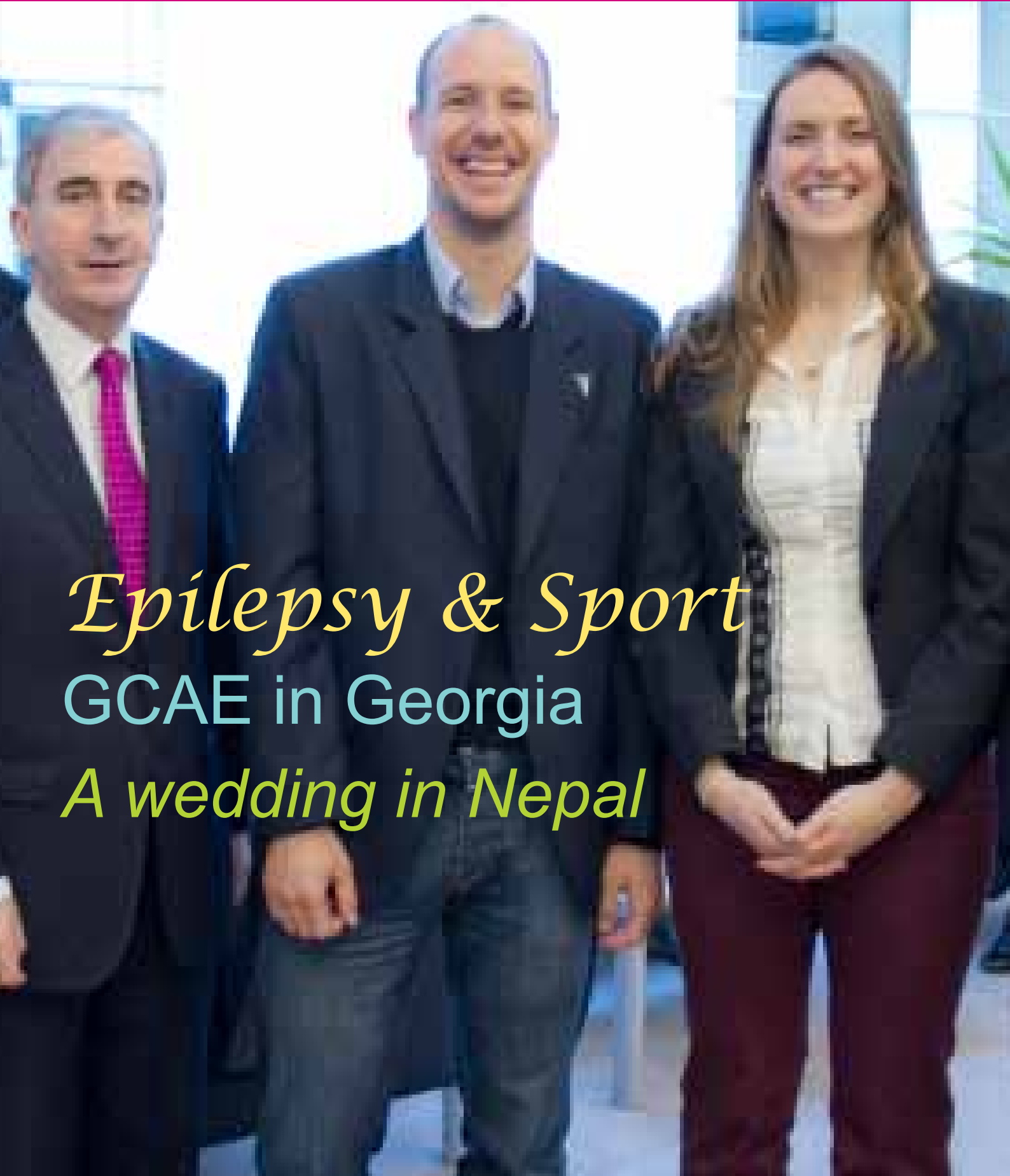


INTERNATIONAL

Epilepsy News



Epilepsy & Sport
GCAE in Georgia
A wedding in Nepal



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



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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

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Epilepsy & Sport

European Parliament hears compelling stories of athletes who complete at international level in spite of a diagnosis of epilepsy

"I hope I can provide a little insight and perhaps a little of my understanding of epilepsy or, in Harry Potter terms, the 'dark arts'."

Thus Emma Beamish began a personal, moving and, at times, amusing account of living with epilepsy. The venue was the European Parliament in Brussels and Emma was one of three international sports people who also happen to have been diagnosed with epilepsy.

The Roundtable event, which took place on 29th November in Brussels, had been organised jointly by the European Advocates for Epilepsy special interest group of MEPs (Members of the European Parliament) and the IBE/ILAE Joint Task Force Epilepsy Advocacy Europe. Hosting the event was Mrs Angelika Werthmann, an

Austrian MEP, who is a member of the European Advocates for Epilepsy Group.

Mrs Werthmann stated: "Six million people are diagnosed with epilepsy in the European Union, although the real number could be much higher - nobody knows, since the social stigma is enormous. Parents, in particular, are afraid of the social disadvantages for their children and therefore keep the diagnosis a secret. I believe it is up to us to open dialogue and to strongly support and encourage people affected by epilepsy also to open up."

Emma Beamish, Ireland, is an Irish International Cricketer who has represented Ireland at the highest level, participating in the 2005 Cricket World Cup in South Africa. She was a member of the Irish team that won the European Championships

and the European 20-20 Championships. She is now a level 2 cricket coach, and about to become a level 2 hockey coach. Her latest sport is Kick Boxing.

Emma is currently studying at Queen's University, Belfast, to become a teacher. On the day Emma spoke in the parliament she was also celebrating her 29th birthday.

Emma's passion in life is sport and she told us that nothing had ever come between her and her sports. Her parents had provided fantastic support to her, which allowed her to have a life the same as everyone else:

"They set the tone; I never knew anything was wrong. I was lucky that my parents provided a support that I didn't know existed. There was a net there. But this is a condition where you cannot wrap people up in cotton wool.

"It is very lonely dealing with something that no one can explain to you. This is why I call it the 'dark arts'. It's there but you can't see it until it's too late."

I started with small goals; I would walk the dog every day. He did very well out of this arrangement

Emma talked openly about periods of anger and fear, of frustration and depression. She told how, at times, she would feel extremely low. But she also talked about how she found her way back into life thanks to psychological help and daily step by step goals she set herself: "My epilepsy has never held me back; it's just made things a little bit tougher, but then nothing worthwhile was ever easy.

"I started with small goals; I believe my first goal was that I would walk the dog every day. He did very well out of this arrangement!"

Emma explained how her entire lifestyle had to change to allow her to compete at the top level in sports. She realised that she needed at least eight hours sleep each night, to eat a healthy diet, and to avoid stress. She also had to ensure that she took her medication as directed to keep her 'on the straight and narrow': "I get little reminders every now and again if I don't keep to the path," she explained.

Her request to society is for openness: to stop speaking about epilepsy quietly in corners and to start speaking openly about the condition. Emma believes that this is the only way to make it 'normal' to have epilepsy and by speaking openly, the ripple effect could be tremendous.



My doctor told me that any physical exercise was out of the question and especially forbade any sort of endurance sports!

Georg Thoma, Germany, is a marathon runner, who has run all over the world and has even run a marathon along the Great Wall of China. He undertakes distance races for charity, including a 630km long charity run across Germany.

In his presentation, Georg talked about how he was very frightened before undergoing brain surgery, thinking how his head would be cut open. Now he is delighted that he had the surgery as it has allowed him, finally, to achieve a seizure-free life.

Georg told how he had realised lifelong dreams and, like Emma, he also pointed out the need to 'open the eyes' of society about the true facts on epilepsy.

Jérôme Becher, Germany, holds the Guinness world record for the longest uninterrupted swim (80km) as well as the European record in 24-hour swimming. Aged 32 years, he is a physical therapist by profession, and runs his own rehabilitation centre.

"I had my first seizure in April 1989 - I was ten and I still remember it very clearly. It was a Monday and my brother and I were on our way to swimming practice. Life changed completely that afternoon: My doctor told me that any physical exercise was out of the question and especially forbade me any sort of endurance sports!"

After his diagnosis of epilepsy, with the great support of his parents, Jérôme continued with his sports activities, and began to set himself bigger and greater sporting goals - although his neurologist was kept in the dark!

"My mother accompanied me to every practice. I swam more and longer distances; I ran more and longer distances. The one thing we didn't do was to tell my neurologist about my sporting efforts."

He has run 15 marathons, with a fastest time of 3 hours and 8 seconds: "I started



Photo above: MEP Mrs Angelika Werthmann, who hosted the Roundtable event in the European Parliament in Brussels
Photo opposite page, from left: Asla Pitkänen, Georg Thoma, MEP Gay Mitchell, Jérôme Becher, Emma Beamish and Mike Glynn. Photo: Martin Lahousse
Photo below left: French MEP Mrs Nathalie Griesbeck meets Jérôme Becher. Photo: Magdalena Neuner

to do open water competitions, which are held in lakes in Germany due to lack of open sea. I started winning 5km and 10km events, won some German championships and simply enjoyed my life without having epilepsy handicap me. At this point, of course, there was no more hiding my secret activities from my neurologist! It helps of course if you can present some solid results that the sport was not aggravating my condition but instead stabilizing me.

Having a seizure at 2 kilometers offshore creates a somewhat more difficult problem then collapsing during a marathon on solid ground

"I never think about the problems with epilepsy during races. It's before each race that I have to ask myself if I can do it without risking my health. And swimming isn't the most preferred sport in neuroscience - having a seizure at 2km offshore creates a somewhat more difficult problem then collapsing during a marathon on solid ground."

Today Jérôme is committed to improving the situation for people with epilepsy, by

increasing public awareness. He explained that people might have the false impression that epilepsy isn't a severe disease because they can see that he is in perfect control of his life. However, he adds that this is because he has found the self-confidence and support to accept his condition and to generate motivation to live all aspects of his life with more awareness: "That's why I have become an ambassador to bring more self-confidence to people with epilepsy and those close to them, to people who are not open enough to talk about it, who are even ashamed of their condition, people that don't get the support they need.

"Standing here in this special place is the very proof that epilepsy is something we ought to talk about and accept and to give everybody the chance to live their life without fear or discrimination. It is our task to bring those people hope and support. We can show them that epilepsy is the last reason why they shouldn't live a rich and satisfying life."

Dr Asla Pitkänen, Finland, is Professor of Neurobiology at the University of Eastern Finland and Secretary of IBE/ILAE Epilepsy Advocacy Europe task force. She is also a member of the ILAE Commission on European Affairs.

Following the speeches of the three sport-people, Dr Pitkänen presented on the medical aspects of epilepsy, the enormous burden that chronic diseases constitute in

general and in particular the economic and social burden of epilepsy. While 25 different epilepsy genes have been identified and despite the high number of anti-epileptic drugs available, up to 40% of people with epilepsy will still have seizures. There is still no cure for epilepsy. Because of this, Dr Pitkänen emphasized the necessity to expand epilepsy research in order to close the huge diagnostic gaps, to reduce side effects of medication and to work towards a situation where everyone with epilepsy will have, at least, total seizure control or, at best, a cure.

Mike Glynn, Ireland is IBE President, Co-chair of the IBE/ILAE Epilepsy Advocacy Europe task force and Chief Executive Officer of Brainwave The Irish Epilepsy Association.

Mr Glynn referred to a number of international rugby players who have epilepsy, including former Scottish player Tom Smith, who is now a rugby coach. In his view, parents must encourage their children to become involved in sports, despite the diagnosis of epilepsy.

Helping a child with epilepsy to live as normal a life as possible, including playing sports with their peers, is important for two reasons - firstly in helping the child with epilepsy to develop self-confidence and self worth and, secondly, to send a clear signal to the general public that most people with epilepsy are no different from

anyone else, apart from a diagnosis of epilepsy, and that epilepsy is not something to be hidden from view.

In addition to Mrs Werthmann, other MEPs who attended the event included Irish MEP Gay Mitchell, who is President of the European Advocates for Epilepsy Group; fellow Irish MEP Sean Kelly, who also spoke at the International Epilepsy Congress in Rome at the end of August; and French MEP Nathalie Griesbeck, a member of the European Advocates for Epilepsy Group. A number of MEP's Assistants were also present.

Several people travelled long distances to attend the roundtable event in Brussels, either representing epilepsy associations or because of a personal interest in Epilepsy. The Hungarian IBE and ILAE associations were represented by Dr Judit Jerney, while Dr Janet Mifsud who is a member of the joint task force is from Malta. The furthest distance was travelled by Claudia Schlesinger, Chief Executive of Enlighten Hong Kong! Not only had she travelled all the way from Hong Kong, she had also done so with her foot in plaster due to - yes you've guessed it - a sports injury!

Pictured below are some of the participants and speakers to the Epilepsy & Sport Roundtable event in the European Parliament in Brussels. Standing next to Mike Glynn is MEP Sean Kelly (wearing a red tie). Photo: Martin Lahousse



Australian Paediatric Neurologist receives Major Award



Professor Ingrid Scheffer was recently awarded the Asia-Pacific L'Oréal-UNESCO For Women in Science Laureate for 2012. The award, which carries a prize fund of \$100,000, was bestowed in recognition of her vital work, over a period of 20 years, in establishing the genetic basis for epilepsy.

Looking back to when she first began her research for her PhD on families with epilepsy, few people believed that her work would achieve any significant outcomes.

“The neurogeneticist I worked with laughed,” Professor Scheffer remembers with a smile. But he warmly congratu-

lated her in 1995 when, as a result of her work with University of Melbourne collaborator Prof Sam Berkovic, the first epilepsy gene was discovered by a team at Adelaide's Women's and Children's Hospital.

Professors Scheffer and Berkovic, who are based at Austin Health, have led the world in their field since then and, of the 25 epilepsy genes now known to exist, the pair has been involved in the discovery of 13.

“People used to think epilepsy was caused by a hit on the head, a scar, a kick from a

horse,” she says.

In fact, at least one-third of people with the condition have inherited it from a parent; have received genes from each parent that, when added together, predispose them to epilepsy; or, because of a mutation, have the first genetic-based case in the family.

IBE extends warm congratulations to Professor Scheffer on a well-deserved award!

Indonesia receives first digital video-EEG system with thanks to Rotary Clubs in Japan and Indonesia

Thanks to the collaboration of the Rotary Foundation and Rotary International Districts 2580 and 3400, activated by Tokyo Asakura Rotary Club and the Rotary Club of Semarang Sentral with nine Rotary Clubs in Indonesia, the first digital video-EEG system was introduced recently to Indonesia at Dr Kariadi General Hospital, Semarang.

The project was supported through the cooperating partnership of Professor Ken-

suke Kawai of the University of Tokyo and Professor Zainal Muttaqin of Dr Kariadi General Hospital.

On November 3rd, a ceremony of celebration and academic seminars were held at Dr Kariadi General Hospital, to which all doctors, staff members and Rotarians in charge were invited. The digital video-EEG system will serve for the development of epilepsy diagnosis and mark a milestone for epilepsy care in Indonesia. Following the introduction of the digital video-EEG

system, activities in several fields including public awareness campaigns on epilepsy, exchange visits of doctors and nurses for training and exchange of medical and clinical information are being planned.

This joint program, titled “Toward better understanding and treatment for epilepsy in Indonesia”, is a trial of the “Future Vision Plan – Global Grant Projects” of the Rotary Foundation and is the result of sponsorship from the foundation and from all Rotarians.



Photo from left: Mrs Maria Susanti, President, Rotary Club of Semarang Sentral; Mr Mitsuo Makino, Past President, Tokyo Asakura Rotary Club; Mr Yukuya Tomii, Immediate Past President, Tokyo Asakura Rotary Club; Prof Kensuke Kawai, Dept of Neurosurgery, University of Tokyo, Japan; Prof Zainal Muttaqin, Dept of Neurosurgery, Dr Kariadi General Hospital, Semarang, Indonesia; Mr Bambang Wibowo, President Director of Dr Kariadi General Hospital; Mr Mohamad Ridlo Eisy, District Governor, Rotary Club of Semarang Sentral; Mrs Ritje Rihatimah, Past District Governor, Rotary Club of Semarang Sentral; and Mrs Ekawati Sudjadi, Past President, Rotary Club of Semarang Sentral.



In Memory

John Gilbert Kirker 1922-2011

It is with great sadness that IBE learned of the death of Dr John Kirker on Monday 14th November. At the time of his passing after a short illness, at the age of 89 years, he was still President of Brainwave The Irish Epilepsy Association, a role he had held with great diligence since 1982.

Dr Kirker was born in Norfolk, England and studied medicine at Trinity College Dublin and at the Royal Victoria and City Hospitals in Belfast.

After completing his internship, he travelled to the US to undertake a fellowship in the newly developed technology of electroencephalography (EEG) with the renowned epileptologist, Dr William Gordon Lennox at Boston Children's Hospital (1948-1949), and with shorter periods working with Dr Frederick Gibbs in Chicago and with Dr Herbert Jasper in Montreal - both pioneers in EEG recording.

Dr Kirker was a consultant physician at Sir Patrick Dun's Hospital (a general hospital) and St Patrick's Hospital Dublin (a psychiatric hospital) and lectured in pharmacology at Trinity College Dublin. In 1956 he was made a Fellow of the Royal College of Physicians of Ireland (FRCPI) and was its first Director of Examinations from 1983 to 1985. He served as RCPI Vice President in 1981 and was President from 1983 to 1985. Dr Kirker served a further nine months as RCPI President in 1989,

following the death of the incumbent President, to complete the term.

During his illustrious career he was Chairman of the Medical Education Committee, Medical Council of Ireland and was directly responsible for the development of electroencephalographic services in Ireland. He remained at the forefront of EEG reading and epilepsy practice for more

than half a century, up to his retirement in the late 1990s.

Of course, Dr Kirker's career stretched far beyond the shores of Ireland; he was also a strong supporter of the International Bureau for Epilepsy over a period of more than 30 years and worked with passion on Driving Commissions for many years.

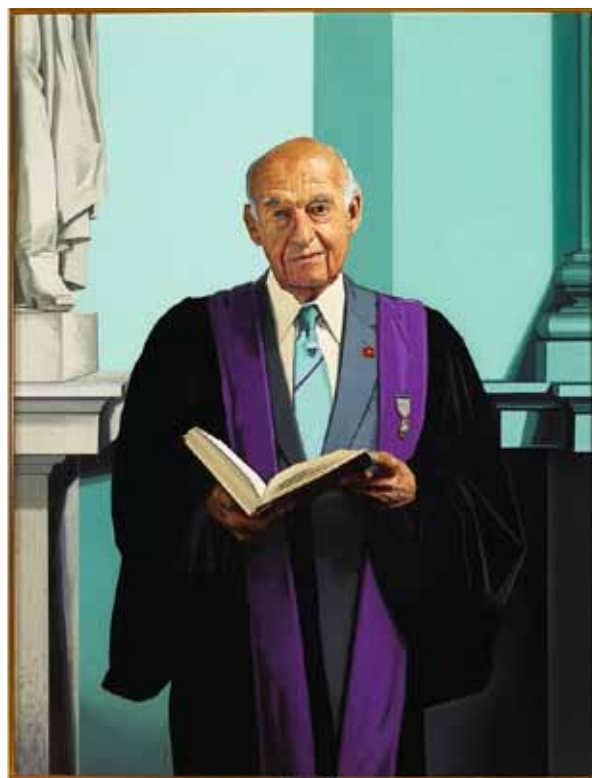
In 1974, Dr Kirker received his first IBE/ILAE award – the Ambassador for Epilepsy Award. More recently, in 2007, he was awarded the Social Accomplishment in Epilepsy Award during the 28th International Epilepsy Congress in Singapore.

His work at international level, on behalf of people with epilepsy, includes:

- Serving as a representative on the Advisory Committee on Medical Training of the European Union in epileptology
- Member of the Organising Committee to the 2nd European Conference on Epilepsy & Society, Dublin 1990

- Chair, Commission on Driving of IBE 1989 - 2001
- Organiser of the IBE Driving & Epilepsy Workshops, Brussels 1995 & 1996
- Chair of the Scientific Advisory Committee, 22nd International Epilepsy Congress, Dublin 1997
- Founding Member of Brainwave the Irish Epilepsy Association (IBE Member) and the Irish League Against Epilepsy (ILAE chapter)

He was also a serving member on the 2nd European Working Group on Epilepsy & Driving - advisory board to the European Union – at the time of his death. This working group was influential in the introduction of the European Union Directive



*Portrait of Dr John G Kirker by James Hanley to commemorate his term as President of the Royal College of Physicians of Ireland. The portrait, which hangs in the college, has been reproduced here by kind permission of the artist.
© James Hanley and RCPI*

on Driving, a directive that is currently being implemented by EU member nations across Europe and which will introduce uniformity of legislation in the provision of driving licences to people with controlled epilepsy.

Something Dr Kirker never mastered was the computer age and the internet, which is why I had the privilege of meeting him on a regular basis over a number of years. I first worked with Dr Kirker, as his assistant, when he was Chair of the Scientific Advisory Committee for the 22nd International Epilepsy Congress, Dublin 1997.

As Chair of the IBE Driving Commission, post the Dublin congress, he would still come to the office for some support with his correspondence, handing over letters handwritten in a neat slanted script

that belied his medical background! These would be typed up and dispatched while John enjoyed a cup of coffee with us. There were always some wry comments shared on a topical subject to bring a smile to the lips of those within earshot!

During the Service of Thanksgiving for Dr Kirker following his death, to our amazement we learned that, just before he became ill, his son had presented him with a new Apple computer. We can only guess that Dr Kirker was finally persuaded to enter the realms of modern communications so that he could Skype his beloved grandchildren who live in the UK.

To those privileged to know him, Dr Kirker was a kind, compassionate and gentle man, with a brilliant brain and that wonderful sense of humour - and who

didn't like any sort of fuss. He took the diagnosis of advanced aggressive cancer and impending death with great fortitude and acceptance, wryly remarking: "I hope I don't linger for too long and put a damper on everyone's Christmas!" He didn't: he had left the world less than a month later; but has left the world a better place for people with epilepsy.

He is survived by his wife Elizabeth, son Stephen, daughter-in-law Fiona, and his three grandchildren Tom, Ed and Alice, who were a delight to him. *AL*

PCDH19 Gene Mutation in Baby Girls



The PCDH19 gene mutation causes severe epilepsy in female babies.

Research that began in 2008 has recently shown that mutations in PCDH19, the gene on the X chromosome that encodes the "Protocadherine 19" protein, cause the onset of a form of drug-resistant epilepsy in female subjects aged between 3 months and a few years.

The seizures, focal or generalized, may be accompanied by a fever and often occur in clusters that can last for several days.

Neuro-imaging techniques such as MRI do not show any cerebral alterations.

This form of epilepsy is often associated with the presentation of mild to severe mental retardation, sometimes with autistic traits.

The mechanism with which the PCDH19 mutations determine this clinical condition is still unknown. Molecular diagnosis is important to initiate the best treatment possible in the acute phase, as well as for prognosis and genetic counseling.

In April 2011, in Italy, the families of some affected girls founded the non-profit organization "Insieme per la ricerca PCDH19" (Together for research on PCDH19).

The primary objectives of the organization are to promote and fund scientific research on PCDH19, and to create a network to connect families in order to support the exchange of experiences and updates.

For more information and to support scientific research in this field, please visit: <http://www.pcdh19research.org>.



Photo: Floris Meinardi

Harry Meinardi

presents the next instalment
of IBE's interesting history

IBE fulfils a need and expands. But this author is constricted to less than 1,000 words and has to become more selective.

It is 1973, the constitution is revised: IBE and ILAE will include the other's President and Secretary General as ex-officio Officers. Honorary Members can be elected - Dr Ampara Arcaya from Chile is the first. The executive gets an Editor of the Newsletter. The Newsletter shall speak for both IBE and ILAE as part of a stepwise attempt to merge. Therefore the December issue informs about the second Scandinavian Symposium on Epilepsy, conferences of the German Section of

ILAE and of the Italian League as well as about the Annual conference of the New Zealand Association, and the founding of the Newfoundland Epilepsy Association in Canada.

Holland establishes CLEO (Commission National Epilepsy Research). It handles grant applications for epilepsy research to be funded both by charities concerned with epilepsy and for an equal amount by Government.

The BEA (British Epilepsy Association) reports about a study conference on how to design protective headgear. The Argentinian League has created an institute for integrated care of persons with epilepsy with clinical neurological and psychiatric services, an office for social workers and psychologists, and a rehabilitation service. Chief advisor is Dr Abraham Mosovich, indeed the one who proposed the motion which initiated IBE.

June focuses on how to help persons with epilepsy to take part in society according to their capacities and to resist being ostracized for being labelled "epileptic". Attitudes towards persons with epilepsy differ by nation, exemplified by official regulations. IBE asks the Council of the European Economic Community to establish driving license regulations common to all nine member countries. Worldwide rules for immigration have improved when

comparing 1964 and 1973.

At the end of the 19th Century conditions for persons with epilepsy ameliorated thanks to "Colonies for epileptics." In the 20th century some of these disappeared while others developed into Special Centres for Epilepsy and new epilepsy centres were created. Several are mentioned in the next issues.

Dr Jaime Fañdino Franky reports how the Colombian League against Epilepsy, and its supporters, has started construction of a rehabilitation institute for persons with epilepsy. (Recently he was once again in the news as, largely thanks to him, the President of the Colombian Republic signed in November 2010, law 1414 on "Protección a las Personas con Epilepsia.") Dr Maurice Parsonage describes a Special Centre in York, one of the three established in England in 1972.

The 6th International Symposium on Epilepsy is held in the recently opened William Lennox Centre in Belgium. However the Epilepsy Social Welfare Foundation, Victoria, Australia reports in 1973 that they have closed their residence for persons with epilepsy as "today's thinking is against the segregation of people with epilepsy". Now in 2011 the conflict between those who prefer to be amongst kin and kindred and those who urge that communities should be multinational, multicultural and disregard differences is still on-going world-wide.

March and June report about travelling seminars starting in Mauritius, where the National Health Care system wanted to discuss whether buying an EEG-machine for epilepsy care was cost-effective. Next stops were in India, which had nuclei of epilepsy care and research that were equal to the best of the world next to situations where even the bare minimum standards were not reached. Methods of improvement were discussed.

Singapore, Indonesia, Australia, Korea and Japan followed. That Australia was included in a tour to update developing countries about advances in epilepsy care and research was basis for Dave Daly, President of ILAE to accuse George Burden of arranging this stop to see his family in

1973-1977
IBE fulfils a need and expands!

Look Back with Pride - Part 4

Australia and that money given to promote knowledge about epilepsy was therefore abused. This unfair accusation led to the resignation of George Burden in 1977. A similar accusation about workshops in South America voiced by Dave Daly, had led to a rift with the secretary-general of ILAE, Otto Magnus, in 1972.

March brings information about the discovery and development of new antiepileptic drugs, and a new method of monitoring drug levels in body fluids. To obtain information from countries devoid of either Bureau or League members, letters were written to ministers of health.

Richard Holmes, since 1974 administrator of the Irish Epilepsy Association, present its profile, as Dublin will be the venue of the IBE/ILAE 8th International Symposium, while next year Amsterdam will host the ILAE 13th Congress/IBE 9th Symposium. Poland, still behind the iron curtain, organises The First European Regional Conference on Epilepsy, sponsored by ILAE and IBE.

Biofeedback training to control seizures, introduced in 1974 by Sterman et al, is explained and discussed. A review of 20 epidemiological studies, reporting prevalence's from 1.5 per thousand (Japan) to 15 per thousand (Africa), asks for more uniform methods and better classification to study epilepsy.

Whether residential care with schooling is to be preferred over home and local schooling with expert advice is discussed, as it still is nowadays. The special centres for epilepsy in England and the Netherlands report a holiday exchange program for their residents with accompanying staff.

The editorial in the March 1977 issue is titled "Collective responsibility" stating "There should no longer be a blind trust in authority. A basic body of knowledge can be acquired which will permit the individual to decide whether the accepted authorities can be trusted."

Gilbert van Wessem reports that, by wearing your Ambassador for Epilepsy badge every day communication about epilepsy can be much improved, doing so he had already 69 discussions ranging from a few minutes to several hours. The Calgary Epilepsy As-



sociation is the first to report the organisation of an annual Epilepsy week. The June and September issues discuss the place of epilepsy in medical education. Also epilepsy and employment are discussed. Thirty-five years later, both still merit attention. In September 1977 new Executives were elected; this information will be dealt with in the next instalment!

*Photo above: Street scene in the city of Phnom Penh, Cambodia, today.
Photo: Ann Little*

MAURITIUS

Educational Seminar for Medical Professionals & Carers Yousouf Noormode, Edycs President, reports



Front row, from left Mrs Aikagjee Yasmine, Program Facilitator; Mrs Roubinah Isseljee, Edycs Epilepsy Care Administrator; Dr Aumeer, neuropediatrician
Back row, left to right: Dr Emilien Gerald, neurologist; Mr Ajay Babajee, Sanofi Aventis; Dr Sajad Foondun, psychiatrist; Mr Noormohamed Auckbur, Program Assistant Facilitator; Mr Anas Mosaheb, clinical nurse; Mr Indiren Vyavooree, Health Care Assistant; Mr Paramasiva Chengan, Deputy President Edycs Epilepsy Group; Mr Joyvani Rose, reflexologist; Mr Yousouf Noormamode CSK, President Edycs Epilepsy Group

Epilepsy affects more than 25,000 people in Mauritius, including Rodrigues island.

A key focus of Edycs Epilepsy Group, IBE's Full Member in Mauritius, is to raise the profile of the organization while increasing both public and professional understanding and awareness of epilepsy.

In partnership with Sanofi Aventis and the Ministry of Health & Quality of Life, an educational seminar on epilepsy for healthcare professionals and carers was launched in November.

The seminar, funded by the Currimjee Foundation, was attended by a hundred medical specialists, clinical nurses and social workers from both public and private health care institutions in Mauritius.

At the official opening of the seminar, Yousouf Noormamode, Edycs Epilepsy Group's President, spoke of the critical need to update epilepsy knowledge among medical professionals and carers in applying practical tools for aiding epilepsy management. Edycs Epilepsy Group is committed to enhancing the health and well being of people with epilepsy by mobilizing financial and technical resources to meet its aims.

The Currimjee Foundation's CSR (Corporate Social Responsibility) Manager, Shafeek Nojib, highlighted the commendable work of Edycs Epilepsy Group in bringing relief and support to the epilepsy community. He added that the Currimjee Foundation was proud to be associated with the event and would continue to



Outstanding Persons with Epilepsy Awards

Outstanding Persons with Epilepsy Awards will again be presented during the 9th Asian Oceanian Epilepsy Congress (AOEC) in Manila, The Philippines in March 2012.

Each IBE Member in the South East Asian and Western Pacific regions may nominate a recipient, with procedures for selection determined by the member association. Guideline are available to those associations who have not previously participated in the event.

The closing date for submitting the names of nominees to the IBE Office ibedublin@eircom.net is 14 January 2012.

The nominees will be presented with their award by IBE President Miike Glynn on 22 March, 2012 during the Welcome Ceremony.

It is anticipated that each nominee will receive an element of financial support to assist their travel to Manila, through bursary funding provided from the budgets of the IBE Western Pacific and South East Asian Regional Committees.

Congress website: <http://www.epilepsymanila2012.org>



The 1st African Epilepsy Congress

To encourage young investigators to participate in the 1st African Epilepsy Congress 2012, which takes place in Nairobi, Kenya, the congress will support attendance for a restricted number of professional healthcare providers, young researchers and doctors from Africa.

IBE is providing a bursary fund of US\$20,000 and applications are invited. Please visit the congress website to download an application form and for information on bursary procedures.

Closing date for submissions is 22nd March 2012.

www.epilepsynairobi2012.org

work together with Edycs Epilepsy Group in creating an enabling environment where people with epilepsy could enjoy their full rights and become fully participating members of the community, despite their health condition.

The full day program focused on three topics delivered by Dr Dominique Lam Thuon Mine, neurologist; Dr S Foundun, psychiatrist; and Dr Gerald Emilien, neurologist. These were:

- Epilepsies and epileptic seizures - global incidence and prevalence and classification
- Epilepsy and Psychiatry
- Anti Epileptic Drug Management

With the permission of Sanofi Aventis, an educational slide show 'Caring for Patients' with Epilepsy,' designed for healthcare professional training, was shown and copies were distributed to participants.

The Action Zone! game, an initiative of IBE supported by UCB Pharma, and previously published 'Research Guide in Epilepsy for Professionals' by Edycs Epilepsy Group were also available.

The seminar received wide media coverage on TV and radio channels as well as in the printed press.

EPILEPSIEN IM SCHULALLTAG

ParEpi Switzerland has just published the second revised edition of its manual on epilepsy in the school.

The book, which contains 68 pages, was updated and content reorganized and is available to order directly from the organisation.

Epilepsien im Schulalltag provides comprehensive information about epilepsy in school and its impact and also answers questions posed by teachers and parents.

Important topics such as medicine, psychology and pedagogy are discussed, and the appendix provides useful addresses and references to literature and movies. The book also provides support to teachers in their work and in dialogue with parents.

For further information or to order a copy of the book (price CHF 22 including shipping) please contact the association at info@parepi.ch.



You don't
have to be a
Newshound!



You just need good
writing skills to win ...

IE NEWS JUBILEE AWARD

Rewarding contributions to IE News

This special award will reward the best contribution submitted to International Epilepsy News and has been introduced as part of IBE's Golden Jubilee celebrations and to mark 48 years of IE News, the quarterly magazine of IBE.

Whether you report on epilepsy at international or local level, on medical or social aspects of the condition, you could win this great award!

Award Rules

- Reports and articles, to be considered for the award, must be submitted by email to ibedublin@eircom.net before the closing date of 31st December 2011.
- Articles must be written in English and be the original work of the applicant.
- The article must be between 750 and 2000 words in length.
- Photographs may accompany the submission but it is not compulsory to do so.
- IBE reserves the right to publish any article submitted.

Prize

There will be one prize winner, who will receive financial support to attend an IBE or IBE/ILAE congress of the winner's choice, up to a maximum of US\$2,000. The prize funds may not be used for any other purpose and must be used before the end of 2013.

Award Criteria

An independent judging panel will judge entries, looking for responsible, informed and original stories. Entries will also be assessed on the following specific criteria. The work:

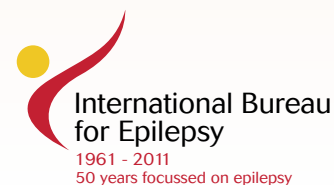
- Helps increase awareness and understanding of epilepsy
- Gives a voice to people with epilepsy
- Is well researched, compelling, and uses language responsibly when writing about epilepsy.

Remember!

Closing Date: 31st December

Entries to: ibedublin@eircom.net

Good Luck!





A New Life for Juneli!

Finance by IBE, cast by NEA, text by Ann Little

Meet Juneli, a young girl from Nepal who has epilepsy. Here she is on her wedding day - pictured second from the left in this beautiful photograph - together with her husband Madhav, her parents and her sister-in-law, as they pose for the wedding album. A charming family portrait.

Or is it? In truth all is not as it seems! Juneli isn't getting married, in real life she doesn't have epilepsy and none of the people in the wedding shot is related to her. Instead, these are all actors who took part in a docudrama made by Nepal Epilepsy Association supported by an IBE Promising Strategies Program grant.

And now that I have ruined it for you, by telling you how the plot ends, let's return to the beginning and Act 1, Scene 1, Take 1!

Despite the fact that Nepal has a wealth of cultural and natural diversity, up to 75% of the country's population of 27 million people are still dependent on agriculture for a living and a significant percentage of people still lives below the poverty line.

Similar to the mean, approximately 1% of people in Nepal have epilepsy and many unrecorded deaths could be due to epilepsy

and related diseases. Due to a shortage of health care centres, sufficient to meet needs, the majority of the population has no access to adequate healthcare.

With this background, the Nepal Epilepsy Association (NEA) is completing production of a short documentary that will provide a means of raising awareness through the media. The focus of the documentary is on the social stigma of epilepsy, its impact on society, and possible ways of prevention and treatment of the condition.

After production, the story of Juneli will be televised on a number of national television channels including the government-owned channel. The documentary will also be shown to local people when they attend one of NEA's free epilepsy camps or its epilepsy clinics, which are based in Lazimpat, Kathmandu and Dolakha.

Filming has been completed and post production editing is now underway. It is expected that the docudrama will be ready for use by the end of the year.

The film tells the life story of a young girl who has epilepsy, from when she is a young child, through her school years, to

her wedding day and early married life. There are two different actors to play the part of Juneli, as she grows from a young child to a mature and beautiful woman!

Along the way, the young girl Juneli is subjected to strange superstitions, such as a belief that smelling shoes will stop a seizure! She is brought to a witchdoctor, her parents believing that this will lead to a cure. At school she is ostracised and must sit apart from the rest of the class.

We see Juneli having a seizure, which is played most convincingly by the actor, following tutoring by NEA Vice President Dr Hemav Rajbhandari.

The climax of the film comes when Juneli's parents persuade her to marry. However, her condition is not disclosed, to her future husband and his family, by Juneli's parents and uncle when the marriage proposal is being arranged. In a beautiful shot, showing the grandeur of Nepal's countryside, we see Juneli running to tell her future husband about her epilepsy.

Madhav agrees to marry Juneli because she has told him about her condition. Then, in true film drama fashion, Juneli has a sei-



Photographs from top of page:

- The production of the docudrama involved an entire school, seen here being filmed at the start of the school day
- Juneli is taken to see a witchdoctor, in the mistaken belief that he will be able to cure her
- NEA Vice President, Dr Hemav Rajbhandari, tutors 'Juneli' in advance of her feigning a seizure
- Against a dramatically beautiful backdrop, Juneli runs to tell her future husband that she has epilepsy



Opposite page, from left:

- Madhav and Juneli on their wedding day, with Juneli's parents and her sister-in-law

Photos courtesy of Nepal Epilepsy Association



zure during the wedding ceremony and is taken to hospital. This results in provision of appropriate treatment and medication and soon Juneli's life is turned around.

Later, as the film ends, Juneli, now in good health, visits her parents with her husband and baby daughter and is able to tell neighbours and relative how well she feels.

According to Nepal Epilepsy Association, this docudrama, highlighting epilepsy, is the first of its kind in Nepal and the association is hoping for great things when the film is released. There are also plans to disseminate the film internationally with the inclusion of English subtitles.

About the Promising Strategies Program

Introduced five years ago, in 2006, the IBE Promising Strategies Program (PSP) provides its less well off members with financial support for projects aimed at improving the quality of life of people with epilepsy. To date, PSP has supported 50 projects in 33 countries around the world, with total financial support in excess of US\$250,000. The most recent call for Letters of Intent, for funding in 2012, has recently closed.



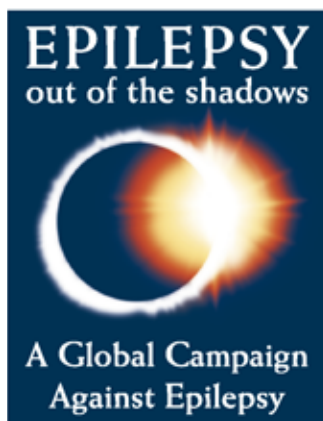
Global Campaign Project concludes in Georgia

Report by Hanneke deBoer, GCAE Secretariat



Main Photo: International symposium and workshop participants

Photo above: Georgia's national TV company interviews IBE President Mike Glynn. In the background is Otar Toidze, Chairman of the Committee of Health Care and Social Affairs of the Georgian Parliament



In 2005, Georgia's Government recognized epilepsy as a national problem and included its management in the primary health care system. In the same year, the Global Campaign Against Epilepsy was initiated in Georgia.

Studies in Georgia suggested that people with epilepsy are usually withdrawn from society, feel isolated and are either overprotected or neglected. Attitudes towards people with epilepsy are often negative and most people would object to their children marrying, or even playing with, a person with epilepsy.

In 2007 the *Epilepsy Management at Primary Health Care Level Demonstration Project* of the ILAE/IBE/WHO Global Campaign Against Epilepsy was launched in Georgia. The project was carried out in four main districts of Tbilisi. The epide-

miological survey covered over 100,000 inhabitants and educational, social and community interventions were performed throughout the entire population of the city. The project aimed at testing the feasibility of diagnosing and treating convulsive forms of epilepsy at primary health care level. The long-term objective was to integrate epilepsy management into the existing primary health care delivery system in rural and semi-rural areas of Georgia in a sustainable manner.

On 26 October 2011 a symposium was organised in Tbilisi to evaluate the results of the Demonstration Project after its completion and to mark its official closure. The symposium had over 150 participants, including national and international officials, Presidents of IBE and ILAE; a representative from WHO Headquarters in Geneva; the WHO Regional Advisor for Mental Health and Brain Disorders; the WHO country representative; members of the Demonstration Project International Working Group; officials from various ministries in Georgia; the Netherlands ambassador to Georgia; and neurologists from Georgia, Armenia and Azerbaijan.

Otar Toidze (Chairman, Committee of Health Care and Social Affairs of the Georgian Parliament) and Natela Okujava (President, Epilepsy and Environment Association of Georgia) opened the event. They discussed the Demonstration Project on Epilepsy Care in Georgia and revealed some of the results. Other speakers at the Opening Ceremony included: Deputy Minister of Labour, Health and Social Affairs; Deputy Minister of Education,



Conclusions

- A total of 10,326 people were screened; 1,859 people screened positive and were identified as possible cases, of whom 88 were established to have active epilepsy.
- The prevalence of epilepsy was higher than previously estimated and the treatment gap was substantial,
- There is a high level of mortality in the younger age group (15-19 years).
- 422 people are now benefiting from the intervention and are receiving subsidized anti-epileptic drugs.

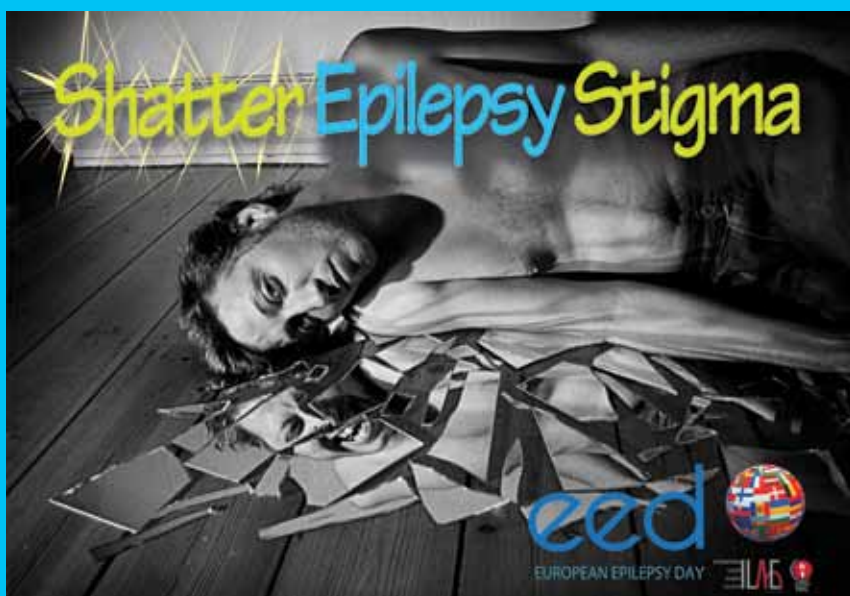
Science and Culture; Vice Speaker, Parliament of Georgia; Vice Speaker of the Academy of Sciences.

The ambassador of the Kingdom of the Netherlands to Georgia, Mr PJ Langenberg spoke about the indirect involvement of the Dutch Government in the Demonstration Project. He was very pleased to hear about the positive impact of the project on the Georgian health care system. In the main, participants were very positive about the results of the Demonstration Project and the progress in epilepsy care in the past four years in Georgia.

Other speakers included: Alfred K Njamnshi, who spoke about epilepsy and epilepsy care in Cameroon; Li Li Min from Brazil who discussed epidemiology and risk factors in Latin America;

Marco Medina from Honduras who presented on the Latin American strategic plan of action on epilepsy: a PAHO/ILAE/IBE Project for the Americas; Jerome Engel jr. from the US discussed epilepsy surgery; and Josemir Sander spoke about premature mortality in epilepsy. Finally Solomon Moshé introduced the International League Against Epilepsy; Mike Glynn introduced the International Bureau for Epilepsy; and Tarun Dua spoke about the World Health Organization.

The symposium was followed by a workshop the following day, during which the Principal Investigators of the Demonstration Projects in Brazil, China, Georgia and Honduras reported on the consequences, outcomes and lessons learnt from the projects in their respective countries.



European Epilepsy Day 2012

Monday 13th February

www.epilepsyadvocacyeurope.org

or

ibedublin@eircom.net for further details



Bulgarian Parliament addresses the call of the European Written Declaration on Epilepsy

Ann Little, IBE Executive Director, reports

I travelled on to Sofia at the invitation of Mrs Veska Sabeva, President of the Association of Parents of Children with Epilepsy (APДЕ), the IBE Full Member in Bulgaria to speak at a special Roundtable meeting organised by the association in the Bulgarian Parliament. This was a very significant meeting, attended by several important people, and was a direct result of the passing of the European Written Declaration on Epilepsy – which was referred to by almost every speaker. The purpose of the meeting was to seek the

implementation of the Written Declaration by the Bulgarian Parliament.

Among the special delegates attending was the Deputy Minister of Health of Bulgaria as well as representatives from other governmental departments. In opening the event, the Chair, Ms Desislava Atanasova who is Chairman of the Board of Health to the National Assembly), also welcomed the MEPs who were present at the event.

Dr S Bozhinova, Dr V Gergelcheva and Dr Rashev – members of the ILAE chapter in Bulgaria – presented on the medical side. Dr Lyubomir Dzhaleva a statistician from the main university in Sofia reported on a number of surveys conducted on behalf of APДЕ; Mrs Annette Marinova, a school teacher who spoke eloquently about the need to educate teachers on how to respond to a seizure in the classroom and on the recent government decision to introduce healthcare as a subject in schools. A parent also spoke movingly of the difficulties in accessing care, treatment and the enormous problems people in Bulgaria meet in continuity of supply

of epilepsy medication. Mrs Sabeva also spoke about the work of her association.

Speaking on behalf of IBE, I highlighted the European Written Declaration on Epilepsy; Epilepsy Advocacy Europe (the joint task force of IBE/ILAE), the European Advocates for Epilepsy Group in the European Parliament and the launch of the first European Epilepsy Day. It was also the opportunity to extend renewed thanks to the 13 Bulgarian MEPs (of a total of 17) who had signed the declaration.

The roundtable meeting was also attended by the National Ombudsman of Bulgaria, the CEO of the national umbrella organisation representing disability groups, the CEO of the national Alzheimer association and representatives from a number of other NGOs in Bulgaria.

There were also a number of parents who spoke passionately about the restrictions on healthcare and the high costs of accessing treatment, and on education and employment issues.

Following the presentations and a lively debate, which the Chair had great difficulty in bringing to a close, the Mrs Atanosova presented a summary of the discussion as a memorandum of concrete steps to improve quality of life of people with epilepsy in Bulgaria, which will be presented to the relevant ministers, including Health, Social Services and Education.

This was a very significant step in follow up to approval of the Written Declaration in September and IBE would hope that other Member States would also organise similar meeting with governments to ensure that the calls for action are addressed.



*Main photo: Bulgaria's Parliament Building in Sofia
Top left: Ms Desislava Atanasova, second from left, opens the Roundtable meeting
Left: A section of the participants who attended the event.*

My Dear Friends

As IBE's Golden Jubilee Year draws to a close, we share a letter sent by Patsy McCall to fellow Ambassadors for Epilepsy during the congress in Rome.

Patsy received an Ambassador for Epilepsy Award in 1978 and was IBE Executive Director from 1979 to 1985.



To my dear friends and colleagues who celebrate today as Ambassadors for Epilepsy - congratulations to all of you. May you and the world continue to be blessed by your efforts – and your creation – of a world without suffering from the causes and consequences of epilepsy.

Although I am sad today that I am not present on the occasion of IBE's 50th anniversary, I am inspired by all of your continued involvement. Some of you may recall that I was a novice in the epilepsy movement, having no personal or professional linkage until I was asked to write Florida's Five-Year Plan on Epilepsy.

To say that its completion catapulted my exposure to national and international involvement in the field of epilepsy is too simple a statement. It has taken me a lifetime to fully appreciate how such a small effort could become the driving force that continues to impact thousands of lives in our small state of Florida. I am privileged to have served as organizer and scribe.

Passionate individuals like Jack McAllister, Merle Evanchyk, Leo J Flannery and Dr B Joe Wilder - my first leaders - infused me with the inspiration and energy that got me started. Their stories and their commitment conveyed to me an element of loving need that moved me to think and organize in ways I had never experienced.

When I was invited to serve as Deputy Executive Director of the US National Commission on Epilepsy and its Consequences, new-to-me leaders like Dr J Kiffen Penry, Dr Richard Masland and Mrs Ellen Grass helped me to focus renewed attention on a

larger spectrum of care, diagnostic issues and research needs, and I continued to organize and to write.

The skill and attention to program needs that were shared with me by Nyрма J Hernandez, Presidential appointee to the Commission from Puerto Rico, continued to feed the passion that I had grown to love inside a worldwide movement.

Somewhere in the midst of these years, I met George Burden, Prof Harry Meinardi, Francesco Castellano, Prof Dieter Janz and an international romance with professionals, family members and people with epilepsy from more than 36 nations began for me.

I came to say that I spoke English in multiple dialects. Ultimately being blessed by marriage to Francesco, I learned another language and came to call Italy my home and Dr Raffaele Canger a family friend.

For many years Hanneke de Boer was my teacher and my friend and I can never repay her for either her time, hospitality or the experiences we shared – including her car. The wonderful Joop Loeber was my mentor through thick and thin. There hasn't been one week in the past 25 years that I haven't thought of some of you. Within the first year of my absence from the international movement, my professional relationship with epilepsy became a personal one. My brother was diagnosed and I am proud to say that, although he called me for advice and one referral, with his wife's loving care he handled the loss

and re-licensure of his driving privileges and continues to work with minimal medication side effects with dignity.

My husband has a condition which his physician refers to as a type of seizure disorder not yet fully recognized by the neurological community. The brand names of several anticonvulsants stock our medicine chest. Five years ago, the younger of my two sons died due to complications of a brain injury. I came to suspect a pattern of seizures from his description of nightly events that were physically painful.

I credit a universal being, whom I choose to call God, with any contribution I am able to make toward our commitment to have a world without suffering from seizures. May you all be blessed. I wish I could have been with you tonight.

Future Congresses 2012



**9th Asian Oceanian
Epilepsy Congress**
Manila, Philippines
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



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