

*International*

# *Epilepsy News*

Newsletter of the

International Bureau for Epilepsy Issue 3 - 2009

## *Epilepsy and Disability* **EU Directive on Driving** *ILAE Celebrates 100 years!*



# The President's Message



Dear Friends

In this, my first President's Message, I would like to begin by thanking Susanne Lund for her informative letters in previous issues of IE News. I hope that I will be able to emulate her writing skills during my term.

A flame was lit for people with epilepsy in 1961 when IBE was born during the 9<sup>th</sup> ILAE meeting in Rome. The emblem of the candle has burned brightly ever since.

In two years time we will celebrate the 50<sup>th</sup> anniversary of the Bureau and I hope that many of you will join us in Rome in 2011 where this important landmark will be hon-

oured during the 29<sup>th</sup> International Epilepsy Congress.

The last four years have seen many important achievements under Susanne's excellent leadership and I hope that I may be able to build on them during the lead up to the 50<sup>th</sup> anniversary and beyond. We have had our second series of elections, seen the establishment and growth of our seven Regional Executive Committees and the creation of the brilliant Promising Strategies program—just to name a few.

I hope my own Presidency will see similar successes building on the work of Susanne's years and in areas of epilepsy in which I am particularly interested such as stigma, driving, employment and generic AEDs. As part of this, I will be co-chairing the Global Campaign against Epilepsy along with Nico Moshé, the new President of ILAE. The Global Campaign has been running for twelve years but there is still much that it can achieve, and this opinion is also shared by Nico. IBE's joint working with the League is, I believe, one of our great strengths and something we must continue to nurture and build on. The great epileptologist Dr William Lennox suggested the creation of the Bureau as long ago as 1936. Sadly, he did not live to see the motion of Dr Abraham Moscovich, of Argentina, to create IBE passed at the ILAE general assembly at the University of Rome in 1961, which led to the establishment of the International Bureau for Epilepsy.

I look forward to working with you for the great cause of epilepsy for the next four years.

All the best,  
Mike Glynn  
President

## PARTNERING SPONSORS

IBE acknowledges the support of its generous partnering sponsors. To learn about partnering opportunities with IBE, please contact:

Ann Little, Executive Director  
Email: [ibedublin@eircom.net](mailto:ibedublin@eircom.net)

**PLATINUM PARTNER:**  
UCB Pharma

**GOLD PARTNERS:**  
Dainippon Sumitomo Pharma Co., Ltd.  
Eisai Europe Limited



The International Bureau for Epilepsy, with membership of 120 epilepsy associations based in 92 countries worldwide, works to improve the quality of life for all people affected by epilepsy.

## International Epilepsy News No. 3 - 2009

**Editor** Carlos Acevedo

**Co-ordinator** Ann Little

**Regional Sub-editors**

**Africa:** Noeline de Goede

**Latin America:** Tomás Mesa

**North America:** Lisa Boylan

**South East Asia:** Marshal Hsi

**Western Pacific:** Sherman Goh

**Advisors**

Abdulaziz Al-Semari: Saudi Arabia

Mike Glynn: Ireland

Eric Hargis: USA

Shung-Lon Lai: Taiwan

Susanne Lund: Sweden

Janet Mifsud: Malta

Vinod Saxena: India

Mary Secco: Canada

Grace Tan: Singapore

Anthony Zimba: Zambia

Solomon Moshé: USA

Emilio Perucca: Italy

Samuel Wiebe: Canada

**Editorial Correspondence**

Ann Little

International Bureau for Epilepsy

11 Priory Hall, Stillorgan,

Dublin 18, Ireland

Email: [ibedublin@eircom.net](mailto:ibedublin@eircom.net)

**Subscription**

Three years: US\$30

Five years: US\$48

Contact [ibedublin@eircom.net](mailto:ibedublin@eircom.net) for further details.

**Copyright**

International Bureau for Epilepsy or as stated. Views expressed and information included herein do not necessarily reflect official policies or endorsements of the International Bureau for Epilepsy or its members.

Articles covering medical aspects of epilepsy are not intended to be taken as advice. All content is copyright and may not be reproduced without prior permission.

The Editor reserves the right to edit content for reasons of space or clarity.

# The Editor's Letter



Dear friends,

This issue of IE-News is going to have a special flavour as we look back at the very successful congress in Budapest. This was a time of great activity as IBE reached the end of a term of office during the General Assembly on 1<sup>st</sup> July. We also had the opportunity during the Opening Ceremony to make a special presentation to the International League Against Epilepsy to

mark the 100<sup>th</sup> birthday celebrations of ILAE. This issue is full of photos to remind us of the congress.

Dr Tomás Mesa is an expert in epilepsy and disability and we have a special report that he has prepared about this difficult issue. We also include a report on an important Latin American Regional Workshop that took place in Santiago de Chile and which involved the PAHO regional offices. The workshop addressed the topic of organic brain disability, of which epilepsy as one of the three most relevant causes, with emphasis on rehabilitation and job placements.

From Europe comes significant news on a new Directive on Driving of the European Union, which will see common regulations come into place for all IBE Member States. Although the Directive relates to Europe, it will be a useful tool for other countries in other regions in trying to establish fair driving regulations for people with epilepsy.

In China the Seahorse Clubs for people with epilepsy have been exhibiting the work of some of its very talented members. Their craftwork was on view in Budapest and shows us the incredible skills of these young people.

Finally you can read an interesting article about the high dental costs faced by people with epilepsy in Denmark to repair the damage caused by their epilepsy—either through falls or as a side effect of medication.

A very busy and interesting magazine for you to enjoy!

Best wishes for everybody.

Dr Carlos Acevedo Sch.  
IE News Editor

## International Epilepsy News on the Web

IE News is now available on the IBE website  
[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

Previous issues can be found under the tab **IE News**, while the current issue is available to IBE Members on the **Members** section.

## Contents

- 4 Organic Mental Disability
- 6 General Assembly in Budapest
- 7 Celebrating the ILAE Centenary
- 8 Budapest Photo Album
- 10 New EU Directive on Driving
- 13 Promising Strategies Program 2010
- 14 Epilepsy and Disability
- 16 Ouch! The cost of Dental Treatment
- 18 The talented Seahorse Club
- 19 Action Zone! In Mauritius



10



8



18



4



14



8

# Organic Mental Disability

**Dr. Carlos Acevedo, IBE Vice-President Latin America reports on an important regional workshop held in August in Chile**

A regional workshop titled “Organic Mental Disability” was held in Santiago de Chile from 19th to 21st August, in which the main issues were intellectual disability, dementia and epilepsy. The workshop was organized by:

- World Health Organization (WHO)
- Pan-American Health Organization (PAHO)
- Chilean Ministry of Health
- Rostros Nuevos (New Faces), a non governmental organisation (NGO).

Attendance numbers reached three hundred, with delegates representing different areas related to disability. The event also had the distinguished attendance of:

- Dr Benedetto Saraceno, Director of the Department of Mental Health and Drug Abuse, WHO, Geneva
- Dr José Luis di Fabio, Manager In the Area of Technology, Health Care and Research, WHO/PAHO, Washington
- Dr Jorge Rodríguez, Coordinator of the Mental Health, Disability and Rehabilitation Project, WHO/PAHO Washington
- Dr Hugo Cohen, Mental Health Sub-Regional Advisor WHO/PAHO for South America
- Dr Armando J Vásquez Barrios, Regional Advisor on Rehabilitation WHO/PAHO Chile
- Dr Víctor Aparicio, Mental Health Sub-Regional Advisor WHO/PAHO for Mexico and Central Latin-America
- Mr Javier Vásquez, Human Rights Lawyer WHO/PAHO Washington.

On an international level, mental disorders represent 22% of all ill-

nesses and by 2020 it is estimated that it will represent nearly 15% of life years lost to illness adjusted to disability at a global level.

Organic brain illnesses are associated with high symptomatic epileptic comorbidity. To this situation we must add a hidden burden of prejudice, ignorance, stereotype and rejection. The confrontation of these organic brain disorders requires preventive measures and rehabilitation in order to integrate people with disability to the family and society.

The aims of the workshop were to improve services for people with a disability related to organic brain damage; to identify their needs; and to establish the main issues and strategies for its management in the Latin American region. To attain this goal, it is necessary to create a contact network, a team strategy and to define the technical cooperation areas of PAHO and WHO for the period 2009/2011.

**On an international level, mental disorders now account for 22% of all illnesses**

During the workshop, there were lectures on the current reality, organic mental disabilities, and the advances and experiences in planning current services in Latin-America. The issues addressed were:

- General and regional viewpoints;
- International evidence of rehabilitation and social placement;
- Experiences in rehabilitation and in social and work placements;

- Ethical and clinical issues;
- Models of community care in organic mental disability and challenges for the future.

It was most important to hear the message of the patients who emphasized their rights and complaints about the current system and the difficulties they face in their daily lives. The final outcome will be a technical document that will provide references for future work on organic mental disabilities in Latin America.

Regarding epilepsy, a general point of view was given, emphasizing the different clinic cases and the need to distinguish between benign genetic cases; severe symptomatic cases; refractory cases and the diversity of current treatments.

Also stressed was the need to use the plural term “epilepsies” instead of singular “epilepsy” and that the percentage of cases that have a disability is low and does not exceed 10% of patients, with children and older people more affected. The brain pathologies frequently related to epilepsy have perinatal brain origin, sequels of central nervous system infections, chromosomic illnesses, vascular brain illnesses, dementia, cerebral paralysis, etc. More than 80% of the cases of epilepsy do not constitute a disability.

The cases of young people with epilepsy and mental disability, aged between the 15 to 25 year, from the Dr Alfonso Asenjo Workshop School that belongs to the Chilean League against Epilepsy, who were successfully introduced into the workforce during the past 10 years, was also presented during the workshop.

It was concluded that rehabilitation



Pictured above: Dr José Luis di Fabio, WHO/PAHO, and a group photo of the workshop participants

and social and work placements require the collaboration of different areas, such as the family, the health system, the community, the education system and, especially, the workplace. Isolated help is really appreciated but it does not last long. The reality is that more than two thirds of people in this group are unemployed; with stigma being one of the biggest problems that affect people with epilepsy, especially if associated with a disability. Therefore, it is essential to consider the requirements of the market place in order to adjust as necessary the curriculum of sheltered workshops. It is also necessary to strengthen young people's social

abilities, to train employers, and to teach family members to avoid over-protection.

At the end of the event, Dr Benedetto Saraceno emphasized the need for the following:

- An agreed international definition of disability;
- Up to date community care models;
- Up to date legal tools;
- Appropriate financing mechanisms;
- Consideration of national realities;
- Workable technical strategies;
- A clear view of the magnitude of the problem

- A joint effort of WHO, PAHO, the government and NGOs.

We must thank the participation of WHO, PAHO, the Ministry of Health and representatives of the NGOs for their devotion to improve the quality of life of this important, discriminated and relegated group of people in our society.

Finally, it is very important to ensure that people with a disability are not denied their civil rights. In this arena the International Bureau for Epilepsy is an effective tool.

## The transformative power of music

"I am alive today because I had a violin." Martha Curtis explained. Epileptic seizures began for Martha at the of age three; her music training began when she was five.

Music performance and intractable epilepsy co-existed in her life for over thirty years until her right hippocampus, amygdala, and half her right temporal lobe were removed in three brain surgeries. Today, Martha is seizure-free, and her ability to perform and memorize difficult pieces of music is greater than before the operations. Her story has featured on "60 Minutes" and "The Today Show" in the US.

Through the generosity of Mrs Elaine Forsgate, who brought Martha to Hong Kong, Enlighten – Action for Epilepsy and 75 guests met with the talented musician at a special event at Hong Kong's Mandarin Oriental Hotel in June. During the event, Martha shared her amazing story and gave a violin performance.

In her multi-media presentation, Martha used words, scans of her own brain, and performed

some of the music that kept her spirit driving forward all these years. Her success story has single-handedly changed preconceived theories about brain and memory function, crediting music with saving her life and allowing her experience beauty.

*Orla Gilroy, CEO Enlighten Hong Kong*



Martha Curtis with Anson Chan and Ada Wong from Enlighten Hong Kong

# GENERAL ASSEMBLY 2009



**THE** closing moments of each term of office are a momentous time and 1st July 2009 was no exception.

With over 100 people attending the General Assembly in Budapest, this was a time:

- ◆ To review the last four years and to accept the reports of Officers, Task Forces, Working Groups, Committees and Commissions;
- ◆ To ballot on the motion to amend the IBE Constitution to introduce Regional Membership;
- ◆ To honour those who had served on the International Executive Committee and who were retiring;
- ◆ To present their Membership Certificates to newly ratified Full and Associate Members;
- ◆ To recognise those Members who had donated to the Solidarity Fund in the last two years;
- ◆ To announce the recipient of the Volunteer Award 2009.

And all that was before the inaugural address of the new President, Mike Glynn. So five hours flew by and before we knew it we were applauding the members of the Incoming Executive Committee!

Thanks to the great work of John Schneider at Epilepsy Foundation, the assembly opened with an audio-visual look back on the trials and triumphs of IBE and its members in the previous two years.

Those Members who have attended a General Assembly in the past will be aware of how much time can be

taken up in verbal presentations of reports. To minimise this aspect of the meeting, all reports were circulated electronically in advance of the assembly so that all Members could have access to the documents. In Budapest delegates were invited to raise any queries they might have on any of the reports before their approval.

### Constitutional Amendment

Aware that in some countries it is difficult to sustain an epilepsy association, either because of low population numbers or limited development, it was proposed by the International Executive Committee to amend the Constitution to introduce a Regional Membership category. This would allow a group of countries to work collectively to create a regional epilepsy organisation and could facilitate people in regions such as the Caribbean islands.

Relevant papers were circulated to Full Members some months ago to allow for electronic balloting. The ballots of those not present, together with the ballots of Full Members present in Budapest, were sufficient to ratify the proposed changes. The amended Constitution has now been widely circulated and is also on the IBE website.

### Volunteer Award 2009

Sister Franca de Simone (pictured right in green blouse), a member of an

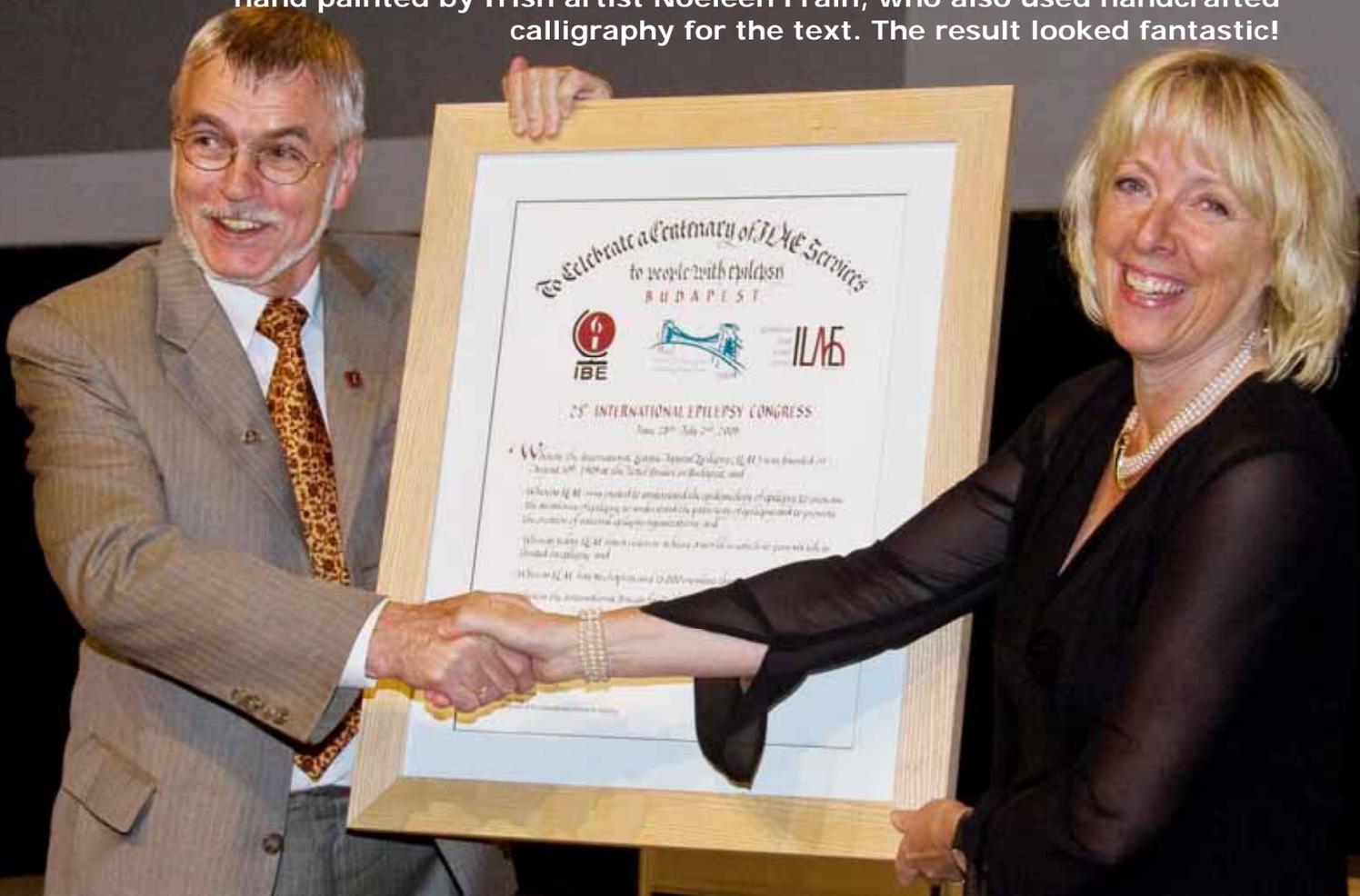
Italian order of religious nuns, was announced as the winner of the Volunteer Award 2009 for her work on behalf of people with epilepsy in the Cameroon, where she had been posted for the previous 35 years. Unfortunately, because of her work commitments, and an imminent move to a new posting in Paraguay, Sr Franca was not able to be with us in Budapest to personally accept her award.

Before the assembly closed, each Member of the International Executive Committee was introduced. A special presentation was made to Susanne Lund, the outgoing President, by Mike Glynn, the incoming President. Susanne was thanked for her great work over the previous four years and received a standing ovation from those present.

The next General Assembly will take place in Rome in 2011 when IBE celebrates its Golden Jubilee.



IBE presented a special proclamation to ILAE at the congress in Budapest to mark the occasion of the League's centenary celebrations. The document was created on high quality handmade vellum. The IBE and ILAE logos were hand painted by Irish artist Noeleen Frain, who also used handcrafted calligraphy for the text. The result looked fantastic!



## To Celebrate a Centenary of ILAE Services to People with Epilepsy

### 28th International Epilepsy Congress, Budapest

**W**hereas, the International League Against Epilepsy (ILAE) was founded on August 30th, 1909 at the Hotel Bristol in Budapest; and

Whereas ILAE was created to understand the epidemiology of epilepsy, to increase the awareness of epilepsy, to understand the pathology of epilepsy and to promote the creation of national epilepsy organizations; and

Whereas today ILAE has a vision to achieve a world in which no person's life is limited by epilepsy; and

Whereas ILAE has 96 chapters and 15,000 members throughout the world; and

Whereas the International Bureau for Epilepsy shares ILAE's vision and goals;

Now therefore be it resolved that the International Bureau for Epilepsy commends ILAE for a century of service to the global epilepsy community and congratulates ILAE on this the occasion of their centenary celebration.



1



2



3



4



5



6



7



8

# Budapest Photo Album

A picture paints a thousand words, as they say, and this small collection of images shows just how busy we were in Budapest. IE News would like to thank all those who sent us their photos of the congress. Unfortunately we do not have space to publish each one, but all of them have been uploaded to the IBE website gallery for you to enjoy.

1. The IBE Members Poster Display ran the length of busy walkways at the congress centre and was made possible through the support of Eisai Europe Limited
2. The IBE Information Stand in the Exhibition Hall was busy with visitors
3. Grace Tan, IBE Treasurer pictured with Robert Cole, Chair Regional Committee Western Pacific
4. A portion of the attendance at the General Assembly
5. The Gala Dinner pre-dinner drinks reception in the grounds of the National Art Gallery
6. Some of those who attended the Editors Network meeting gathered for a group photo
7. Hungarian dancers entertained during the Opening Ceremony
8. Australian delegates enjoying the Gala Dinner
9. Delegates from the Czech Republic at the EpiStop Association Members Poster
10. Some of the artwork of Budapest schoolchildren at the Children's Art Exhibition
11. A special meeting took place between IBE and the Japan Epilepsy Association
12. A corner of the Exhibition Hall
13. Delegates from Thailand pose at the poster of the Epilepsy Association of Thailand.



9



10



11



12



13

# New EU Directive on Driving and Epilepsy

Mike Glynn, Chair of the IBE Driving and Epilepsy Task Force, reports on the recently adopted European Directive 209/112 EC

The IBE Driving and Epilepsy Task Force has received confirmation from Brussels that European Directive 209/112 EC came into law on the 29th August 2009. This Directive puts into force the recommendations on Epilepsy and Driving of the expert working force led by Dr Eric Schmedding, which reported to the European Commission in 2005. The Directive also addresses amendments to legislation for driving and diabetes and driving and eyesight problems.

European Union member states have a time period of up to one year to introduce new legislation or to amend existing legislation in line with the Directive. For many of the member states that gained access to full membership of the EU in the recent past, this may represent a huge change since some of these countries

as yet have no legislation and operate total bans on driving for people with epilepsy. In general, these sorts of bans lead to many more people with epilepsy driving who should not, because of the unfairness of the total prohibition, than in other countries.

The regulations provide for a one year seizure-free period for Group 1 vehicles (cars, vans, motorcycles). For some member states, such as France and the Netherlands, these new regulations may mean that people with epilepsy will be worse off than before because the seizure-free period can be shorter at present in these countries. For people with epilepsy who wish to drive Group 2 heavy goods vehicles (buses, lorries etc.) the new Directive may offer some hope. In many countries there is a total ban on anyone who has had a

seizure driving these types of vehicles but, under the new regulations, someone with epilepsy who has been seizure-free and off all anti-epileptic drugs for 10 years or more, may apply for a licence. Most EU countries will have to amend their existing legislation to reflect these changes.

It is very important that IBE member associations in EU countries now bring this Directive to the attention of their legislators and ensure that the regulations are implemented. The Driving and Epilepsy Task Force will be examining ways that it can assist IBE member associations and ILAE chapters to ensure that these regulations are brought into being and applied fairly in their countries. The full text of the Directive, and further information, can be found on the IBE website [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org).

## Excerpt from the Directive

### *Group 1 (cars, vans, motorcycles):*

**12.1.** Drivers assessed under group 1 with epilepsy should be under licence review until they have been seizure-free for at least five years.

If the person has epilepsy, the criteria for an unconditional licence are not met. Notification should be given to the licensing authority.

**12.2.** Provoked epileptic seizure: the applicant who has had a provoked epileptic seizure because of a recognisable provoking factor that is unlikely to recur at the wheel can be declared able to drive on an individual basis, subject to neurological opinion (the assessment should be, if appropriate, in accordance with other relevant sections of Annex III (e.g. in the case of alcohol or other co-morbidity).

**12.3.** First or single unprovoked seizure: the applicant who has had a first unprovoked epileptic seizure can be declared able to drive after a period of six months without seizures, if there has been an appropriate medical assessment. National authorities may

allow drivers with recognised good prognostic indicators to drive sooner.

**12.4.** Other loss of consciousness: the loss of consciousness should be assessed according to the risk of recurrence while driving.

**12.5.** Epilepsy: drivers or applicants can be declared fit to drive after a one-year period free of further seizures.

**12.6.** Seizures exclusively in sleep: the applicant or driver who has never had any seizures other than seizures during sleep can be declared fit to drive so long as this pattern has been established for a period which must not be less than the seizure-free period required for epilepsy. If there is an occurrence of attacks/seizure arising while awake, a one-year period free of further event before licensing is required.

**12.7.** Seizures without influence on consciousness or the ability to act: the applicant or driver who has never had any seizures other than seizures which have been demonstrated exclusively to affect neither consciousness

nor cause any functional impairment can be declared fit to drive so long as this pattern has been established for a period which must not be less than the seizure-free period required for epilepsy. If there is an occurrence of any other kind of attacks/seizures a one-year period free of further event before licensing is required.

**12.8.** Seizures because of a physician-directed change or reduction of anti-epileptic therapy: the patient may be advised not to drive from the commencement of the period of withdrawal and thereafter for a period of six months after cessation of treatment. Seizures occurring during physician-advised change or withdrawal of medication require three months off driving if the previously effective treatment is reinstated.

**12.9.** After curative epilepsy surgery: see "Epilepsy".

### *Group 2 (buses, lorries, etc.):*

**12.10.** The applicant should be without anti-epileptic medication for the required period of seizure freedom.

An appropriate medical follow-up has been done. On extensive neurological investigation, no relevant cerebral pathology was established and there is no epileptiform activity on the electroencephalogram (EEG). An EEG and an appropriate neurological assessment should be performed after the acute episode. EN L 223/34 Official Journal of the European Union 26.8.2009

**12.11.** Provoked epileptic seizure: the applicant who has had a provoked epileptic seizure because of a recognisable provoking factor that is unlikely to recur at the wheel can be declared able to drive on an individual basis, subject to neurological opinion. An EEG and an appropriate neurological assessment should be performed after the acute episode.

A person with a structural intracerebral lesion who has increased risk of seizures should not be able to drive vehicles of group 2 until the epilepsy risk has fallen to at least 2 % per annum. The assessment should be, if appropriate, in accordance with other relevant sections of Annex III (e.g. in the case of alcohol).

**12.12.** First or single unprovoked seizure: the applicant who has had a first unprovoked epileptic seizure can be declared able to drive once five years' freedom from further seizures has been achieved without the aid of anti-epileptic drugs, if there has been an appropriate neurological assessment. National authorities may allow drivers with recognised good prognostic indicators to drive sooner.

**12.13.** Other loss of consciousness: the loss of consciousness should be assessed according to the risk of recurrence while driving. The risk of recurrence should be 2 % per annum or less.

**12.14.** Epilepsy: 10 years freedom from further seizures shall have been achieved without the aid of anti-epileptic drugs. National authorities may allow drivers with recognised good prognostic indicators to drive sooner. This also applies in case of "juvenile epilepsy".





# LESIA completes stigma initiative

third of pupils do not know what epilepsy is. Moreover, they are not interested in learning about this condition. Half of children who responded do not realise that they could help a child with epilepsy through offering friendship.

Therefore, to spread this information in the society, all available mass media was used: radio, TV, the press. There were radio reports, which explained LESIA activities, highlighted problems of people with epilepsy and showed that the integration of people with epilepsy is not possible without the support of society.

Two leaflets were published with a total edition of 14,000. One was designed to provide brief information about epilepsy, the other one contained instructions on providing

first aid to a person having a seizure. These leaflets were distributed countrywide, mostly to young people.

For the first time in Lithuania, there was a film created (10 minutes duration). Those taking part in the film included not only doctors and specialists but also people with epilepsy. They disclosed major problems and sadnesses in their lives. The film was shown during the popular TV show "ABC of Health". At the end of the initiative, LESIA arranged a press-conference, which was attended by reporters from various newspapers, health magazines, and by radio reporters. It was the perfect opportunity to explain about epilepsy, its peculiarities, problems of integration and to invite media representatives to cooperate further.

LESIA hopes that "I am the Same as You" has reached its goals: to decrease stigma and to bring society closer to people with epilepsy.  
*Dr Danute Murauskaitė, CEO LESIA*

The Lithuanian Association for the Integration of People with Epilepsy (LESIA) has completed an initiative "I am the Same as You", aimed at decreasing stigma in society. The impetus for this initiative came from a public opinion poll (1,000 adult respondents), which proved that there is still lack of information about epilepsy in society. The poll was also conducted in Lithuanian schools, with 990 pupils of various ages involved. The results showed that one



*Teachers test their knowledge with 'Action Zone!'*

Caritas Malta Epilepsy Association recently held its fifth in-service course for teachers in collaboration with the Education Department. Twenty-two participants attended both from both private and government schools ranging from primary to secondary classes.

During the three-day course, general information about epilepsy, the different types of seizures and how

## Teaching the Teachers in Malta

*Victoria Dimech reports*

to manage the condition were given. Very interactive discussions took place during which participants were invited to ask questions or to express their views about the different aspects of the condition. There was also time to play 'Action Zone!' which was found to be simple but informative.

What was considered very interesting and effective were the different life experiences which were shared with those taking part by people who have epilepsy. This made the course more tangible and realistic. Through this type of activity our association makes more contact with all schools and as a result we are contacted by more people to share our expertise and experience. Our sixth course is already in the pipeline.

# Promising Strategies 2010

Members have been invited to apply for funding under the 4th Round of the Promising Strategies Program, with the closing date for the first element, the submission of Letters of Intent, being 31st October. So far, this very successful initiative has provided funds to 29 projects in developing regions. Now IBE is looking to support even more

people with epilepsy by introducing mechanisms to ensure funding is spread as globally as possible. A shortlist of projects will be made in November by the International Executive Committee and these will be invited to submit full proposals. Successful projects will be announced in March 2010, after a review of the submitted proposals is completed.



## Come to Porto!

**25th—27th August 2010**

The charming Portuguese city of Porto has been chosen to host the 12th European Conference on Epilepsy & Society in August 2010. So be sure to mark these important dates in your diary.

The European Regional Committee is now busy completing the conference programme and planning special social events for delegates.

More information will be available shortly!

Annual Report 2008



The latest annual report is now available. The report has been circulated to Members, is available to view on the IBE website and may also be requested in writing to the IBE office at [ibedublin@eircom.net](mailto:ibedublin@eircom.net).



The term 'Disability' is used to describe people with physical or intellectual impairment of heterogeneous brain etiology, which limits their independence and functioning. In Chile Law No 19.284 defines disability as any person that, as a consequence of one or more physical, psychic, sensory deficiency, congenital or acquired, predictably as permanent and, no matter what caused it, limits by at least a third educational capacity and employment or social placement. According to WHO/PAHO estimates suggest that, of the general population, between 7.5 and 10% could be considered to be disabled.

On the other hand, in epilepsies, which international prevalence reaches 4 to 8 every 1,000 of the population, most have a normal life, without intellectual impairment and just a minority, less than the 10%, have or develop a mental sub-normality, which is considered as an intellectual disability.

Mental disability is defined as an intellectual capacity less than 2 DS of the average or an intelligence quotient of less than 70. It is specifically defined as a deficit or concurrent disturbance, starting prior to 18 years of age, of the current adjusted activity, at least in two of the following areas: communication, personal care, daily living skills, social skills, and personal abilities, use of community resources, self-control, education, employment, health,

leisure time and safety.

In people with epilepsy and a disability, different issues may negatively influence them, making the disability worse. Some of the issues are the side-effects of antiepileptic drugs, especially those that cause sleepiness or memory and concentration alterations. Other issues are, the quantity and seriousness of central nervous system injuries, especially if located in brain zones related to cognitive functioning, mainly temporal and frontal lobe. We need to consider the negative psychosocial environment too—for example, the stigma of having epilepsy.

In order to give good care and treatment to these people, we have to improve not only their quality of life due to their epilepsy, which generally is more complex in its treatment and crisis control, but also we have to consider the problems caused by their disability. On one hand there are the educational aspects, for their families and their environment—such as friends, teachers, employers, health professionals, and authorities; they have to be educated about epilepsy and disability in every aspect that relates to each group. Nowadays, these patients are not institutionalized as before, but are part of the community; therefore, if possible, we have to incorporate them completely. One of the most important international activities has been the ILAE/IBE/WHO Global Campaign Against Epi-

lepsy. We also must take into account the best educational options and pedagogical aspects for them to have the chance to aspire for a job or career, in order to reach a good social standing. The health aspect is very important, because it is needed to attain the best drug management, with the lowest side-effects, that gives the best crisis control and has the cheapest price. Then, a basic issue is to achieve the best employment placement. A good example of this is ADA (Americans with Disabilities Act), public law of the United States of America (Public Law 101-336, 1990), which aims to integrate people with disabilities in each segment of society and to assist in their finding, and keeping, employment. Finally, the psycho-social aspects must also be considered, which means their duties, rights, leisure time, safety, living skills, family, etc., in order to give them a better quality of life.

One of the challenges of the IBE is to reevaluate the current status in different regions of the world, to see how issues such as education, school, and pedagogy, legal and work placements for people with disability and epilepsy are being addressed. Even though they are a minority group, people with epilepsy and a disability deserve comprehensive support to improve their quality of life. Everything above mentioned is required to identify the best options and to help them to full social inclusion.

# EPILEPSY AND DISABILITY

# EPILEPSIA Y DISCAPACIDAD

**Report by Dr Tomás Mesa**

**Director – Chilean League  
against Epilepsy and  
Secretary of the IBE Latin  
American Committee**

**Director Liga Chilena  
Contra la Epilepsia y  
Secretario Comité Latino  
Americano del IBE**

Se habla de 'Discapacidad' al referirse a un grupo de individuos con impedimentos físicos o intelectuales de etiología cerebral heterogénea, que limita su independencia o funcionamiento. En Chile, la ley 19.284, considera discapacitada, a toda aquella persona, que como consecuencia de una o más deficiencias físicas, psíquicas o sensoriales, congénitas o adquiridas, previsiblemente de carácter permanente y con independencia de la causa que la hubiera originado, sea obstaculizada, en a lo menos un tercio, su capacidad educativa, laboral o de integración social. Según estimaciones de OPS/OMS, en la población general habría entre un 7.5 a 10% de personas discapacitadas.

Por otra parte, en las epilepsias, cuyo prevalencia global alcanza 4 a 8 por 1,000 habitantes, la mayor parte de los individuos que la presentan, tienen una vida normal, sin impedimentos intelectuales y solo una minoría, menor al 10%, presentan o desarrollan un retraso mental, siendo este considerado como una discapacidad de tipo intelectual.

La Discapacidad Intelectual, se define como una capacidad intelectual menor a 2 DS del promedio o un coeficiente intelectual menor a 70. Se precisa como un déficit o alteraciones concurrentes, de inicio previo a los 18 años, de la actividad adaptativa actual, en al menos dos de las siguientes áreas: comunicación, cuidado personal, vida doméstica, habilidades sociales o

interpersonales, utilización de recursos comunitarios, autocontrol, académicas, trabajo, ocio, salud y seguridad.

En las personas con epilepsia y discapacidad, una serie de factores pueden influir negativamente, agravando la discapacidad. Entre estos, están los efectos colaterales al utilizar medicamentos antiepilépticos, especialmente aquellos que producen sedación, sueño o alteraciones de la memoria y concentración. Además, la cuantía y gravedad de las lesiones en el sistema nervioso central, especialmente si están ubicadas en zonas cerebrales que tienen relación al rendimiento cognitivo, especialmente lóbulo temporal y frontal. Por otro lado, hay que considerar el ambiente psicosocial negativo, como por ejemplo el estigma de tener epilepsia.

Para el buen manejo y tratamiento de estas personas, no solo hay que considerar mejorar la calidad de vida por su epilepsia, que en general son de mayor complejidad en su tratamiento y control de crisis, sino que tener en cuenta los problemas que acarrea su discapacidad. Por un lado están los aspectos educativos a sus familiares y entorno. Entre estos, están los amigos, maestros, empleadores, profesionales de salud y autoridades, a quienes se debe educar sobre epilepsia y discapacidad en todos los puntos que les atañe a cada estamento. Hoy en día, estos pacientes no son institucionalizados como antiguamente, sino que son parte de la comunidad, por lo que debemos incorporarlos en lo posible plenamente. En este sentido, unas de las actividades internacionales más importantes, ha sido la Campaña Global de Sacar a la Epilepsia de las Sombras. Por otro lado considerar todos y los mejores aspectos escolares o pedagógicos: para que tengan la posibilidad de aspirar a un oficio o profesión para lograr una buena inserción social. El aspecto de salud es sumamente importante, ya que se debe lograr el mejor manejo de sus medicamentos, los con menos efectos colaterales, que controlen de mejor

manera sus crisis y al menor costo posible. Posteriormente un ítem fundamental es aspirar a su mejor inserción laboral. Un ejemplo de buen manejo de estos, es ADA (Americans with Disabilities Act), ley pública de Estados Unidos de Norteamérica (Public Law 101-336, 1990), cuyo objetivo es integrar a los individuos con discapacidad en cada segmento de la sociedad y otras nuevas iniciativas para lograr puestos de trabajo. Por último considerar los aspectos psico-sociales, es decir sus deberes, derechos, ocio, seguridad, vida doméstica, familia...etc, para poder darles la mejor calidad de vida.

Unos de los desafíos para el IBE, es re-evaluar el estado actual en las diferentes regiones del mundo, como están entre otros, los aspectos educativos, escolares o pedagógicos, legales y de inserción laboral de estas personas con discapacidad y epilepsia, que a pesar de ser una minoría entre la gente con epilepsia, se merecen todo el apoyo para su mejor calidad de vida. Todo esto para poder configurar las mejores opciones y ayudarlos a la más plena inserción social.

## **Bibliografía**

1. Epilepsy and Employment: is there a problem?. Edited by John E. Chaplin PhD. Prague 1999.
2. European White Paper on Epilepsy. EUCARE. 2001.
3. Taller: Inserción Laboral en Personas con Discapacidad y Epilepsia: Liga Chilena contra la Epilepsia. (LICHE). Santiago de Chile. 20 de Agosto 2004.
4. Seminario en Guatemala: Discapacidad y Epilepsia. IV Congreso Latinoamericano de Epilepsia. Ciudad de Guatemala. Guatemala. 8 de Septiembre 2006.
5. Discapacidad Mental. Atrévete 2004;57:17-20. (Revista del Fondo Nacional de la Discapacidad. Chile).
6. II Seminario Internacional de Discapacidad Mental de base orgánica. América Trabaja para Cambiarle la Cara a la Discapacidad Mental (19 al 20 de Agosto 2009. Santiago de Chile).



Katja's crown is clearly visible  
Photo: Flemming Platz

# OUCH!

## Danes fight for dental cover

"It is not exactly fun to have multiple dental crowns, a golden tooth, a bridge with three artificial teeth and chronic inflammation of the jaw because of epilepsy"

*Katja Lundh*

*Text by: Helle Juhl*

*Translated by: Kitt Kolster*

### **Epilepsy can be a heavy economic burden**

Having epilepsy is not good for your teeth. Many dental injuries are caused by seizures and falls: still epilepsy patients are not reimbursed for their extra dental costs by the public system. The consequences are poorer dental health and quality of life. This is one of the results of a report on epilepsy and dental health produced on behalf of the Danish Epilepsy Association.

The report also points to the fact that Danish epilepsy patients are worse off economically than the rest of the Scandinavian countries. In Norway, Sweden and the Faroe Islands patients are automatically granted reimbursement of dental treatment caused by epilepsy.

### **A psychological load**

Some of the predominant dental injuries caused by epilepsy are:

- Broken teeth and dental crowns due to clenching hard of teeth hard during a seizure
- Teeth that are knocked out or break from a fall in connection to a seizure
- Enamel cracks or injuries of the dental roots following hard blows
- Injuries to the enamel due to side-effects of medicine (mouth dryness, vomiting and acid reflux)
- Injuries impairing the development of teeth as a consequence of epilepsy in early childhood years.

Poor teeth are a burden, not just economically but also psychologically and socially. Many people with epilepsy describe how they try to hide their teeth while speaking to others and how they feel inferior because of their teeth. They are also constantly scared that a new injury might necessitate dental treatment that they simply cannot afford.

### **Inexpensive though not economical**

If a person is granted reimbursement of his medical costs, the reimbursement usually covers the least expensive treatment - which is not always the most economical in the long run. An inexpensive set of dentures breaks more easily during seizures.

Poor dental health for a person with epilepsy can become a heavy burden economically, as well as socially and psychologically.

### **Dental records of Katja Lundh**

50 year old Katja Lundh does not really have much to laugh about because epilepsy has taken a heavy toll on her dental health. Her teeth are permanently damaged from epileptic seizures, and getting by on a mere early retirement pension, Katja Lundh cannot afford to have her teeth fixed in the best possible way.

“The local authority has, on occasion, granted me reimbursement of dental costs covering the least expensive solution, which is not always the best; and you cannot apply for reimbursement in connection with injuries following a non acute disease,” Katja explains.

### A heavy economic burden

Ever since she was a child, Katja Lundh has suffered from multiple types of epilepsy; she has seizures that cause loss of consciousness and also other very severe seizures. Seven years ago she tumbled off her bicycle during a seizure and hit her head so violently that her brain was injured. As a result, she had to give up her job as a psychologist. Since then she has been on early retirement and she is also a single mother. Therefore the vast dental costs are a heavy burden on her, in addition to the physical and psychological inconveniences.

“It is not exactly fun to have multiple dental crowns, a golden tooth, a bridge with three artificial teeth and chronic inflammation of the jaw because of epilepsy. Even though I am no longer as young as I used to be, I have always been careful about my teeth, which should be in a better condition. According to my dentist the state of my teeth is undoubtedly linked to epilepsy,” Katja explains.

### Old injury re-surfaced

Some injuries like, for instance, the two dental crowns, are directly caused by epileptic seizures. Katja Lundh also has injuries to teeth that have cracked when seizures make her clench her teeth hard. And then there are injuries following on a non acute disease as a consequence of medical side effects or old seizures.

Once she had an inflammatory blister just above her front teeth which was caused by an encapsulated inflamma-

tion from a severe epileptic seizure which happened twenty years earlier. During a new seizure the encapsulated inflammation burst open and the infected matter spread out through the mouth. On that occasion she had to have a drain hole drilled in her jaw, and was prescribed penicillin before the inflammation was fully treated.

Yet, it is one of her crowned teeth that bothers her the most because the crown itself is visible.

“On average, I have about two major and life threatening seizures a year. The recovery time is six to eight weeks. What a relief it would be if I could just go to my dentist without having to worry about the cost or how this is going to be covered” Katja comments sadly.



John Bowis, recently retired Member of the European Parliament (MEP) for London, was conferred with an honorary Fellowship of the Royal College of Physicians by President, Sir Ian Gilmore, in London on the 1st July.

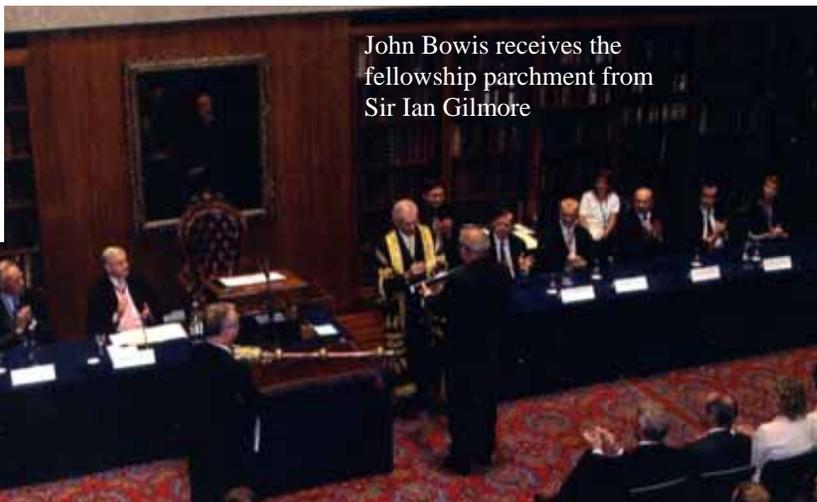
John has been a terrific supporter of people with epilepsy, and of IBE, for many years. He has spoken at European and International congresses and also played an active role in the joint IBE/ILAE EUCARE initiative. He assisted at the launch of the EUCARE White Paper on Epilepsy at the European Parliament in 2001.

A strong believer in the need to bring epilepsy out of the shadows, in his speech at the launch of the White Paper on Epilepsy he stated:

“If Julius Caesar, Peter the Great, Dostoevsky and Byron all achieved so much in their chosen careers while coping with epilepsy, why are people so reluctant to be open about it today?”.

More recently he headed up the EU Advocates Group of the EUCARE Political Action Group and orchestrated a meeting of the Political Action Group with other MEPs with an interest in epilepsy.

## Stalwart Supporter is Honoured



John Bowis receives the fellowship parchment from Sir Ian Gilmore

John was presented with an IBE/ILAE Ambassador for Epilepsy Award in 2005. Although now officially retired, John has said that he will continue to support IBE and its work.

He was previously awarded the Order of the British Empire (OBE) by Queen Elizabeth to recognise his untiring charitable work.



Xiaolan with her Fuwa bead dolls

In the “Seahorse Club” of Shanghai, a self-help group for people with epilepsy, there is an art gallery that features the paintings, calligraphy, photography and handicrafts, which were created by members of the club. Among these artistic works, the handcraft flowers, dolls, fans, cross-stitching and small animals are the most attractive. The materials for creating these pieces are very cheap and readily available in our daily surroundings and are then transformed into elegant works of art through the unique design and skilful work of the members. In June 2009, these handcrafts were brought to the 28th International Epilepsy Congress in Budapest, Hungary, and were exhibited on IBE’s Information Stand in the Exhibition Hall.

Ye Zhuang is a 26-year-old woman who has been suffering epilepsy for almost 10 years. Her hobby is making stocking fabric handcraft, such as flowers and butterflies. Through her creative and talented hands, nylon stocking fabric in a rainbow of colours and patterns magically are

changed into a range of different flowers, including roses, tulips, and cherry blossom. Twigs, bouquets and even potted landscapes are possible. She can also produce several types of butterflies with different postures. Ye used to own a craft shop, but had to close it due to the severity of her seizures. However, she never stops making handcrafts, since she considers this hobby to be the most important part of her life. She enjoys it because she can forget her seizures when concentrating on her craft making. “I have a dream”, says Ye, “I hope that one day, when my seizures become well-controlled, that I will be able to open my own shop to sell these stocking fabric crafts, and be able to manage the shop on my own.”

Xiaolan Tao is a shy and reserved

girl. She cannot go to school because of her seizures. She has been learning handcraft making at the “sunny school” (a special school for people with a disability) where she spends most of each day.

She is good at making fans decorated with Chinese painting. She sent one of her handmade Chinese fans to the President of the 12<sup>th</sup> Summer Special Olympics. Another fan was sent to IBE at the end of 2007 as a Chinese entry in the Freedom in Mind Experience exhibition. In 2008, she made a set of bead dolls called Fuwa, the official mascots of the Beijing Olympic Games. She has just finished some papier maché mascots—Haibao—to welcome the 2010 Shanghai World Expo. These handcrafts are not only good souvenirs of

## Seahorse Club shows its craftwork talents

Dr Ding Ding of the China Association Against Epilepsy, tells us about the talented members of the Seahorse Club, a self-help group of persons with epilepsy in Shanghai, China



Ye and Li are interviewed by the media



**Origami Animals**  
Li Tang



**Chinese Painted Fans**  
Xiaolan Tao



**Stocking Fabric Cherry Blossom**  
Ye Zhuang

important events in China, but also a reflection of her passion for life.

Li Tang has been fighting seizures for almost 20 years, and even now the seizures haven't stopped despite undergoing epilepsy surgery. She used to make fabric flowers as a temporary job, which proved to be useful training for her hands. Most of her handcrafts are origami animals made from poster paper. She can make miniature pieces of furniture using poster paper. In addition to these crafts, she likes to do cross-stitching which requires more patience and concentration.

Like other young woman, Li loves to work; even if it is a very simple job without any salary. She is so smart that she is able to learn new skills

within a very short time. Several months ago, she became an electronic data entry person in a company, after being trained to use a personal computer. She sees this as a new start in her life. She says, "I can handle my work and rest time very well. I want to maintain a good standard everyday in order to ensure that I am adequate for this job; I don't want to lose this position."

On the International Epilepsy Caring Day, June 28, 2009 in Shanghai, Ye, Xiaolan and Li were interviewed by the media about their handcrafts and about living with epilepsy.

In order to help more people with epilepsy, the Seahorse Club plans to organize a handcraft course that will be taught by these three young

woman. The 2-week course will give people with epilepsy, especially adolescents, a good opportunity to learn a craft making skill, beginning with simple hand skill training. Three women will teach how to make stocking fabric butterflies, bean dolls, and paper animal models. Analysis of the effectiveness of the program will be carried out to provide preliminary evidence of the behaviour intervention approach, other than anti-epileptic drugs, not only for the trainees with epilepsy, but also for the trainers who have epilepsy.

"Helping others makes me happy." Ye, Xiaolan and Li became busier, but happier.



## Action Zone! is still a Winner

Although almost three years have passed since Action Zone! was produced, this educational tool still remains a big hit with epilepsy associations, hospitals, care centres and families around the world. It is amazing how many of our Members send us photos where we can see the game in use.

This photo is from ECDYS in Mauritius shows participants at an Educational Workshop for NGO leaders with their copy of the game.

In the short report from Malta on page 12, you can see that our friends in Malta also use the board game to educate about epilepsy.

# Getting ready for 2010

IBE will be involved in the organisation of the following regional congress, which will take place in 2010.



## **2nd East Mediterranean Epilepsy Congress**

Dubai, UAE

3rd - 6th March 2010



## **12th European Conference on Epilepsy & Society**

Porto, Portugal

25th - 27th August 2010



## **6th Latin American Epilepsy Congress**

Cartagena, Colombia

Dates in August 2010



## **8th Asian & Oceanian Epilepsy Congress**

Melbourne, Australia

21st - 24th October 2010