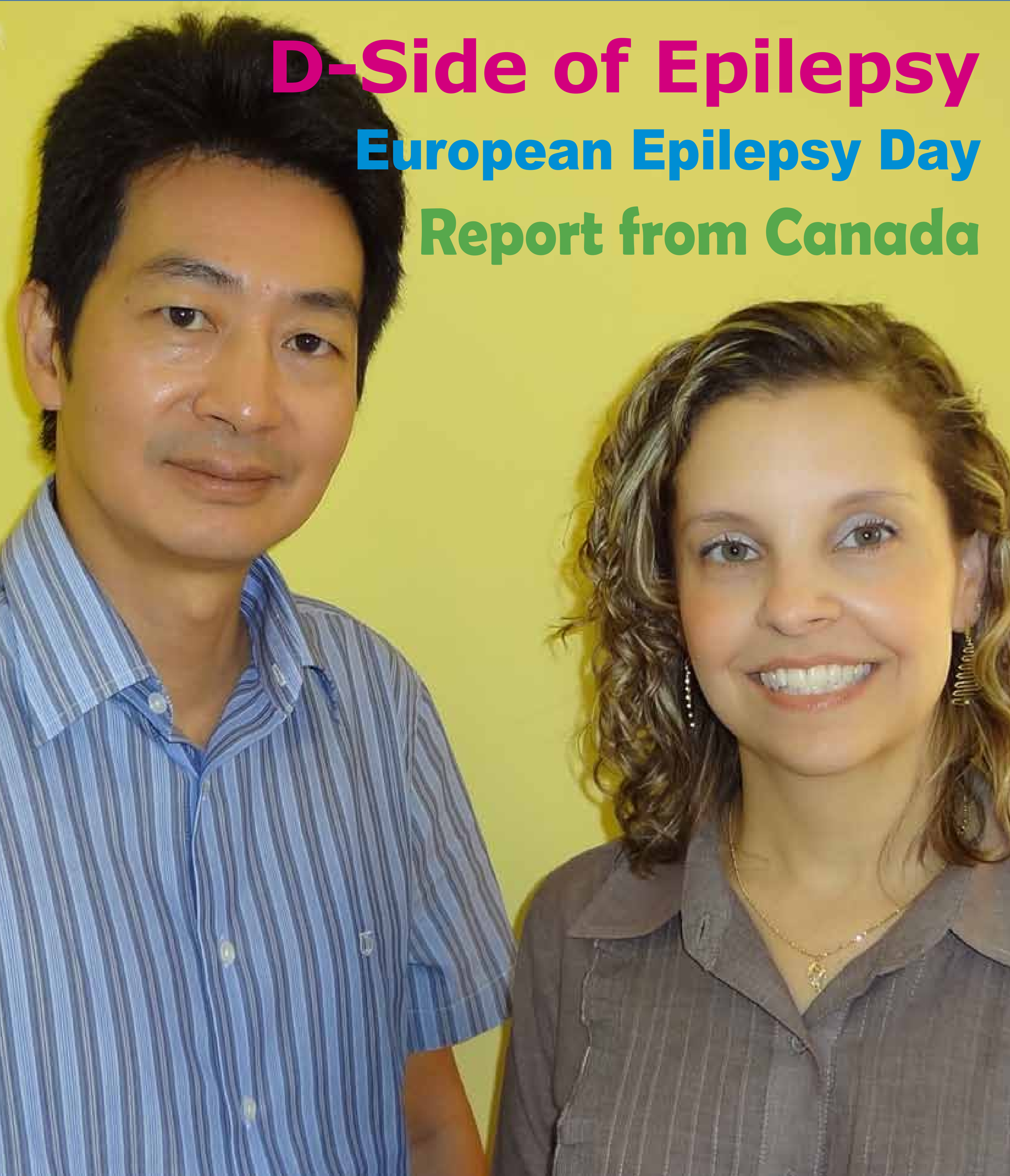
NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 4 2011

INTERNATIONAL
Epilepsy News



D-Side of Epilepsy

European Epilepsy Day

Report from Canada

Looking back on a successful year!

IBE's Golden Jubilee year is now coming to a close and we can look back at a year of many great achievements. In Europe we celebrated the launch of the 1st European Epilepsy Day in the European Parliament in February; creation of the European Advocates for Epilepsy of MEPs in April; and approval of the European Written Declaration on Epilepsy in September.

In Latin America and the Caribbean, also in September, to our delight, the Latin American Strategic Plan of Action on Epilepsy: PAHO/ILAE/IBE Project for the Americas was approved. This tremendous achievement will see epilepsy as a priority in the national health plans of each country in the Americas for the next 10 years – for the first time in PAHO's 100 years history.

In Asia, many IBE member associations have been successful in changing the negative symbols for epilepsy, which had been used for hundreds of years, to more positive language symbols. This will be very important in reducing stigma.

Among IBE's Jubilee projects were the very popular Epilepsy Without Words photography competition; publication of a concise history of IBE; as well as other activities during the congress in Rome.

Further funding was provided to members in less well-off countries for initiatives to increase the quality of life of people with epilepsy, bringing to 50 the number of projects now funded and with more than US$250,000 funds invested by IBE.

This year, IBE and ILAE took the historic decision to hold the first ever African Regional Epilepsy Congress (AREC) in Nairobi in 2012 to which IBE is providing bursary funding of US$20,000. In all, IBE has committed up to $50,000 for the 1st AREC. Plans for the congress are already well underway and information on the scientific program and bursaries can be found on the congress website. Likewise, next year will see the Asian Oceanian Epilepsy Congress held in Manila, the Philippines, one of the poorest countries in Asia.

Other initiatives for 2012 include the 2nd European Epilepsy Day on 13th February and Latin America Epilepsy Day on 9th September. China and other Asian countries will celebrate their International Epilepsy Day on the 28th June. There will be a further round of Promising Strategies and many other events are in the early stages of preparation.

Wishing you best wishes for the New Year.

Mike Glynn
President

IBE

EDITORIAL TEAM

Editor: Carlos Acevedo
carlosedoacevedo@yahoo.com
Co-ordinator: Ann Little
ibedublin@eircom.net

Regional Sub Editors:
- Tomás Mesa (Latin America)
- Lisa Boylan (North America
- HV Srinivas (South East Asia)
- Robert Cole (Western Pacific)

Advisors:
- Mike Glynn
- Grace Tan
- Abdulaziz Al Semari
- Shunglon Lai
- Susanne Lund
- Janet Mifsud
- Lilia Núñez-Orozco
- Vinod Saxena
- Mary Secco
- Anthony Zimba
- Nico Moshé
- Emilio Perucca
- Sam Wiebe

ISSUE 4- 2011

International Epilepsy News is the quarterly newsletter of the International Bureau for Epilepsy (IBE) and is circulated to IBE members, supporters and other subscribers in more than 120 countries. All enquiries to:

**International Bureau for Epilepsy
11 Priory Hall, Blackrock,
Co Dublin, Ireland.
E: ibedublin@eircom.net
T: +353 1 210 8850**

www.ibe-epilepsy.org

All rights, including moral rights, reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, without the prior permission in writing from the publisher. The Editor reserves the right to edit content for reasons of space or clarity. The views expressed in this magazine are not those of the publisher. Articles covering medical aspects of epilepsy are not intended to be taken as advice; they are not intended to replace medical care.

INTERNATIONAL RELATIONS

ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

WHO

IBE is in official relations with the World Health Organisation (WHO).

SPONSORING PARTNERS

IBE acknowledges the support of its partnering sponsors listed below. Please contact us if you would like to learn about sponsoring opportunities with IBE.

Gold Partner

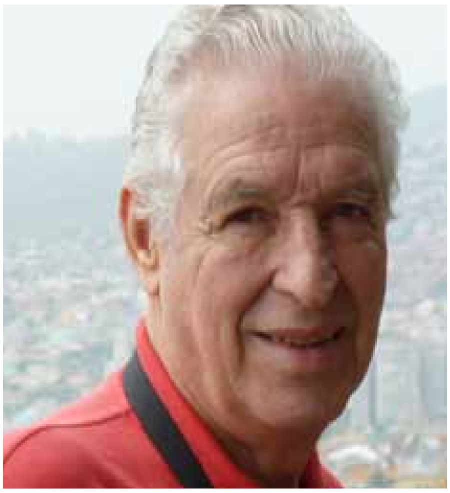
- Dainippon Sumitomo Pharma Co., Ltd

Silver Partners

- Eisai Europe Limited
- GlaxoSmithKline
- UCB Pharma

Other Partners

- Cyberonics



Another busy issue for you to enjoy!

This issue of IE News features an extensive report on the roundtable event held in Brussels in November at the European Parliament, with the participation of MEPs, the IBE/ILAE Epilepsy Advocacy Europe Joint Task Force and a large number of other participants. During this event sporting heroes with epilepsy gave personal testimonies of life and sporting successes.

In October in Tblisi in Georgia, an important demonstration project came to an end after four years of work, with two days of activities. Participants included the main authorities of IBE/ILAE, representatives of the WHO, members of local authorities as well as several politicians.

Meanwhile, Executive Director of IBE, Mrs Ann Little, travelled to Sofia in Bulgaria, at the invitation of the Bulgarian Full Member, to present in the Bulgarian Parliament, during a workshop meeting dedicated to promoting the European Written Declaration on Epilepsy.

We also have hints about initiatives in Indonesia, Mauritius and a special article from Nepal. As always a pearl is the story of IBE from 1993 to 1997 prepared for us by Harry Meinardi.

It is essential to mention the beautiful letter of Patsy McCall, IBE Executive Director from 1979 to 1985 sent to us at the time of the International Epilepsy Congress in Rome..

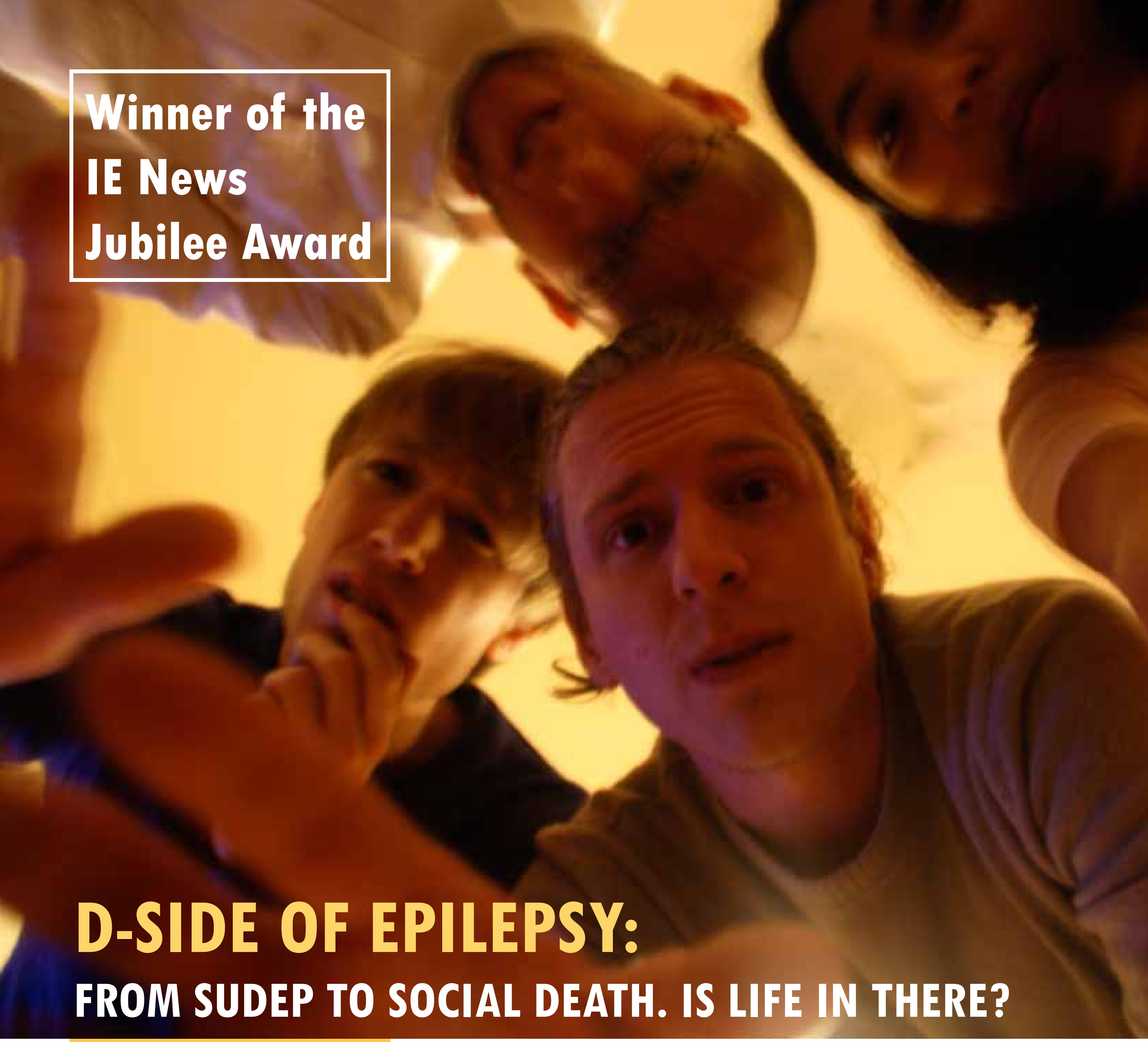
Finally, we include the departure of a good friend, John Gilbert Kirker a great man in the social field of epilepsy both in Ireland and at international level.

In closing, may I take the opportunity to wish you all a very Happy New Year.

Kind regards,

Dr Carlos Acevedo
Editor

Contents



Winner of the IE News Jubilee Award

D-SIDE OF EPILEPSY:

FROM SUDEP TO SOCIAL DEATH. IS LIFE IN THERE?

D-SIDE? - You Decide!

There are several views. This can be seen as a part of the story not told, as we used to have side A and B of vinyl records. The D- can also be interpreted as Dark-side, or as in the text, the Death-side. D- can be read as THE Side of epilepsy, the relevant part. Apart from the possible interpretations, we also meant to play with sounds; it is for you, reader, to take a stance on this issue, it is for you to decide what to do next.

Paula T. Fernandes & Li M. Li

Department of Neurology, Faculty of Medical Sciences, State University of Campinas (UNICAMP), Assistência à Saúde de Pacientes com Epilepsia (ASPE), Cooperação Interinstitucional de Apoio à Pesquisas sobre o Cérebro (CInAPCe). The authors, whose prize is support of up to US$2,000 to attend a future IBE/ILAE epilepsy congress, are pictured on the front cover.

Epilepsy is a common neurological condition. Most people with epilepsy can have their seizure controlled with relatively non-expensive antiepileptic drugs and, therefore, they can have a good quality of life.

Nevertheless, the ever happy-ending story today is not quite like this. As a matter of fact, evidence from the scientific community has brought forward and confirms what people with epilepsy and their families have been living with in silent, quiet desperation over the ages. The global burden of epilepsy is heavier than you can imagine: put in plain words, epilepsy destroys lives. At one end there is SUDEP (Sudden Unexpected Death in EPilepsy), a phenomenon that has been better recognized over the past 20 years, with a frequency of around 1% in those patients with uncontrolled seizures[1].

However, through the spectrum of epilepsy we observe another phenomenon of a psychosocial nature, here called SESODEP (Slow, Expected, Social Death in EPilepsy), that progressively and in a pervasive manner wipes your identity down to just

Who's more scared?
Photo by: Chyoug-Mei (FiFi) Chang,

a blur of a shadow. Can we terminate these two phenomena? Yes. The group of patients with un-controlled seizures has a higher risk factor for SUDEP than those with controlled seizures.

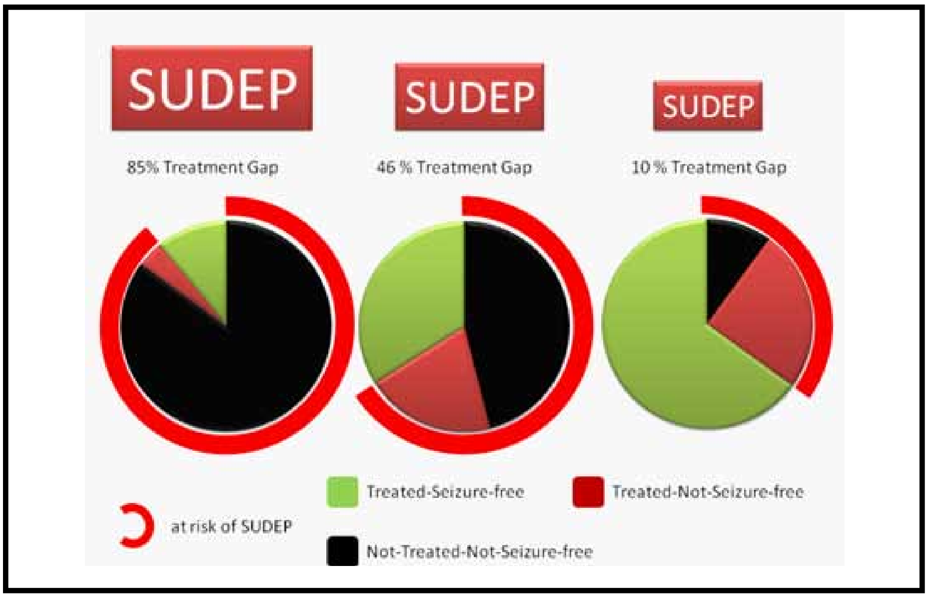


Figure 1. Treatment gap of epilepsy and relation to SUDEP

Legend Figure 1: *Three scenarios of epilepsy treatment gap (10%, 46% and 85%) are presented. It is assumed that antiepileptic drug treatment can lead to 70% seizure control. If we assume a world population of 7 billions, there would be 70 millions people with epilepsy, if treated adequately, 70% can be seizure-free. This leads to the following proportions in the three scenarios of treatment gap: 10% treatment gap (treated seizure-free=44,100,000, treated-not-seizure-free=18,900,000, not-treated-not-seizure-free=7,000); 46% treatment gap (treated seizure-free=26,460,000, treated-not-seizure-free=11,340,000, not-treated-not-seizure-free=32,200); 85% treatment gap (treated seizure-free=7,350,000, treated-not-seizure-free=3,150,000, not-treated-not-seizure-free=59,500,000). Assuming that 1% of not-treated plus 30% of treated-not-seizure-free are at risk for SUDEP, this leads to the following amounts of SUDEP: 10% treatment gap (SUDEP=259,000); 46% treatment gap (SUDEP=435,400); 85% treatment gap (SUDEP=626,500).*

This is particularly alarming in countries where the treatment gap (% of patients with active epilepsy that does not receive medication or appropriate AED treatment) is high (Figure 1).

On a global scale, it has been estimated that the treatment gap is somewhere around 85%! Solution? It requires a sustained healthcare system, centered on a primary healthcare setting, which can provide good resolution to most of these cases, referring the more complex cases to secondary or tertiary centers. In addition, more effective treatment is required; 70% seizure control is just not good enough. The numbers from Figure 1 show that 30% of treated-not-seizure-free patients contribute to 70% of 259,000 cases of SUDEP. As for SOSEDEP, this phenomenon is not closely coupled to seizure control or the state of the health care system, as we can see SOSEDEP worldwide in rich and poor countries somewhat evenly.

Unfortunately, we don't have psychosocial pills to control stigma. This is one of the areas in epilepsy in which research

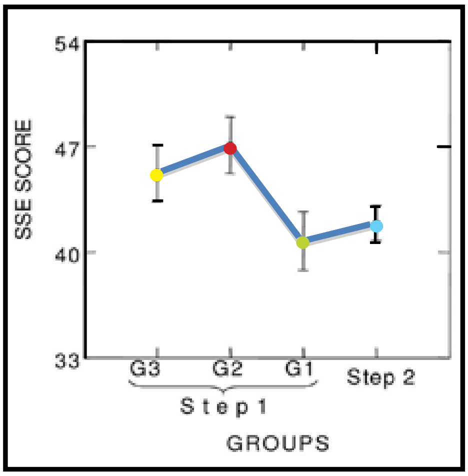


Figure 2. General score from the SSE from the schools in two steps

Legend Figure 2: *We performed this study in two steps. Step 1: evaluation of students from public and private schools in Campinas, which were divided in 3 groups: Group 1: students had seen an example of appropriate behaviors (keep calm, protect the head, educate people, and do not put anything in the patient's mouth) towards someone having a seizure. Group 2: students had seen an example of inadequate attitudes (act nervously, say "be careful, it is contagious", push the tongue, and put a pen in the patient's mouth) and Group 3: control group. After the intervention, the students answered a questionnaire - Stigma Scale of Epilepsy (SSE), which evaluates the perception of stigma in epilepsy (0 = no stigma; 100 = highest level of stigma). After this evaluation, an educational lecture about epilepsy was performed. In the step 2, the students answered the same evaluation (SSE) six months later. The results of this study are so interesting. In the step 1, we observed significant differences between the three groups: group 1 showed a lower score of SSE (SSE: 41.05); group 2 showed a higher level of stigma perception (SSE: 48.92) and group 3 was in the middle (SSE: 46.19) [(ANOVA (2,179) = 3.25; p=0.04); Tukey: group 1< group 3 < group 2]. In the step 2, the mean level of stigma perception was 44.5.*

on stigma intervention is badly needed. Our experience from the Demonstration Project in Brazil as part of the ILAE/IBE/WHO Global Campaign Against Epilepsy, which was executed by ASPE (Assistência à Saúde de Pacientes com Epilepsia), has demonstrated that it is possible to modify the stigma perception on epilepsy[2-6].

First is to how you behave in front of a person having a convulsion (Figure 2)[7]. If you have an appropriate attitude (keep calm, protect the head, educate people, and explain that you should not put anything in the patient's mouth) you will help lower epilepsy stigma perception in bystanders.

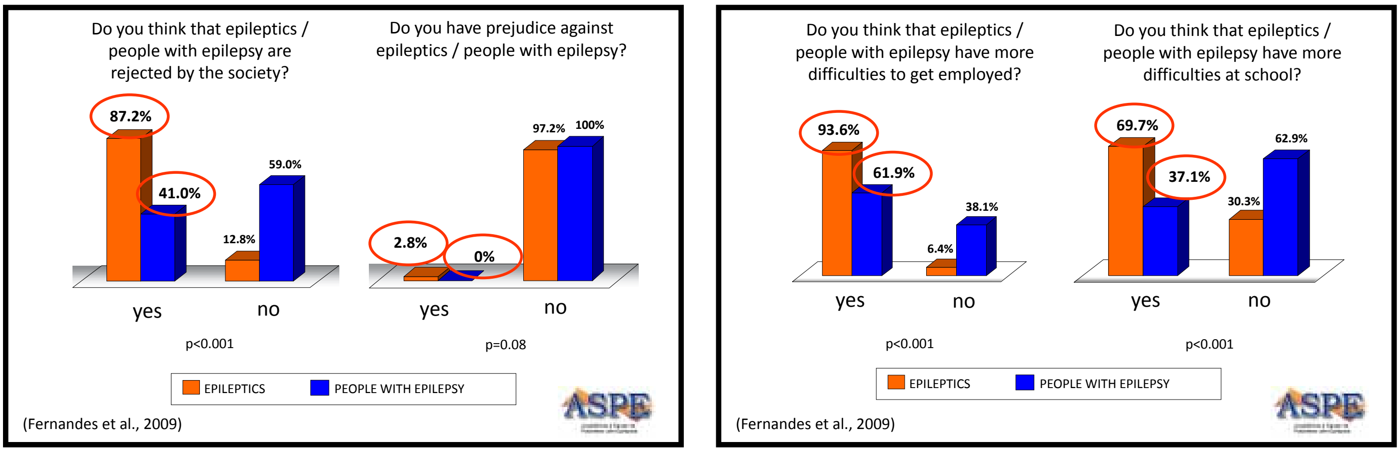
But, if you have an inappropriate attitude (act nervously, say "be careful, it is contagious", push the tongue, and put a pen in the patient's mouth) you will increase the epilepsy stigma perception. This conclusion derived from results of an intervention study, where a group of adolescent bystanders that witnessed an appropriate attitude had lower perception of stigma measured by Stigma Scale of Epilepsy (SSE)[8] than the group of bystanders that witnessed an inappropriate attitude towards a person having a convulsion. A third group of adolescents that was not exposed to either procedure scored SSE in between the two intervention groups. Moreover, in the same study, after the intervention we provided correct the information on epilepsy, and observed that this action helped decrease stigma perception, as observed in a re-assessment 6 months later.

Another aspect, in addition to attitude, is language usage. We often hear the terms "epileptic" and "people with epilepsy" (PWE) used interchangeably. Does it make a difference in the perception of stigma? Yes, it does (Figure 3); the term "epileptic" is associated with higher stigma perception than term "people with epilepsy"[9].

Inappropriate language hides the true identity of the PWE and increases the problems of dealing with epilepsy in our society. When you say "epileptic," you create a label, emphasizing the disease and its symptoms and not the person with the condition. And it is clear that a negative perception promotes negative behaviors. And, in epilepsy, it merely reinforces the stigma and contributes to putting the PWE on a second level behind epilepsy.

In general, epilepsy is not a benign condition. Epilepsy has complex biological-psycho-social built-up. It is time to increase interventions as well as to look for new innovative approaches to correct this situation. The joint effort of Global Campaign Against Epilepsy, under the auspices of ILAE, IBE and WHO, has developed over the years a set of procedures and has gathered multicultural experiences aimed at bringing people with epilepsy "Out of the Shadows."

As for now, put simply, all we ask of you is to stand by us so we can stand up for you.



(Fernandes et al., 2009)

(Fernandes et al., 2009)

Figure 3. Appropriate language - difference in the use of terms "epileptics" and "people with epilepsy"

Legend Figure 3: *in this study, we performed a survey with adolescents and applied two versions of SSE plus 4 questions about stigma perception, which the difference was only in relation to the terms: for one group (group 1), we used the term "epileptic" and for the other group (group 2), we used "person with epilepsy". The findings showed significative difference between the two groups in relation to SSE: the score was 45 (CI = 42.4-48.2, SD = 14.9) for Group-1 and 49 (CI = 46.9-52.0, SD = 13.4) for Group-2 (T-test [212] = 2.151; p=0.03). In relation to 4 questions (work, school and prejudice perception), the majority of subjects answered that "epileptic" had more difficult at school, to get employed and had more perception of prejudice.*

References

1. Hesdorffer DC, Tomson T, Benn E, Sander JW, Nilsson L, Langan Y, Walczak TS, Beghi E, Brodie MJ, Hauser A. Combined analysis of risk factors for SUDEP. Epilepsia, 2011; 52 (6): 1150-1159
2. Li LM, Sander JW. National demonstration project on epilepsy in Brazil. Arquivos de Neuropsiquiatria, 2003; 61(1): 153-6.
3. Fernandes PT, Salgado PC, Noronha ALA, de Boer HM, Prilipko L, Sander JW, Li LM. Epilepsy stigma perception in an urban area of a limited resource country. Epilepsy & Behavior 2007;11 (1): 25-32.
4. Li LM, Fernandes PT, Noronha ALA, Marques LH, Borges MA, Cendes F, Guerreiro CAM, Zanetta DMT, de Boer HM, Espindola J, Miranda C, Prilipko L, Sander JWAS. Demonstration Project on Epilepsy in Brazil: situation assessment. Arquivos de Neuropsiquiatria, 2007; 65: 5-13.
5. Fernandes PT, Noronha ALA, Sander JWAS, Li LM. Stigma scale of epilepsy: The perception of epilepsy stigma in different cities in Brazil. Arquivos de Neuropsiquiatria, 2008; 66: 471-476.
6. Fernandes PT, Salgado PCB, Noronha ALA, Barbosa F, Souza EAP, Li LM. Prejudice towards chronic diseases: comparison among AIDS, diabetes and epilepsy. Seizure, 2007; 16: 320-323.
7. Reno BA, Fernandes PT, Bell GS, Sander JW, Li LM. Stigma and attitudes on epilepsy: a study with secondary school students. Arquivos de Neuropsiquiatria, 2007; 65 (Supl 1): 49-54.
8. Fernandes PT, Salgado PCB, Noronha ALA, Sander JWAS, Li LM. Stigma Scale of Epilepsy: validation process. Arquivos de Neuropsiquiatria, 2007; v. 65, p. 35-42.
9. Fernandes PT, de Barros NF, Li LM. Stop saying epileptic. Epilepsia, 2009; 50(5): 1280-1283.

Congratulations!

ILAE supports expansion of Promising Strategies Program

To mark IBE's Golden Jubilee in 2011, the International League Against Epilepsy presented the Bureau with a 4-year bursary fund to support the further development of a successful Promising Strategies Program. The annual fund is US$5,000. After reviewing the 50 projects supported by the program since 2005, the International Executive Committee selected the Seahorse Club in Shanghai to receive this year's award. Dr Ding Ding, a driving force behind the group, will accept the award on their behalf during the 9th Asian & Oceanian Epilepsy Congress in Manila.

It all began in late 2007, when the Seahorse Club conducted an art and crafts competition in Shanghai for persons with epilepsy. The artworks created were elegant and valuable, representing a fighting spirit to overcome difficulties faced by those living with epilepsy. The artworks were showcased at the 28th International Epilepsy Congress, Budapest 2009 and the 8th Asian & Oceanian Epilepsy Congress, Melbourne 2010.

In follow up to the competition, a 4-week course in handcrafts also proved both popular and successful. Feedback from Seahorse Club members indicated that the activities were much appreciated and there was a request for a studio where they could relax and create artworks. The result was an Art Studio for people with epilepsy in Shanghai. Based on the train the trainers model, the studio, which received Promising Strategies funding in 2009 provides an artistic environment for people with epilepsy and their care-givers, where they can learn about and share art techniques, and can also exchange their experiences related to epilepsy.

From small beginnings, the Seahorse Club has grown from strength to strength with further successful exhibitions and increased standards in the wonderful artwork created by its members - as you can see from the photos above. Congratulations to all!

LITHUANIA 2011

Mrs Hanneke de Boer (left)
with Dr Danute Murauskaite
in Vilnius, Lithuania

LESIA President, Dr Danute Murauskaite reports on successful initiatives in 2011

The Lithuanian Association for the Integration of People with Epilepsy LESIA met with great success in its promotion of the first European Epilepsy Day in 2011, taking advantage of all mass media opportunities to highlight the event. In addition, conferences were arranged in all branches of LESIA, working together with local municipalities. It was also important that European Epilepsy Day was celebrated in the Lithuanian Republic Parliament. A member of Parliamentary Health Committee, Mrs Dangute Mikutiene, arranged a press conference together with LESIA, medical representatives and members of the press. At this conference Mrs Mikutiene, a member of the Lithuanian Republic Parliament, criticized officers who do not pay appropriate attention to a common effort and systematic approach to the problems of epilepsy.

A second very important initiative was the creation of an Advocacy Group for Epilepsy in the Lithuanian Parliament, also initiated by Mrs Dangute Mikutiene. We hope that this group will accelerate solutions to the problems related to epilepsy.

A very significant event happened during the summer of 2011. At the invitation of LESIA, Mrs Hanneke de Boer, coordinator of the ILAE/IBE/WHO Global Campaign against Epilepsy '*Out of the Shadows*', visited Vilnius. Our organization wanted to ensure that, in our work, we were moving in the same direction as the rest of Europe and the world. We were glad that our government was interested in this visit and the Advocacy Group for Epilepsy, led by Mrs Mikutiene, arranged a meeting in the parliament buildings.

Participants at this meeting included the Advisor of the Lithuanian Republic President, members of parliament, representatives from the Ministry of Health Security and the Ministry of Social Security and Labour, scientists and representatives of LESIA.

Mrs de Boer opened the meeting with a report on activities of the International League Against Epilepsy, the International Bureau for Epilepsy, and on the Global Campaign Against Epilepsy. She spoke about the efforts being made by IBE and ILAE, working together with the WHO, to increase attention paid to the problems caused by epilepsy and to introduce new directions in this work. LESIA President, Dr Danute Murauskaite, spoke about the difficulties encountered by the association and about the problems faced by people with epilepsy.

This meeting was very significant due to its conclusions: the Ministry of Health Security and the Ministry of Social Security and Labour were requested to produce proposals for the implementation of a systematic approach to solve the problems caused by epilepsy and the difficulties faced by people with epilepsy.

LESIA has worked a great deal with Lithuanian Members of the European Parliament and we are very pleased that each one has signed the EU Written Declaration on Epilepsy, which was passed in the European Parliament in September. This event gives a lot of hope to all those who work with people with epilepsy.

In addition, LESIA has initiated an analysis of Lithuanian laws in the healthcare and social welfare areas with respect to the needs of people with epilepsy and United Nations Convention on the Rights of Persons with Disabilities.

Our ongoing work with people with epilepsy continues to be the provision of services of social rehabilitation.

We are placing a lot of hope in 2012!

NOTICE ME!

Jadwiga Grochowalska, President of the Slawno division of the Polish Association of People Suffering from Epilepsy writes about an unusual public awareness campaign

ZAUWAŻ MNIE

14 LUTEGO to nie tylko
dzień świętego Walentego,
ale również
dzień chorych
na padaczkę

‘Notice Me’ is a nationwide campaign in Poland, which was first launched in Warsaw in 2009 and now involves nine epilepsy associations, including the Slawno division of the Polish Association of People Suffering from Epilepsy - the main author and organizer of the campaign.

Each year on 14th February, Epilepsy Day, a range of events are organised for people with epilepsy, their family members and friends. As part of these activities special ‘Valentine Cards’ are distributed, which include information about epilepsy. Anyone, who wishes to, can also receive special ‘Valentine’ stickers: a symbol of solidarity with people with epilepsy.

The principal aim of the campaign is to alert society and the mass media to the needs of people who have epilepsy and to make everyone aware of the fact that people with epilepsy need to be understood and accepted. Another goal is to educate people on how to behave when they witness a seizure. A lot of people in Poland are still unaware of the symptoms and do not know how to react in such a situation. Due to uncontrolled seizures and lack of public understanding, a large number of people with epilepsy and their carers are forced to resign from their studies, their employment and their dreams.

The campaign which, thanks to the support of several institutions, companies and ordinary people continues to grow, shows that people with epilepsy are able to a lead normal social life if they feel accepted and properly treated. In 2010, to make the campaign more visible to the public, new activities were introduced including promotional ‘spots’ shown in Multikino cinemas, preparing a website and shooting an educational film.

In 2011 the campaign had another new event – a Nordic Walking trail. The motto of the trail was “Notice me - walk healthy”. People with epilepsy, their families and friends, as well as many people who identify themselves with the idea of the campaign, took part in the event. The participants set off on 14th February from Sławno to reach the finish on 26th February in Warsaw, after covering 460 kilometres. The walkers attracted attention in every town on the route, bringing local interest to the campaign and inviting inhabitants to accompany the group as it walk through the town.

In 2012 the ‘Notice me’ campaign will be also strongly connected with a Nordic Walking event. The slogan is the same too: ‘Notice me. Walk healthy.” This year, the participants will have to cover a 400 kilometre distance from Częstochowa to Grudziądz. People with epilepsy, as well as people who want to draw attention to the needs of people with epilepsy, will take part in the walk. Over the course of two weeks, they will visit about 13 towns where they will carry out outdoor educational campaigns. The aim is to encourage all those who enjoy Nordic Walking to join the march. The final event will take place in Grudziądz on 25th February.

The press and television are becoming more and more interested as each annual event takes place and TV coverage has been shown in the main national news programmes.

European Epilepsy Day 2012

BRAINWAVE

The Irish Epilepsy Association launches videos for EED 2012

Four people with epilepsy tell their very different stories

http://www.epilepsy.ie/go/seizureaware

Eoin Kernan, who features in one of the videos produced by Brainwave for EED 2012, has had epilepsy since he was 21. His diagnosis involved a difficult learning curve for Eoin, his family and friends. Eoin says that his diagnosis of epilepsy has made him even more adventurous and hasn't affected his passions for sailing, travel, music and going night-clubbing with friends.
The soundtracks were recorded in Windmill Lane Studios, Dublin - famous as the studio regularly used by U2 (*see Eoin in studio above*) - and were filmed in the historic Law Society offices in Dublin (*photo right*).

APAE - BULGARIA

In Bulgaria, the Association of Parents and Children with epilepsy organised a special Press Conference to highlight European Epilepsy Day, using the slogan `Shattering Epilepsy Stigma'. The main participants to the conference where representatives from the Ministry of Health, National Health Insurance Fund, the Bulgarian office of the European Commission and parents of children with epilepsy.

Rocky Stories

Finnish Epilepsy Association FEA

In Finland the theme for European Epilepsy Day 2012 was crystallized in the motto "Rocky Stories". On the one hand, rocks symbolize the effects of epilepsy at individual and societal levels. On the other hand, rocks can be carried collectively showing that the burden can be lightened by comprehensive care, rehabilitation and appropriate support.

The image of the Finnish campaign shows a rock held in in the hand of 17 year old Catarina Skog. She talks openly about her epilepsy: the tattoo on her wrist is a signal of lifelong epilepsy and is also informative in a case of seizure.

Twenty-six EED information events and lectures took place throughout Finland. The events, under the rubric "Epilepsy - much more than seizures", were targeted at the public at large. Banners were placed on bridges over some highways in the capital Helsinki. The Finnish Epilepsy News promoted the campaign message in a number of ways. Furthermore the special webpage of the campaign showed life stories of people with epilepsy. On the website and facebook pages we even gathered signatures of citizens supporting the implementation of the EU declaration on epilepsy. The citizens' petition will be presented to the MEPs later this spring. Affiliates of FEA were provided with posters, flyers and T-shirts to assist their campaigning.

See more on the webpage: epilepsia.fi/kampanja_2012

Facebook: facebook.com/villiavirtaa (mostly in Finnish).

Young Epileptologists in Georgia celebrate EED

Nino Gzirishvili, who is Vice President of the Georgian Society of Young Epileptologists, sent us images of the group's activites for European Epilepsy Day 2011 and 2012, with colourful street parades and other public awareness activities.

EED 2012 in Italy

A Valentine Key

An unusual safeguard against epilepsy in Monselice

For nearly a century, hundreds of residents from Monselice, in the Italian Veneto region, have visited the Shine of the Seven Churches each year on February 14th - Valentine's Day - where they receive a special blessing and a 'golden key' which, according to legend, should prevent their children developing epilepsy.

This year was a special occasion as the people of Monselice (pictured left) also celebrated European Epilepsy Day as part of this unusual event. Members of the local epilepsy association (pictured below) were on hand to promote epilepsy awareness.

Photo above left: thousands of the special 'golden keys'.

EED 2012 - ORISTANO

In Oristano, below left, colourful balloons and bright red hearts drew attention to an information table in a shopping centre, manned by volunteers.

EED 2012 - BUSSOLENGO

In Bussolengo, the inclement weather, with driving snow, didn't deter some brave, determined people from promoting European Epilepsy Day on behalf of the local branch of AICE.

Mr Buzek spoke passionately on the need to reduce epilepsy stigma

From left: Emilio Perucca, Co-Chair Epilepsy Advocacy Europe; Gay Mitchell MEP, who hosted the event, Mike Glynn, Co-Chair Epilepsy Adovacacy Europe and Jerzy Buzek, MEP

European Epilepsy Day in the European Parliament

Former EU President Jerzy Buzek opens the Epilepsy without Words photography exhibition

The exhibition reception was attended by a large number of MEPs, some of whom are pictured here with Mike Glynn and Emilio Perucca, Co-Chairs of the Joint Task Force Epilepsy Advocacy Europe

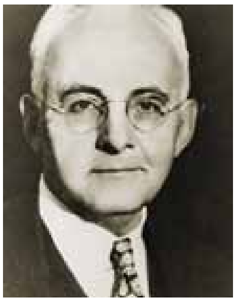
THE ORIGINS OF THE

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY
ILAE
ESTABLISHED 1909

Part Three: The period 1946 - 1957

In the first part of his series on the history of ILAE, which was published in Issue 3-2010 of IE News, Ted Reynolds described the foundation of ILAE and its journal *Epilepsia* in 1909. Part two of the story recounted the period before and after World War II. Now the story continues, looking at the period 1946 to 1957.

In Issue 3-2010, I described the foundation and promising early years of ILAE and its journal *Epilepsia* between 1909 and the outbreak of the First World War, when it ceased to function. In Issue 1-2011, I reported the revival of ILAE and *Epilepsia* in London and at the Lingfield Colony in Surrey in 1935 and its struggle to continue during the Second World War.



WILLIAM G LENNOX
1884-1960

He served continuously from 1935 to 1953 as President and/or Editor of Epilepsia ensuring the survival of ILAE during World War II and its post-war development.

The ILAE survived the Second World War thanks to its American President, William Lennox, and the continuing activity of the USA Chapter, including the foundation of a Layman's League with over 2,000 members, a forerunner of later IBE Chapters.

By the end of the war ILAE had 3 Chapters i.e. in the USA (including members from Canada), the UK and Scandinavia.

The next business meeting of ILAE was held in New York in December 1946, in conjunction with the annual meeting of the American Chapter, together with the Association for Research in Nervous and Mental Disease. Two new Chapters were admitted - from Holland and Argentina. William Lennox was re-elected as its President and as Editor of *Epilepsia*. The journal was financially supported both by the American Chapter and by its affiliated Lay League but, now once more, had an international editorial board.

Hans Schou from Denmark continued as Secretary General and Bernard Ledeboer, from Heemstede in Holland, emerged as Vice President. Ledeboer was later to become Secretary General - 1949 to 1957 - thus renewing the early influence, through Louis Muskens, of the Netherlands as a leading country in the epilepsy movement.

The ILAE next met in Paris in 1949 in conjunction with the International Neurological Congress, as in 1935 and 1939, but also the relatively new International Society of Electroencephalography. McDonald Critchley from the National Hospital in London became the newly elected President. He was a distinguished neurologist, but although he did not have a special interest in epilepsy. His appointment reflected the continuing close links between neurology and epilepsy and he later became President of the World Federation of Neurology. William Lennox, however, continued as Editor of *Epilepsia* and also as "Honorary President" of ILAE, a well deserved but unique title, never since used. France was admitted as a 6th Chapter but the Scandinavian Chapter ceased to function over the next few years, perhaps with the departure of Schou. Sweden was later admitted in 1961 and Denmark in 1973.

A new era for ILAE began at the 1953 Congress in Lisbon, again in conjunction with the International Neurological Congress.

HANS I SCHOU
1886-1952

Secretary General and Editor of Epilepsia prior to and, briefly, after World War II, but based in Copenhagen during the war. His duties were limited by the occupation and largely undertaken by Lennox.

A Earl Walker, a Canadian neuro-surgeon, working at John Hopkins Medical School in Baltimore, was elected President (and again for a second term in 1957), emphasising the growing links between epilepsy and neurosurgery, especially temporal lobectomy which had been pioneered mainly at the Montreal Neurological Institute and the Maudsley Hospital in London. He too went on to become President of the World Federation of Neurosurgical Societies.

A new name to appear was Henri Gastaut, from Marseille in France, as "President Elect." This was an entirely new constitutional post, perhaps created for him, but never to be repeated because he had to wait until 1969 to become President, after first serving three terms as Secretary General!

Four new Chapters were admitted in 1953 i.e. Brazil, Chile, Japan and Peru. Thus South America now had as many chapters as Europe and a pattern was set for the steady growth of ILAE during the second half of the 20th century.

Also in 1953, William Lennox finally stepped down after 18 years of continuous service as President and as acting or de facto Editor of *Epilepsia*. He had ensured the survival of ILAE and the journal during the war, dominated their post-war development, facilitated a novel Layman's League in America with which he persistently lobbied in the USA for political recognition of the neglected needs of people with epilepsy.

One disappointment was that the Layman's League withdrew its funding for *Epilepsia* in 1949, presumably to concentrate on social and political activity. The last issue of the second series of the journal appeared in 1950.

At the same time a new constitution for ILAE was being developed and was adopted at the 1953 Lisbon Congress. The object of ILAE was now stated to be: "The advancement and dissemination, in all countries, of knowledge concerning the epilepsies in every field, the encouraging of research into the cause and cure of the epilepsies and the promotion of better treatment and care for persons suffering from these diseases." Unlike the 1939 constitution, there was now no mention of "social aspects of the disease".

These latter developments were probably some of the seeds that led to the later development of IBE in the 1960's.

Reference:

Shorvon S, Weiss G, Avanzini G, Engel J, Meinardi H, Moshé S, Reynolds E, Wolf P. International League against Epilepsy 1909-2009: A Centenary History. Chichester, Wiley-Blackwell 2009.

The 1st African Epilepsy Congress

Congress Bursary Fund

Have you applied yet?

IBE is providing a bursary fund of US$20,000 to assist a number of delegates, of limited means, to attend the inaugural African epilepsy congress in Nairobi and applications are now invited.

Please visit the congress website to download the bursary application form and for information on application procedures . The closing date for submissions is 22nd March 2012, so there is no time to waste!

On the congress website ou will also find information on the scientific programme and on other activities taking part around the congress.

www.epilepsynairobi2012.org

Resignation of Vania Silva Power

IBE was very sorry to receive Vania's letter of resignation recently, as she leaves the IDM office and the Bureau to take up a new career opportunity in Dublin.

From Vila Real in Portugal, Vania began working with the IBE/ ILAE congress office in 2003, at the time of the International Epilepsy Congress in Lisbon. Since 2008 part of her working hours was spent on secondment to the IBE office.

Throughout the past eight years Vania has developed very good working relationships with IBE member associations, committees, commissions and, of course, congress delegates and her presence will be missed by many people.

We wish Vania well in her new career!

IOM undertakes study of epilepsy in US

The Institute of Medicine IOM is close to completing a new study on the public health dimensions of the epilepsies in the United States - including health care and human services, health literacy, and education.

The report from the study, which is due to be published on 30th March, will recommend priorities in these areas in order to better understand the public health impact of the epilepsies and to meet the needs of people with epilepsy and their caregivers. Specifically, the IOM study focussed on the following questions:

- How can the public health burden of epilepsy for patients and families be more accurately assessed?
- What priorities for future population health studies could inform treatment and prevention?
- How can the access to health and human services and the quality of care for people with epilepsy be improved?
- How can the education and training of professionals who work with people with epilepsy be improved?
- How can the understanding of epilepsy in patients and the general public be improved to create supportive communities?

On Friday March 30th the IOM report will receive its public release and will be available on the IOM website free of charge.

The Institute of Medicine of the National Academies is an independent, nonprofit organization in the US that works outside of government to provide unbiased and authoritative advice to decision makers and the public. Established in 1970, it is the health arm of the National Academy of Sciences, which was chartered under President Abraham Lincoln in 1863.

Nearly 150 years later, the National Academy of Sciences has expanded into what is collectively known as the National Academies, which comprises the National Academy of Sciences, the National Academy of Engineering, the National Research Council, and the IOM.

The aim of the IOM is to help those in government and the private sector make informed health decisions by providing evidence upon which they can rely. Each year, more than 2,000 individuals, members, and nonmembers volunteer their time, knowledge, and expertise to the work of the IOM.

Arfa Karim, the Pakistan child prodigy, who died from epilepsy aged 16 years

Computer prodigy's death due to epilepsy

The youngest ever Microsoft professional, Arfa Karim from Pakistan, has died at the age of 16 years in Lahore. She was suffering from idiopathic epilepsy seizures, which led to brain damage. She completed the Microsoft Certified Professional MCP course in 2004, at the age of just 9 years. The MCP is a designation for independent experts in Microsoft technologies.

When she had finished the course, Microsoft owner Bill Gates invited her to visit the company's headquarters in the US. She was invited to Microsoft Headquarters again in November 2006, when she was 11 years old, as a part of the keynote session in the Tech-Ed Developers conference held in Barcelona.

In an interview with Todd Bishop of Geek Wire, Arfa recounted that, by the age 10 years, she had already decided on her philosophy for life: "*If you want to do something big in your life, you must remember that shyness is only in the mind. If you think shy, you act shy. If you think confident you act confident. Therefore never let shyness conquer your mind.*"

Epic Effort!

On 18th February next, 24-year old Simon Hutchinson, from Cavan in Ireland, will set off on a gruelling 29,000 kilometer cycle race across five continents and more than 20 countries, hoping to complete the journey in less than 160 days and to break the world record in the process.

Simon is entered in the first ever World Cycle Racing- Grand Tour, described as the "longest, toughest, most dramatic adventure competition ever", departing from Greenwich, London and finishing in the same city just before the start of the 2012 Olympic Games. He is using the punishing challenge to raise much needed funds for Brainwave – The Irish Epilepsy Association.

"The current world record is held by race organiser Vin Cox at 163 days 6 hours and 53 minutes. To beat it, I plan to cycle 140 out of the 160 days, averaging 200 kilometers a day", says Simon. Simon continues: "my cousin has had severe epilepsy since she was born 19 years ago. She requires constant care and attention and, several times, I've felt powerless to help her. I hope that, by raising awareness of epilepsy as well as funds, I'll be doing a little to help her and other people affected by epilepsy."

Simon is no stranger to extreme challenges or charity fundraising. Last year he and a friend raised over €10,000 and travelled to Haiti to help build communities there. Also last year, he ran six marathons in five weeks and took part in a 500 kilometer cycle and climb over three days for charity.

But cycling around the world presents a different set of challenges and a strict training and preparation regime is requred.

"Training has been going really well. I'm covering 3,000 - 4,000 kilometers a month and working towards cycling over 200 kilometers each day", says Simon. "I'm well aware that the real work will begin when I set off in February", he added.

Brainwave, who see this epic journey as a tremendous opportunity to raise awareness about epilepsy, is hoping that epilepsy organisations based in the countries and regions through which Simon with travel, may be able to provide support as he makes his way around the globe. The sort of support that is needed includes offers of accommodation for one night – a room or even use of a garden or secure area in which to pitch a tent. Likewise, a hot meal or use of facilities such as laundry would be most welcome. Perhaps your members, volunteers or other epilepsy advocates may be able to help.

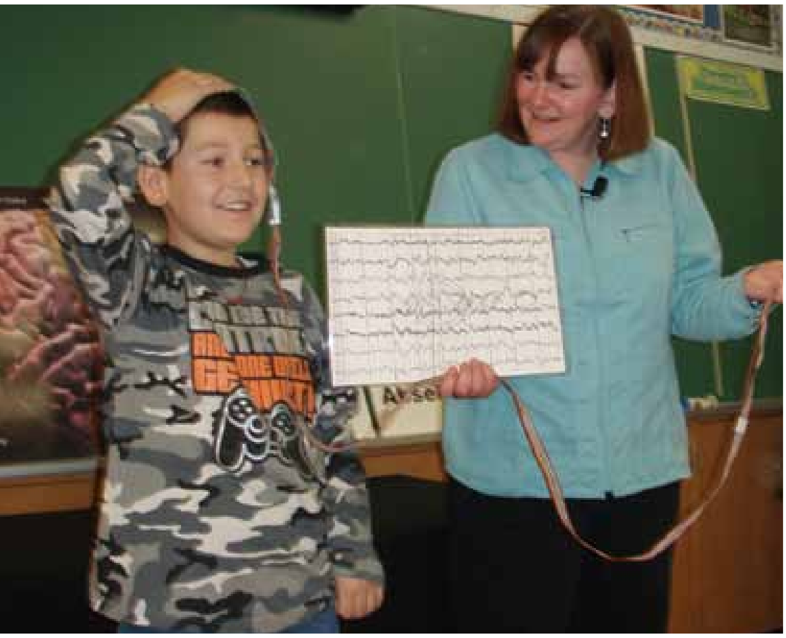
Given the distance being covered and with some rough terrain expected, details of the locations of reputable cycling shops in the towns and cities along his route would also be useful to have.

In return for any assistance you or your members can offer, Simon is willing to take part in any publicity or epilepsy awareness efforts in your area that might benefit your organisation - provided, of course, that these can be arranged to coincide with his schedule!

Simon's route heads east and passes through at least 21 countries. Starting in England, the trail progresses through France, Belgium, Netherlands, Germany, Poland, Ukraine, Romania, Bulgaria and Turkey, moving on to India, Thailand, Malaysia and Singapore. Simon will then cycle across Australia and New Zealand before crossing America from coast to coast. He also hopes to take in Peru to Bolivia. The cycle will finish back in Europe with the final stages in Ireland and the UK.

If you feel that you can help in any way or would like to have more details on the itinerary, please get in touch with Peter Murphy at Brainwave: email pmurphy.brainwave@epilepsy.ie.

©Brian Mulligan



One in 10 Canadians will have a single seizure in their lifetime. One in 100 will have a second seizure and be diagnosed with epilepsy. Unfortunately, due to stigma, ignorance and discrimination, they may not disclose their epilepsy to their classmates, teacher, friends, neighbours, relatives or employer.

Affecting the lives of hundreds of thousands of Canadians, epilepsy remains misunderstood by the public at large. This lack of familiarity with even the most basic facts about epilepsy has dire consequences – most notably and tragically, the people who deal with its effects every day and feel the stigma that comes with being perceived as different. In 2003, the Canadian Epilepsy Alliance took the initiative, in the struggle to promote greater awareness about this common neurological disorder, by going directly into the classroom.

An unfortunate accident in a London, Ontario school served as the catalyst for this endeavour. A thirteen-year-old boy had one of his convulsive seizures at school when a well-meaning teacher panicked and placed an object in the boy's mouth, injuring him. This is not proper first aid for a seizure. The boy refused to return to school the next day because his epilepsy had been "exposed". Education about the brain, epilepsy, and proper seizure first aid help dismantle the damaging myths surrounding epilepsy. It also leads to greater empathy, opportunity and inclusion for people living with epilepsy. The program works, because it is proactive – it teaches what to do before a seizure happens and this alone reduces fear. This is the core of the Canadian Epilepsy Alliance education programs in the schools.

Developed as a supplement for Ontario Grade 5 health and science curricula, the 45-minute "Thinking About Epilepsy" program has reached more than 35,000 students in Southwestern Ontario since its inception.

The model proved so successful that it was quickly adapted for use in other parts of Ontario and Canada, as well as the United States, Israel and Australia. The program was evaluated by researchers at the University of Western Ontario in partnership with two local school boards. Twenty-four schools participated in the research, and a total of 783 children were given the questionnaire to measure their pre and post presentation knowledge and attitudes.

The research showed that the program increases epilepsy knowledge; teaches seizure recognition; reduces the fear people have of epilepsy and seizures; teaches seizure first aid; promotes tolerance and acceptance of those affected; reinforces that epilepsy should not stand in the way of achievement and encourages disclosure for those living with the condition.

Epilepsy in the Classroom

Canadian Epilepsy Alliance introduces two successful programs

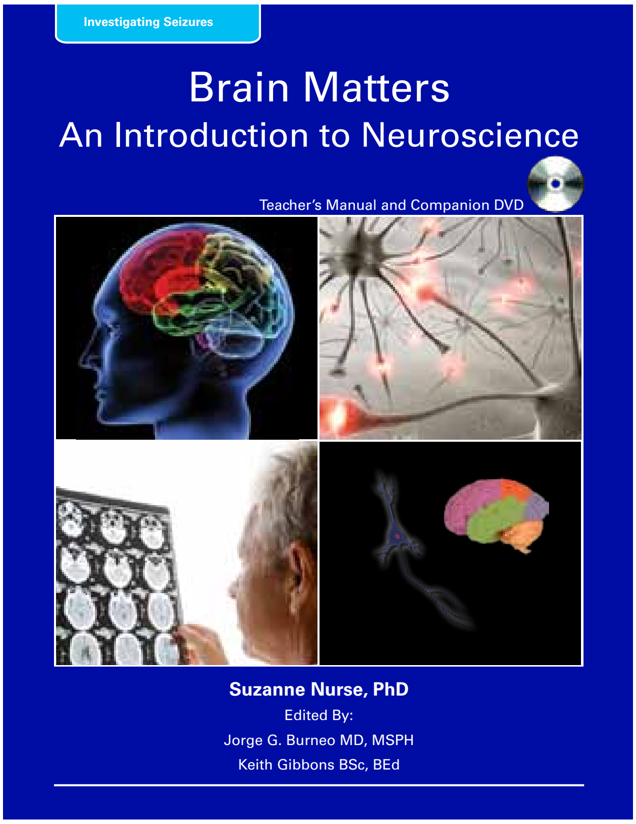
Mary Secco, Executive Director of the Canadian Epilepsy Alliance and IBE Vice President North America, writes about epilepsy educational initiatives in Canadian Schools

In response to the research findings from the "Thinking About Epilepsy" program, the Canadian Epilepsy Alliance developed a second program – this time targeted at Grade 12 biology students.

The unit, titled "Brain Matters: An Introduction to Neuroscience," meets the expectations of the Ontario Grade 12 biology curriculum, and includes a facilitator's manual, companion DVD, case studies, classroom demonstrations and videos. It also includes interviews with professionals who encourage future healthcare workers to choose epilepsy as a career choice.

Together, "Thinking About Epilepsy" and "Brain Matters" have greatly contributed to breaking down misconceptions about epilepsy and equipped a generation of Canadian youth with vital information about epilepsy and seizure first aid.

The successful implementation of these programs represents a crucial step in the struggle to create a world in which everyone, whether they are currently living with epilepsy or not, can face the challenge posed by this disorder with dignity and in solidarity with others.



Investigating Seizures

Brain Matters
An Introduction to Neuroscience

Teacher's Manual and Companion DVD

Suzanne Nurse, PhD
Edited By:
Jorge G. Burneo MD, MSPH
Keith Gibbons BSc, BEd

Top left: *Grade 5 children learn how to act when a seizure occurs.*
Bottom left: *Mary Secco demonstrates and EEG*
Pictured right: *Manual from the Grade 12 'Brain Matters' program*

Future Congresses 2012

9th Asian Oceanian Epilepsy Congress

Manila, Philppines
22nd - 25th March 2012
www.epilepsymanila.org

1st African Epilepsy Congress

Nairobi, Kenya
21st - 23rd June 2012
www.epilepsycongress.org

7th Latin American Epilepsy Congress

Quito, Ecuador
14th - 17th November 2012
www.epilepsyquito2012.org

Congress Secretariat: 7 Priory Hall, Stillorgan, Dublin 18, Ireland
Telephone: ++353-1-20-567-20   Email: info@epilepsycongress.org
www.epilepsycongress.org