, Dr John Paul Leach, told of advances in the prevention of epilepsy deaths and offered much hope for the future.

Of course, the 50th anniversary celebrations continued after Rome; one of the ongoing projects is the "IE News Jubilee Award". Getting news out about epilepsy has been a hallmark of IBE's work for the last 50 years and this award is intended to reward the best articles in 2011. All IBE member associations are encouraged to get details from [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org) and apply!

Mike Glynn,  
IBE President

**You don't  
have to be a  
Newshound!**

**You just need good  
writing skills to win ...**

**IE NEWS JUBILEE AWARD**

**Top photo:** Ambassadors for Epilepsy pose for a group photo during the celebrations in Rome.  
**Photo above:** Postcard used to promote the IE News Jubilee Award during the congress in Rome. There will be one prize winner, who will receive financial support to attend an IBE or IBE/ILAE congress of the winner's choice, up to a maximum of US\$2,000. The prize funds may not be used for any other purpose and must be used before the end of 2013.

# European Committee Meetings in Rome

held on 30th August 2011  
during the 29th International Epilepsy Congress

## European Regional Executive Committee Meeting

*Important issues discussed during the meeting*

- a) EREC budget. EREC stressed that a budget of 5000 dollars annually limits the scope of activities of the committee.
- b) Changes to congress procedures, approved by the International Executive Committee in 2009, regarding disbursement of congress surplus. Following finalisation of congress finances and receipt of surplus to IBE, 25% of the IBE share, up to a maximum of \$10,000 will be provided to the host country to fund a special project. The host association must submit a proposal outlining the planned project for approval by the International Executive Committee.

It was stressed by IBE President Mike Glynn that an equal amount is given to all regions who explained that the procedures have been approved by a motion of the International Executive Committee.

The next ECES will take place in Slovenia in 2013, most likely the 2nd or 3rd week of September. Member countries will be asked for topics and speakers.

## European Regional Committee Meeting

*Important issues discussed*

In attendance: 26 representatives from Austria, Bulgaria, Denmark, Greece, Finland, Ireland, Malta, Netherland, Norway, Sweden and UK.

The chair invited some of the members to join a sub-committee to help collect information for the Epifocus magazine.

It was agreed that a summary of each European Regional Executive Committee (EREC) meeting be circulated to members.

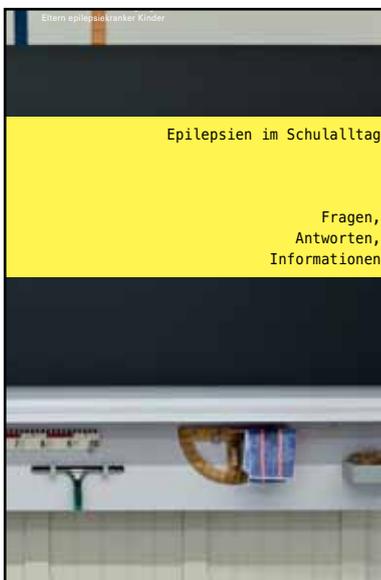
Due to the poor response to the survey on driving regulations, this would be resent to members.

The EREC report will be re circulated if members have not already received it.

A template will be created and sent out to all members asking them for ideas for topics and speakers for the next European Conference in Slovenia



*IBE's Jubilee Birthday Cake which was enjoyed at the end of the IBE General Assembly. Photo: Richie Stokes*



## Epilepsien im Schulalltag

### New Publication from ParEpi in Switzerland

We are pleased to introduce to you the second edition of a publication on epilepsy in school life in its new appearance!

The publication, which contains 68 pages, was updated by us and the content reorganized. It is now available to order (email [info@parepi.ch](mailto:info@parepi.ch), price CHF 18.50 plus CHF 3.50 for postage and shipping).

This publication provides comprehensive information about epilepsy in school life and its impact in detail and also answers your questions. The causes of learning difficulties in children with epilepsy are not always clear, and require an in-depth discussion.

Important topics such as medicine, psychology and pedagogy are discussed, and the appendix provides useful addresses, and references to literature and movies.

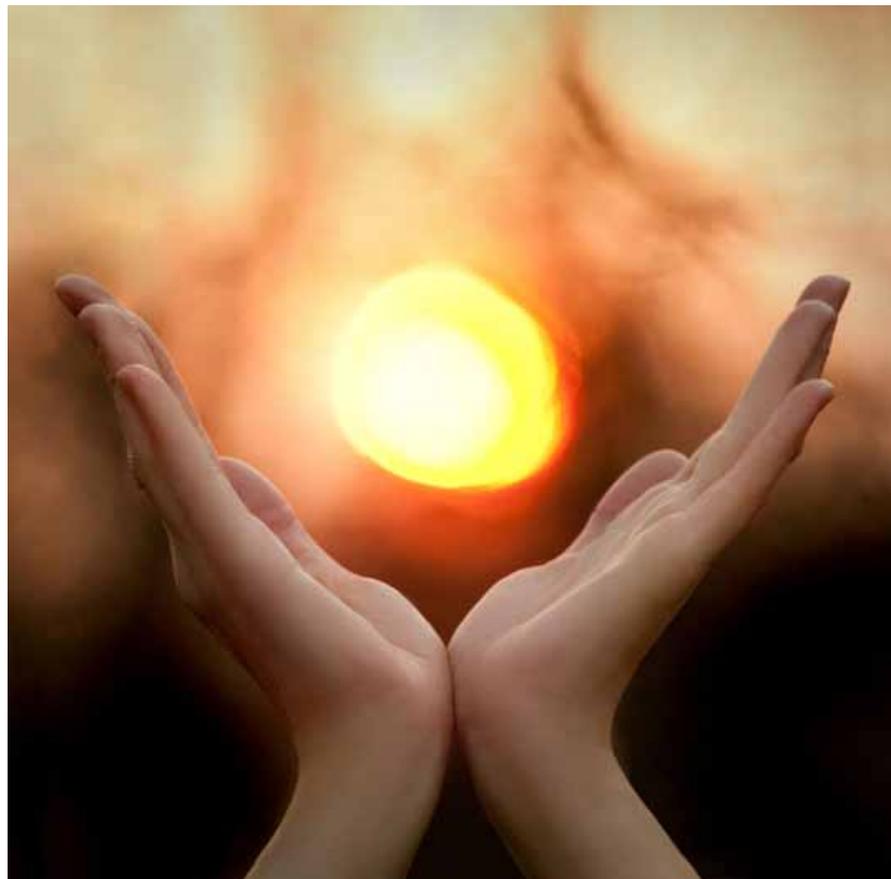
Teachers are supported with this publication in their work and dialogue with parents and all interested persons are encouraged to find common solutions to problems.

For further information please do not hesitate to contact us. We are happy to accept order enquiries at email: [info@parepi.ch](mailto:info@parepi.ch).

# Deutsche Epilepsievereinigung e.V. – Germany shares its diary of activities for 2012

## The German Epilepsy Association plans to execute the following projects in 2012:

- Workshop “Memory Practice,” which takes place in Berlin between the 22nd and 24th April 2012
- Seminar on how to deal with epilepsy and depressions in Jena between from 18th to 20th May 2012
- General meeting in Berlin on the 22nd June 2012
- Seminar on “New ways about epilepsy treatment” in Berlin from 22nd to 24th June 2012
- Workshop for leaders of self-help-groups to discuss subjects such as conflict solving, funding, raising awareness, etc. in Jena from 31st August to 2nd September 2012
- Workshop “Epilepsy and Self-Control” in Bielefeld from 21st to 23rd September 2012
- National Day of Epilepsy 5th of October 2012  
Theme: Epilepsy in Childhood
- Workshop for families with children affected by Lennox-Gastaut syndrome. During the workshop, which will take place in Berlin from 9th to 11th November 2012, we will offer care and assistance for the children, to enable parents to exchange experiences with other participants and to have time to relax (max. 14 families)
- Production of a documentary film “Young adults with epilepsy” 2011-2012



*Photograph by Andraž Gregorič, Slovenia. Titled ‘You are not alone’. An entrant to the IBE Golden Jubilee Epilepsy Without Words photography competition*

## Greek National Association Against Epilepsy: Epilepsy on the wheels



In June 2011 the message “Out of the Shadows” travelled 600 km from Northern to Central Greece. Two young women, city cyclists, decided to set out on the 24th of June from Thessaloniki and cycle all the way to Athens in order to spread the message about epilepsy and raise awareness for the Greek Association Against Epilepsy and its activities.

The Greek Association Against Epilepsy was delighted to support this initiative by providing all the necessary means and facilities for the completion of the journey. The cyclists left from Aristotelous Square in central Thessaloniki on the morning of Friday 24th June, in the presence of many members of the Cycling Club of Thessaloniki, who supported the cause, as well as many TV and print journalists. They covered 105 km on Day One to arrive in the beautiful seaside town of Platamonas. On the second day, they made their way to Larisa, one of the 5 biggest cities of Greece and then continued to Lamia, in Central Greece and Halkida, capital of the island of Evia. On the fifth and final day they arrived in Athens, applauded by the people who welcomed them to the city after having covered 600 km of cycling.

Through her dedication to the cause and her persistence, one of the two cyclists - a person with epilepsy herself – promoted the very clear message that people with epilepsy can lead a normal and very active life.

This initiative was scheduled on the occasion of the 6th Panhellenic Congress on Epilepsy, which, as in other years, presented a 2-hour session addressed to the public, as part of the Association’s activities in the Global Campaign

# DANISH PEOPLE WITH EPILEPSY TAKE TO THE STREETS!

On October 5th, over 300 Danish epilepsy patients gathered to demonstrate against budget cuts in a highly specialized epilepsy treatment available only at the Danish epilepsy-hospital Filadelfia. The demonstration was the culmination of ongoing huge frustration over the budget cuts shared by patients, relatives and professionals. Orchestrated by the Danish Epilepsy Association, in cooperation with patients from the hospital, the demonstration was a huge success that attracted both local and national media attention.

## Background to the crisis at Filadelfia

Filadelfia is the only hospital in Denmark that specializes in the treatment of epilepsy patients with complex diagnosis, and the hospital is a cornerstone in the Danish epilepsy treatment system. At the end of September the budget negotiations for the year 2012, between the 5 Danish hospital-regions (who hold responsibility for Danish hospital operation) and Filadelfia, resulted in a new agreement that will include a severe budget cut in 2012 and hence forward.

As an immediate consequence Filadelfia has announced the closing of two hospital departments, including the department for the physically and mentally disabled and the department for adolescents with severe epilepsy. Furthermore close to 100 staff members have been laid off. These steps, however, are not sufficient if the economic agreement does not improve and thus creates a need for further cutbacks at the end of 2011. This of course creates a lot of concern among Danes with epilepsy, their relatives and people with a professional interest in epilepsy.

## Members of Danish Epilepsy Association in action

As soon as the negative consequences were known, the Danish Epilepsy Association called on our members through website posts, on its Facebook-page and in e-newsletters to become involved in the campaign against the severe budget cuts. We encouraged our members to contact all central decisions-makers (from the Minister of Health and the members of the Danish Health Committee, as well as chairmen of the 5 hospital-regions) with their personal story with epilepsy. The idea was to gener-



Top: Members of the Danish Epilepsy Association protest in the streets.

Bottom: President of the Danish association, Mrs Lone Norager Kristensen

ate a massive “voice” of personal accounts of how poorly treated epilepsy impacts with everyday life. At the same time we co-ordinated nation-wide media coverage with statements from both patients and professionals. The message of how epilepsy treatment provided at Filadelfia positively affects the quality of life of people with epilepsy has been effectively told.

## Lessons to be learnt

David Axelrod – former senior advisor to President Obama – once said that one should never let a good crisis go to waste. This budget cut crisis has not been wasted and a lot of positive lessons have been learned. Executed properly, the orchestrated voice of our members, and other people

with epilepsy, can have a massive media impact and help get a message out. Use of electronic platforms, when communicating with members, is of vital importance and can generate very fast results. However, decision-makers are not persuaded by massive media coverage alone. Media coverage will give you a sound basis for starting a political dialogue with people in central places, but at the end of the day you are still fighting for limited resources, and your arguments need to be bulletproof. We find that ours are... but the jury is still out with regard to how the crisis will end, as we are waiting for a final answer from the 5 hospital regions and our Minister of Health.



# European Written Declaration on Epilepsy

Athanasios Covanis, Chair, EREC writes

Photo: Ann Little

## Text: Written Declaration on Epilepsy

### The European Parliament,

- having regard to Rule 123 of its Rules of Procedure,
- A. whereas epilepsy is the most common serious disorder of the brain,
- B. whereas 6 000 000 people in Europe have epilepsy, with 300 000 new cases diagnosed each year,
- C. whereas up to 70% of people with epilepsy could be seizure-free with appropriate treatment, while 40% of people with epilepsy in Europe do not receive such treatment,
- D. whereas 40% of children with epilepsy have difficulties at school,
- E. whereas people with epilepsy in Europe experience high levels of unemployment,
- F. whereas people with epilepsy are exposed to stigma and prejudice,
- G. whereas epilepsy damages health but also disrupts every aspect of life, and can impose physical, psychological and social burdens on individuals and families,
- 1. Calls on the Commission and Council to:
  - encourage research and innovation in the area of prevention and early diagnosis and treatment of epilepsy;
  - prioritise epilepsy as a major disease that imposes a significant burden across Europe;
  - take initiatives to encourage Member States to ensure equal quality of life, including in education, employment, transport and public healthcare, for people with epilepsy, e.g. by stimulating the exchange of best practice;
  - encourage effective health impact assessments on all major EU and national policies;
- 2. Calls on the Member States to introduce appropriate legislation to protect the rights of all people with epilepsy;
- 3. Instructs its President to forward this declaration, together with the names of the signatories, to the Commission and the Parliaments of the Member States.

February 14th 2011, organized by IBE and supported by ILAE, the first European Epilepsy Day was launched in Strasbourg and celebrated throughout Europe with great success. The majority of EREC members were able to attend the event (Thanos Covanis, Michael Alexa, Aisling Farrell, Victoria Dimech, Janet Mifsud). During that unique event a European Advocates for Epilepsy working group of Members of the European Parliament (MEPS) was created. The leader Mr Gay Mitchell, President of the group and four other MEPs subsequently co-signed the Written Declaration and in April 2011 and submitted it to the European Parliament for approval. The challenge! In order to have a Written Declaration carried, a minimum of 369 MEP signatures were needed out of the total number of 738 MEPs. There were four opportunities to garner signatures to achieve this goal: in May, June, July and September when MEPs had their plenary sessions in Strasbourg.

A well orchestrated promotion to achieve this goal was initiated from the central IBE office and Epilepsy Advocacy Europe (EAE), the joint IBE/ILAE Task Force, to all IBE members and ILAE chapters in Europe to raise awareness of their national MEPs to encourage them to sign the declaration. A total of 459 signatures were finally obtained and the Written Declaration on Epilepsy was approved. From now on this document will give us the opportunity to access to funds for research activities in epilepsy and thus improving treatment issues and healthcare services of people with epilepsy.

EREC would like to thank all those involved in this great achievement:

- Gay Mitchell, for his initiative, and all the MEP who actively participated and or signed the Declaration
- Epilepsy Advocacy Europe, which was responsible for the initiative
- The IBE and ILAE offices who supported the joint task force in its efforts
- All of you for being so active in promoting this important issue and achieving the fantastic 459 signatures.

# UK public Take epilepsy action



Over the years, Epilepsy Action's members have said that one of the biggest issues for people with epilepsy is the misunderstanding that continues to surround the condition. It would make a world of difference if the general public could recognise different kinds of seizure.

It would make an even greater difference if they knew what to do if someone had a seizure in a public place. This was the inspiration for the charity's latest campaign Take epilepsy action, which launched in September. Its aim is to raise awareness of different kinds of seizures and appropriate first aid.

The feedback from members was supported by a recent survey, commissioned by Epilepsy Action. The survey revealed that nearly nine out of 10 people in Britain would get basic first aid for epileptic seizures wrong. In fact, almost a third (32 per cent) of people would actually do something dangerous when trying to help someone who was having a seizure.

To tackle this problem Epilepsy Action developed a wallet-sized 'ACTION card' for members of the public to carry with them. It features easy-to-understand advice



about how to give first aid to someone having a seizure. A new two-minute film was also produced and placed on the charity's website to demonstrate first aid for tonic-clonic seizures.

Epilepsy Action took its campaign to 13 cities across the UK, including London, Belfast, Edinburgh and Cardiff. It held a series of eye-catching first aid demonstrations in city centre locations to catch the attention of the public and the media. Members showed their support for the campaign by attending launch events, telling their stories to the media and handing out first aid information to the public.

The campaign has been a huge success so far and over 9,000 items of information,

including posters and ACTION cards, have been distributed. It has also received excellent feedback from both the public and Epilepsy Action members. Martin Jessop from Liverpool said: "Epilepsy is something that has a huge impact on the lives of people with the condition. It's really important that the general public understand more about epilepsy and what to do if they see someone having a seizure. It's also important for people to appreciate that there are lots of different kinds of seizures."

For more information about the Take epilepsy action campaign and to watch the campaign film, visit [www.epilepsy.org.uk/campaigns/take-epilepsy-action](http://www.epilepsy.org.uk/campaigns/take-epilepsy-action)



## Driving Survey

**Has your association completed the EREC Driving Questionnaire? If not, it's still not too late.**

**Contact Vania Power at the IBE office [ibeadmin@eircom.net](mailto:ibeadmin@eircom.net) for further information.**

**This survey will provide vital information on the current situation on driving regulations for people with epilepsy in Europe. Please help us by taking part!**



## Improving legislation for people with epilepsy in Italy

AICE, IBE's member in Italy, has been working very hard over the last few years to address the legal gaps that existed in Article 320 published as a Decree of the President of the Republic no. 495 in 1992. This decree, as written, has resulted in unfair discrimination against people with epilepsy. There are several reasons: Firstly because all types of seizures are grouped under the only one term "epilepsy", imposing the same restrictions on all seizure types. Secondly, the law did not allow for a possible cure of epilepsy and it imposes unfair lifelong restrictions for people with epilepsy with respect to driving.

In addition AICE has shown a third discriminating condition for people with epilepsy: the lack of, or inadequate access to, inclusion into society for people with drug resistant epilepsies.

AICE has been addressing this triple discrimination, since 1996. Lobbying took several forms in attempts to obtain administrative and judicial recognition of

cases of a cure from epilepsy and also to present to Parliament a new draft law on January 14th 2009, seeking full citizenship for people with epilepsy. This request was also made in anticipation of the European Directive No. 112 of August 25th 2009.

This draft law sought the recognition of a possible cure in cases of epilepsy, the inclusion of those who have drug resistant epilepsy, and proposed adequate measures to support the mobility of people with epilepsy. It also included measures for people with epilepsy who were fit to drive as well as for those who, because of illness, could not drive.

When the Italian State, in September of 2009, started work on the transposition of European Directive No. 112, AICE proposed to the Italian member of ILAE, a common proposal which provided for the recognition of cases of cure and measures for the mobility of people with drug resistant epilepsies. However, for various reasons, there was a lack of consensus on

the text to be drafted and AICE proceeded alone.

Finally, our hard work has borne fruit and, through Legislative Decree No. 59 of April 18th 2011, the Italian state finally now recognises that epilepsy can be cured.

AICE is now committing itself to begin another legislative process for approval of the Proposed Act 2060 which improves situations in which cases of epilepsy cures are recognised and improves access to societal inclusion in cases of epilepsy drug resistance. It also recommends the establishment of a Permanent National Committee for epilepsy, and a better transposition of European Directive No. 112 including measures to support mobility for people with drug resistant epilepsy.

The discussion on this new law was due to start on November 18th 2011; however the present Italian parliamentary crisis means that this process may be side-tracked.

# Epilepsy Services in Norway

## Report from the Norwegian Epilepsy Association

The Norwegian Epilepsy Association (NEA) was established in 1974 and works for the empowerment and increased quality of life for people with epilepsy in Norway. We are proud to say that since 1974 we have come very far, and today people with epilepsy have a good support system in Norway. For instance, one is entitled to a consultation with a neurologist or a paediatrician within 30 days of epilepsy onset, and there are a number of government benefits that are designed to lessen the economic consequences of chronic medical conditions.

National expertise on epilepsy is also well developed. For more than a hundred years, the National Centre for Epilepsy (NCE) has been an important force for increased medical understanding and improved treatment methods. Today the centre can offer comprehensive treatment for people with epilepsy, and employs a number of experts in rare epilepsy disorders.

Nevertheless, we still see that people with epilepsy meet many challenges in Norway that need to be addressed. Both medical questions and issues concerning employment and equality are important for the association, and for the past couple of years NEA have increased our political advocacy efforts, to ensure that people with epilepsy receive first class treatment, rehabilitation and aid in order to be active in society and not to suffer financially due to the epilepsy. The organisation has been quite successful in this, and is proud to be an important factor in ensuring good quality of life for people with epilepsy.

Like any IBE member organization, creating social awareness about epilepsy is also a very big part of what we do in NEA, and here we really do have our work cut out for us. Despite a very competent medical community, very little knowledge of epilepsy has permeated the rest of Norwegian society. Few Norwegians would know how to administer proper first aid



for a GTC seizure, and, when it comes to focal seizures, many people are not even aware of their existence. This lack of knowledge can be detrimental, as when the sufferer of a seizure is shunned and dismissed as a psychotic or a drug addict. We're currently setting up a project where we enact seizures in streets and on public transportation to address this problem.

It also causes unnecessary challenges for many children when their teachers are unaware of different types of seizures and are unable to provide first aid. NEA has been particularly concerned in spreading information to schools and teachers' colleges for this reason.

This lack of knowledge also extends into the field of social sciences. This is a major problem, since we do know that the social consequences of epilepsy can be quite severe in Norway. Although the numbers vary, estimates say that as many as 50% of people with epilepsy in Norway are currently receiving disability benefit and are seen as unfit to be in the work force.



As to what the main causes for this might be, we can only guess. Many other conditions have high comorbidity with epilepsy, which may be a significant factor.

We also know that many people with this condition feel isolated and alone in Norway. It may be that in a highly regulated society, where making a spectacle is generally frowned upon, mechanisms of social marginalization can be especially hard on people with epilepsy. In the NEA we have conducted surveys among our own members, but these studies have an obvious selection bias, which makes generalization difficult.

What we wish to see is a national register for epilepsy, which could be made available to scientists. Such a register already exists for cancer, and has proven to be an important source of data for both medical and social research.



# Michael's Roman Diary

Michael Alexa, Vice Chair of the European Regional Executive Committee, reports on the 29th International Epilepsy Congress



Usually the place of the next international Epilepsy Congress is very hard to guess. But this time it was very clear: after the Golden Jubilee of the ILAE, which was celebrated in its founding city – Budapest – in 2009, it was obvious that the congress in 2011 would be celebrated in IBE's founding city – Rome. Everyone who visits Rome falls in love with the city. But this time it was different. The conference center was outside the city as there is no large congress venue in the city centre – it was a little disappointing although there was no alternative.

## SUNDAY

The first session was on Sunday, 28th August – “Setting future direction for IBE: the next 50 years”. This was a very important workshop for me as it highlighted where the IBE is right now and where it wants to head to in the future. One of the positive findings was the launch of the 1st European Epilepsy Day on the 14th February 2011. It led to the creation of the Written Declaration on Epilepsy. But although the Written Declaration has since passed, there has a lot of work to be done:

- On the political level the legislations of the 27 member states of the EU should be unified
- At international level organisations such as the IBE become increasingly important and the IBE should be working on an international legislative agenda for epilepsy in conjunction with the WHO and the ILAE (100 countries have already signed but

145 countries are needed) – President Obama signed this treaty in 2009.

- At the communicational level the world has changed a lot. One of the most important inventions of the last 30 years was the internet which has been developed in 1989. It was followed by facebook (a social network) in 2004. Facebook was followed by youtube, twitter, i-phone and google+. The IBE – as well as the member organisations – should make those changes too.
- On the fundraising level competition is increasing every day. 20 years ago information was written, now it is electronic – and nobody knows where we'll be in 20 years from now.

Sunday ended with the opening ceremony of the 29th International Epilepsy Congress. During the Opening Ceremony a lot of awards have been awarded.

## MONDAY

Monday, 29th August started with the presidential symposium – Avoiding epilepsy deaths. SUDEP doesn't have to happen. But – as usual – it's a question of money. A speaker rose an interesting point: on the one hand we spend a lot of money to prolong lives of people who faint, and on the other hand we can't prevent death in individuals with epilepsy.

After that I turned to epilepsy and arts. Art of persons with epilepsy can be a powerful tool in helping persons with epilepsy in gaining understanding and acceptance from physicians, scientist and the public. They also stated that the art may be a window onto the brain and inspires us to search for correlations between features of the art and epilepsy related brain functions. So the Epilepsy Without Words award – hosted for the first time during the Rome conference and was very successful -

should be repeated in the future.

At lunchtime I had a business meeting – the Stand Up for Epilepsy project. In 2012 the Summer Olympic Games take place in London – and a few weeks after that the ILAE European Congress on Epileptology also takes place in London. So it's planned to photograph a person with epilepsy with a famous sportsman of the country. The aim of this project is to use the Olympic Games to raise awareness about epilepsy - worldwide!

The Editors Network meeting was very fruitful. It showed a lot of possibilities how the collaboration between the countries can be intensified!!!

## TUESDAY

Tuesday, 30th August began – as every other congress day – very early. As I mentioned earlier, the congress venue was outside the city while I had chosen to stay in a hotel in the city centre. Thank goodness the bus worked well – but still I had to get up very early, as the departure was scheduled for 07:30! A very interesting workshop was “When do we consider epilepsy cured?”.

- Can it be cured: Up to now, there is no evidence yet available, that epilepsy can be cured once it begins.
- Syndromes: It depends of a lot of factors to consider the epilepsy cured – e.g. the syndromes as well as the seizure control differ in population or the effects on the long-term prognosis of epilepsy syndromes are still ill-defined!
- Surgery: When is a patient cured? Directly after surgery or after surgery AND being off AED's? -> The sooner a patient is being operated, the better are the outcome rates.
- Social functions: PWE are less often married, have a lower educational



level and are less often employed.  
**A lot of work needs still to be done!!!**  
 Tuesday afternoon was ruled by the EREC meeting and the European Regional Committee meeting – both of them I had to attend. A summary can be found in this issue too. For Tuesday evening I was able to organize a ticket for the IBE Jubilee concert – it was very good.

### WEDNESDAY

Wednesday, 31st August – Celebrating the IBE Golden Jubilee at the General Assembly – we'll focus on it later on!

Wednesday began after only a few hours sleep – after the concert on Tuesday evening I went to a teaching session “Synergizing and advocacy: bringing IBE and ILAE together at national and regional level”.

The best example for working together is the Written Declaration on Epilepsy which has, fortunately, been passed by the European Parliament!!! Without the collaboration of Epilepsy Adocacy Europe, the joint task force of IBE and ILAE; the IBE European Regional Committee and the ILAE Commission on European Affairs, together with IBE and ILAE member organisations in Europe, this success would not have been possible! Another example that the local League and Bureau offices are working together was shown by Canada. Both parties have their defined roles when a new project is being set up and they are working closely together. You'll also find a joint conference between the IBE member and the ILAE chapter in Canada. In India a trust was founded from the income of the 18th International Epilepsy Congress. It provides the IBE member and the ILAE chapter with enough money – only from interest earned – to fund themselves without using any of the capital. After the teaching session I went to the plenary session “Epilepsy dur-

ing puberty – the wonder years”. Especially women who suffer from epilepsy need to be watched carefully, as during puberty the epilepsy remission, the epilepsy onset and the epilepsy exacerbation might change. It's also shown that sex hormones can effect seizures and vice versa. The AEDs also need to be chosen wisely as they've got a wide range of side effects (e.g. influencing the intellect, weight gain, weight loss).

The afternoon was filled with the general assembly of the IBE.

### THURSDAY

Thursday 1st September – last day of the conference!!!

The day before we've heard some interesting facts about epilepsy during puberty – this day one of the plenary sessions focused on “older, slowing down and seizing up – epilepsy strikes again”. Seizures in the elderly are common and that epilepsies are usually symptomatic and rarely idiopathic. There are also different treatment options: when you're not sure, a “wait and see” strategy is warranted, when you're sure, treatment should be started – but as older people take more medications, a higher risk of drug interactions will be found. The Quality of Life is being influenced by social anxiety, family anxiety, employment, psychological factors, ignorance, prejudice and stigma.

After this session I attended my last business meeting – the CEO Meeting. It was my 7th meeting in 5 days.

### TIME OUT

Afterwards I was able, as usual, to spend some time in Rome – as my return flight took off on Sunday. I hope that you've received some nice impressions about the 29th International Epilepsy Conference and look forward to seeing all of you again in some of the following conferences.

**Photos:**  
*Page opposite: Michael at the Trevi Fountain*  
*Above left: Participants at the Editors Network meeting (photo Denise Chapman)*  
*Above right: Vania Power at the IBE Stand in the Exhibition Hall (photo: Richie Stokes)*  
*Below: Festive balloons celebrate IBE's Golden Jubilee (photo: Susanne Lund)*  
*Bottom: A section of the Milestones Walkway, highlighting special achievements in IBE's 50 years history. (photo: Susanne Lund)*



# Meet the National Association of Hungarian People Living with Epilepsy!

The population of Hungary is around 10 million, of whom approximately 80,000 people have epilepsy. Our association was founded in 2004, to provide active help and assistance for to all people with epilepsy in Hungary.

Our main target is to change the negative discrimination of society against people living with epilepsy, to improve the quality of their



life, as well as the opportunity for education and employment. Despite the many obstacles we face (the lack of a permanent office, the passivity of our fellows, the lack of financial assistance) we achieved the following results:

Every year around the 14th of February we start a media campaign, to inform society about our activity. In 2009 on the first day of the 28th International Epilepsy Congress, which took place in Budapest, we organised a publicity walk, with the attendance of many well known people. We regularly organise information campaigns for schools. We organize, every year The Day of Epilepsy, with cultural and literature competitions for our members.

We have created a professional webpage ([www.epilepsziás.hu](http://www.epilepsziás.hu)), which contains usefull informations for all. Every year we organise a camp for people living with epilepsy. In 2010 we entered a photo competition against discrimination, where we took the 5th place. The title of our photo was: "I am epileptic, not stupid!" The photo had a great success. We regularly attend different civil fairs.

We have published an informational booklet, which presents the day in the life of a young boy living with epilepsy in the form of a cartoon, which will be sent to all major hospitals, municipalites and schools. This year we signed agreements with two employment centers, to give extra assistance for our members to find a job.

In 2012 we would like to establish an office, where we can establish a fulltime basis for creating a national web of associations of people living with epilepsy. In our office we could hold different courses and presentations, and even social events for our members. We plan to have art therapy activities, and to assure full time psychological support for our members. In 2012 we plan to lobby for a change in the referring law, to improve the life of people living with difficulties. Currently we are working on a 3-year strategy, which will help to combat discrimination against people living with epilepsy.

For any details or additional information please contact Mr Zsolt Szabó (pictured centre in top photo), President of the National Association of Hungarian People Living with Epilepsy, e-mail: [solesz65@gmail.com](mailto:solesz65@gmail.com)

## European Congress News!

Ljubljana to host  
13th European Conference on Epilepsy & Society  
in September 2013

**More details available soon**

