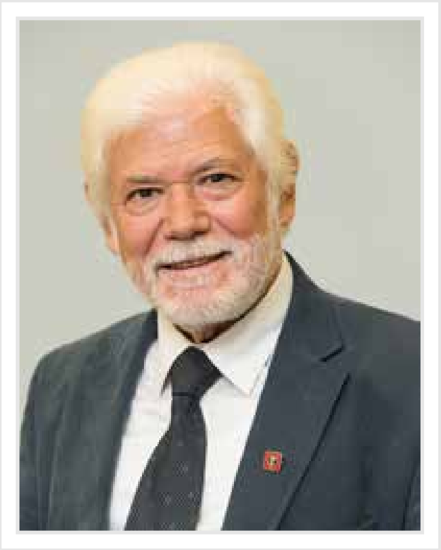
NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 4 2015

INTERNATIONAL Epilepsy News 1963-2015

Reporting epilepsy news for **52** *years*

Hanneke de Boer
1946-2015

PRESIDENT'S LETTER



A sad moment for IBE

Dear Friends

I was shocked and saddened to hear about Hanneke's death October 12th, 2015. We knew the seriousness of her health but she was always reporting back that her health was getting better. The last few months of her life she decided to have progressively less contacts with all of us and peacefully died at her house.

I met Hanneke in the early 90's and I was impressed with her ability to communicate and her innate skills in the organization of time and space. She was down to earth and her company pleasant, constructive with an integral humor part of her make-up throughout.

To many worldwide she was known for her spoken presentations and lectures, given with great clarity and effect. She was able to pass any message in simple and understandable English for everybody. She was one of the best IBE advocates that had committed her life to improve awareness, education, care of PWE in order to reduce their treatment gap and improve their quality of life.

She was serving as the past President of IBE when during the International Epilepsy Congress in Buenos Aires in 2001 she approached me to ask if I would like to be actively involved with IBE. Since then our contacts had become frequent either for various IBE business meetings or to bilateral invitation to congresses for speeches, all to stress important issues for people with epilepsy and how to improve quality of life, including protecting their rights in education, employment, driving and social activities.

During those years Hanneke chaired the European Commission, subsequently European Regional Committee, and co-chaired EUCARE and played an important role in the publication of White Paper on Epilepsy.

The activity that she was emotionally involved was the Join ILAE/IBE/WHO Global Campaign against Epilepsy-Out of Shadows launched in 1997 in Dublin and continued until recently under Global Outreach Task Force. She was proud to talk about the demonstration projects particularly those in China, Georgia and Latin America. Hanneke's collaboration with WHO was excellent and played an important role in creating the documents referring to Epilepsy Care in the WHO Regions of the World.

It was always a great pleasure working with her. I was welcome to her house and she was welcome to my house. She was keen to cook. I enjoyed the special soup blending with special wine under the strict observation of the boss-cat. She enjoyed coming to Greece and we do have wonderful memories.

This is more than an obituary for Hanneke. It is also an appreciation, a dedication, indeed an attempt at a celebration of the remarkable individual that began the venture within the epilepsy community some years ago when she dedicated her life to accomplish the vision and mission of IBE.

We will all miss her but she has deeply registered in our brain as a wonderful memory.

With best wishes to all,

Athanasios Covanis
President

IBE
International Epilepsy News
Issue 4 - 2015

INTERNATIONAL RELATIONS AND PARTNERSHIPS

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

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

CoNGO
IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA
IBE is a member of the European Federation of Neurological Associations (EFNA).

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Dear Readers

On 12 October, IBE received the news that Hanneke de Boer, one of IBE's longest serving advocates had died. Although many of us knew that she was unwell and not expected to recover, the news was still hard to believe.

In this issue we include an obituary for Hanneke. For almost 30 years, she devoted her life to IBE, during which time she met countless people in every region of the world, each one of whom she touched with her energy, her drive and her determination to get things done. We have also tried to include as many photos of Hanneke's time with IBE and we hope that you will enjoy them and remember her with a smile.

We also say goodbye to another supporter of the Bureau, Christoph Pachlatko, who died suddenly later in October.

But life moves on, and the magazine also brings news of new initiatives. There is the Photo Competition as part of International Epilepsy Day celebrations; a report on the EU funded ESBACE project; and reports from meetings in Italy and Ghana.

Held back until next time, due to pressure of space, is the next instalment of the history of ILAE, as documented by Ted Reynolds. Instead, Ted has shared with us his collaboration with Hanneke on the launch of the Global Campaign Against Epilepsy.

Until next time - good reading,

Ann Little
Editor

Coming in the next issue

International Epilepsy Day
epilepsy.org

Getting ready for 2016

IN MEMORIUM Hanneke de Boer 1946-2015

On Monday 12th October, following a long illness, faced stoically and with great dignity, Hanneke de Boer passed away peacefully in the tall narrow house that she loved and which had been her home for almost 30 years. A light was extinguished on a life that had been devoted to epilepsy since she first joined SEIN (Stichting Epilepsie Instellingen Nederland) in 1965. Hanneke was truly one of the greatest and longest serving advocates for people with epilepsy – not only in her beloved native Netherlands, but right across the world. Her entire life was devoted to the cause of epilepsy.

Hanneke was a young girl when her parents divorced. While she continued to live with her mother, her brother and father move some distance away to another part of the Netherlands. For many years after that, she saw her brother and father only rarely. For someone who has such a talented ability to make friends and who loved being in the company of others, this cannot have been an easy time.

Hanneke was born in 1946 and was just 19 years old when she first went to work as a trainee vocational consultant with SEIN at the Meer en Bosch centre in the picturesque town of Heemstede. It was to be a lifetime career and, while she spent a while at the epilepsy centre in Chalfont in the UK in the 1970's, she would remain employed by SEIN until shortly before her death, a half-century after her work had first begun. Hanneke's main interest was in empowering people with epilepsy to find gainful employment by working with both people with epilepsy and potential employers. However, hers was always the personal touch, and it was not unknown for her to provide 'out of hours' support to those struggling with their education courses.

The IBE office moved from the UK to Heemstede in the early 1980's and while the main office moved to Dublin in 1997, a support office remained in place at SEIN until about 2004. Hanneke first became involved with IBE when she was appointed Chair of the Employment Commission in 1983. She became Editor of IE News in 1985, making her a member of the Executive Committee. She served as Secretary General from 1989 to 1993, as President from 1993 to 1997, and as Past President from 1997 to 2001.

Even after her time on the board, she still continued to be involved in assisting the Heemstede office until it closed.

She received the first international award to recognise her service to people with epilepsy in 1987 when she was named an IBE/ILAE Ambassador for Epilepsy and at the 26th International Congress in Paris in 2005 she was awarded the IBE/ILAE Social Accomplishment Award.

The greatest of the IBE/ILAE awards - Lifetime Achievement - was bestowed on her at the Opening Ceremony of the 28th International Epilepsy Congress in Budapest 2009. Those who were present on the night will have seen Hanneke filled with pride and joy as the announcement of her award was met with prolonged noisy applause.

Her dedication to epilepsy was also recognized at national level in the Netherlands. She received the Award of the Christian Society for the Care of People with Epilepsy in 1982, was awarded the Spike and Wave award of the Dutch Branch of ILAE in 1997, and was inducted as an Officer of the Orange Order of Nassau by the Royal Dutch House. This is one of the highest awards presented in the Netherlands and is rarely given. To mark the occasion, many friends and colleagues travelled to Amsterdam for the awards ceremony and a surprise souvenir book containing photos, messages and anecdotes provided by friends was created to mark the occasion and given to everyone on the day.

During her time on the IBE Executive Committee she was involved in the organisation of several international congresses: Israel (1987), India (1989), Brazil (1991), Norway (1993), Australia (1995), Ireland (1997), Czech Republic (1999) and Argentina (2001). She was also on the organizing committee of the European Congress on Epilepsy & Society in Italy (1988), Ireland (1990) and Scotland (1992), and was a speaker at many more.

It was during a holiday in the Scottish Highlands following the 1992 congress in Glasgow that Hanneke was to have an accident that would seriously damage her ankle, an injury that would have lasting effects on her ability to walk normally.

For many years she chaired the IBE European Commission, which would later be renamed as the European Regional Committee (EREC) following the adoption of IBE's new Constitution in 2005, which introduced IBE's seven regional structures.She was co-chair of EUCARE (European Concerted Action and Research on Epilepsy) from 2001 until 2009, chairing the Patient Advocacy Group sub-group, which played a major role in the publication of the European White Paper on Epilepsy in 2001. EUCARE was restructured in 2009 and is now the joint task force on epilepsy in Europe of IBE and ILAE - Epilepsy Advocacy Europe.

However, the achievement of which she was most proud, and in which she devoted almost 20 years, was the ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the shadows.' The campaign was launched Dublin and Geneva in 1997, right at the end of her term as IBE President, an initiative in which Hanneke and (then ILAE President) Ted Reynolds had worked so tirelessly to introduce.

She was a co-chair of the Global Campaign for many years, later becoming Secretary of Global Outreach in 2009 and a member of the Global Outreach Task Force in 2013. Within the work of the Global Campaign were efforts to close the treatment gap, which was achieved to a tremendous degree in China. Without doubt, the Global Campaign will be her lasting legacy. She never fully retired from her work and, until recent months was still a member of the Global Outreach Task Force and Chair of the IBE Legislation Task Force.

It would be an injustice to measure Hanneke's life by means of congress committee membership or by way of the many commissions she sat on or workshops she organised. Her dealings with people were much more personal than that. She travelled extensively throughout her time with IBE and had a particular interest in supporting people with epilepsy in Africa.

She also travelled to China on many occasions and played a major role in SEIN's application to become a WHO Collaborating Centre, in which it works closely with the China Association Against Epilepsy. We must also mention Georgia, where Hanneke greatly supported an ILAE/IBE/WHO Demonstration Project over a number of years. Latin America was another region in which Hanneke took an interest, in particular in Chile and Colombia. She spoke in the parliament in Colombia to support efforts to introduce employment legislation to protect people with epilepsy.

Hanneke had tremendous energy and drive. There was never a locked door to which she would not eventually find the key and her will to improve the quality of life of people with epilepsy around the world was unfailing. At the same time, she had great diplomatic skills, which were very evident in her close working relationship with WHO.

Outside her work, Hanneke was an excellent host. The door to her home in Haarlem, where she lived with her beloved cat, was always open. Countless people whom she will have met during her work, from all corners of the world, were made welcome. She would drive guests to her lovely home, reversing up the very narrow dead-end street while the cat watched from the tall front window. She loved to cook and she loved a glass of red wine and, most of all, she loved to share these with her guests.

While she may have travelled to every corner of the world, Hanneke was a true Dutch national. She always celebrated the Queen's (now King's) Birthday. Orange is not the easiest colour to carry off in an outfit yet Hanneke would wear it with aplomb even if that meant arriving at a meeting in a foreign city should the day fall when she was travelling. She was also a great ambassador for Dutch cheese!

Her past-time was her garden, a small space that she crammed with pots and plants full of colour all year round. In true Dutch style, she also decorated the pavement outside her hall door with more plants and garden ornaments while, indoors, windowsills housed the healthiest of houseplants among the scores of little blue and white KLM Dutch houses that she collected.

In more recent years she began to see her brother more often and built a strong friendship with her niece, creating the family network that she didn't have as a young girl. Towards the end of her life, her niece moved in to Hanneke's home to help care for her in her final days.

Hanneke dealt with her illness quietly and privately and so it was with some shock that we learned that her time was limited. There wasn't the opportunity to say good bye but there are thousands of memories of difficult situations settled with diplomatic flair, of great achievements and successes due to long hours of hard work, of small kindnesses that meant a lot, and, above all, of laughter.

She will be deeply missed.

From left: Sofia Kasradze (Georgia), Natela Okujava (Georgia), Hanneke, Ley Sander (SEIN) and Tarun Dua (WHO) in Tbilisi, Georgia in 2009

Hanneke:
A busy life remembered in images

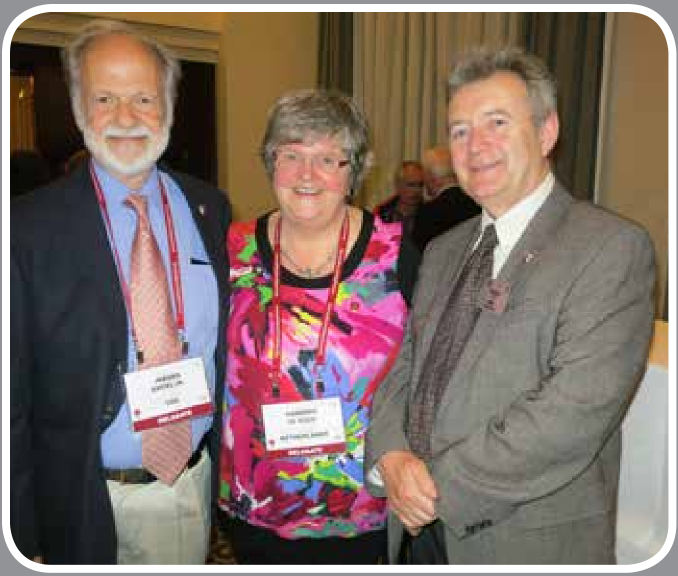


Photo captions, by column, from left column opposite page

- Front row at an IBE Committee meeting, Heemstede 1990
- Receiving her Ambassador for Epilepsy Award, 17th Epilepsy International Congress, Israel 1987
- Attending the 1st Latin American Epilepsy Congress, held in Santiago de Chile 2000
- As Past President, at the Spring Meeting of the Executive Committee, Basel, Switzerland 2002
- Enjoying a Swiss fondue dinner during the Spring Joint IBE/ILAE Executive Committee meeting, Switzerland, 1986
- At her desk at SEIN in Heemstede with a backdrop of Global Campaign framed resolutions and posters, 2006
- Meeting of EUCARE, held in France, circa 2008
- Epilepsy Day event at the IBE chapter in Cartagena, Colombia at the time of the Latin American Epilepsy Congress 2010
- Ceremony to celebrate present and former IBE and ILAE Presidents, 2nd African Epilepsy Congress, Cape Town 2014
- With Pete Engel and Richard Holmes, who were ILAE and IBE Presidents when Hanneke was Past President
- Planning meeting on proposed PAHO Strategic Plan for Epilepsy, Cartagena 2010
- With Sebastiana Nkomo, WHO AFRO Regional Advisor for Mental Health, epilepsy training event in Accra, 2013
- At 13th European Conference on Epilepsy & Society Conference, Ljubljana, Slovenia 2013. This was the last IBE conference attended by Hanneke

Personal tribute to Hanneke de Boer

In place of the planned instalment of the History of ILAE, Ted Reynolds shares with us his personal memories of Hanneke de Boer, spanning 25 years

It was my privilege to know and collaborate with Hanneke de Boer for 25 years from 1989 to 2014. We worked particularly closely when we were Presidents respectively of ILAE and IBE from 1993 to 1997 and thereafter in promoting the ILAE/IBE/WHO Global Campaign from 1997 to 2014. All the Officers of ILAE and IBE that I have met over those years were committed to the objectives of the League and the Bureau on behalf of people with epilepsy, but none more so than Hanneke.

Hanneke's dedication to promoting the needs and advancing the hopes and aspirations of people with epilepsy and their families by personal and collective action is testified, not only by her track record, but also by my personal observations and reflections.

At a professional level she had an extraordinary capacity for detailed attention to agendas, priorities, plans of action, and minutes. But implementing such actions and goals required considerable diplomatic and social skills, which she combined with a steely determination.

In a large joint Executive there can be, at times, one or two dissenting voices, but during our joint Presidency relations between the League and the Bureau were excellent, in large measure due to Hanneke's patient and diplomatic attention to everyone's point of view and her persuasive powers of keeping everyone on board.

Notwithstanding early family adversity, Hanneke had a kind, friendly and generous nature. Wherever she travelled in the world she arrived bearing Dutch gifts, mostly from the workshops of SEIN. Our garden now includes Dutch bulbs and the house is adorned with several multi-coloured boxes and candles to remind us of Hanneke and her friendly visits. When our first granddaughter was born 7 years ago Hanneke promptly sent us a pair of baby clogs, which was typical of her generosity. Many of us felt we were part of her wider family circle.

At the launch of the 2nd Phase of the Global Campaign Against Epilepsy, Geneva 2001, from left: Ted Reynolds, Gro Harlem Brundtland, Hanneke and Pete Engel

Hanneke was also courageous. It is not always easy to travel the world as a single lady, however eminent. In some new countries you never know what sort of reception awaits. We flew together to Riyadh at the invitation of the first Pan Arab Epilepsy Congress, in my case accompanied by my wife, Angela. No woman is allowed to enter Saudi Arabia without her husband or an approved male escort and the designated Saudi male escort was not there to meet her. Hanneke's passport was therefore confiscated for several hours while we waited for another male escort to arrive. Martin Brodie was on our flight and could have accompanied her into Riyadh but he was not her husband! Hanneke was then whisked off to a separate hotel from the rest of us. When we met her the next day she told us she had already had an offer of marriage from a member of the hotel staff!

Hanneke was not a revolutionary, but she was cautiously open to new ideas. She was initially sceptical of my proposal for a Global Campaign, fearing it would undermine the finances of IBE, which were less healthy than those of ILAE. But once persuaded of the merits of the concept, she became the most persistent and vocal advocate of the Campaign, which benefitted enormously from her detailed planning skills and determined diplomacy.

We had great fun together, assisted by many colleagues, developing and launching the Declarations on Epilepsy in five different continents between 1998 and 2000. This culminated in the 2nd Phase launch of the Campaign in Geneva in 2001 supported by the new Director General of WHO, Dr Gro Harlem Brundtland whose speech on that occasion was, I think, a milestone in the social history of epilepsy.

Numerous planning visits to Geneva and elsewhere also resulted in a very close friendship between Hanneke and Leonid Prilipko, WHO's Campaign leader, which sadly ended prematurely with Leonid's untimely death. Nevertheless Hanneke continued her enthusiastic advocacy and global travels on behalf of the Campaign, with more sedentary, mainly literary, support from myself as we undertook various Reports, most recently in 2014.

I never saw Hanneke display anger, however frustrated by obstinate colleagues; and she could occasionally be obstinate herself. In the face of unresolvable divergence of views, one of her techniques was to withdraw from communication. But she always soon emerged as her usual friendly self, often with some new approach to the problem. However, when she faced her final challenge she again withdrew from her numerous concerned colleagues and friends, sadly not to re-emerge, but leaving us full of admiration for her life, career and legacy, almost wholly devoted to the care of people with epilepsy at the local, national and international level.

Latin American Day of Epilepsy

On 19th of September, the IBE chapter in Brazil - Associação Brasileira de Epilepsia, in collaboration with the Brazilian League of Epilepsy (Liga Brasileira de Epilepsia) and the Brazilian Academy of Neurology (Academia Brasileira de Neurologia) hosted an event to raise awareness for epilepsy at the Ibirapuera Park in São Paulo city.

In celebration of September 9th, the Latin American Day of Epilepsy, the event facilitated a conversation between neurologists, patients and the general public.

"The idea is to overcome the stigma that people with epilepsy can't participate in sports. Exercising is beneficial and, according to some studies, actually reduces the frequency of seizures," explained doctors present. Events included Capoeira - a traditional Brazilian dance, an awareness walk, educational stories for children, and face painting.

The event was a way to further educate the general public about epilepsy, so that the prejudice that exists against people who suffer from epileptic seizures can be overcome.

Edycs Epilepsy Group visits Indian Epilepsy Center

Youssouf Noormamode (pictured third from left), President of Edycs Epilepsy Group Mauritius and Chair of the IBE African Regional Executive Committee, recently visited the Indian Epilepsy Centre in New Delhi and met with Dr Satish Jain, Director and President of the Indian Epilepsy Association. They discussed mutual concerns on epilepsy care and shared experiences on efforts to assist people with epilepsy in India and Mauritius. Discussion also focused on developing joint venture programs in training medical professionals in the management of the disease.

Mr Noormamode also attended the International Workshop on Resource Mobilization, organised by the Resource Alliance from 24th to 27 August 2015. The International Workshop programme included inspirational plenaries, masterclasses, workshops and fund raising clinics and was attended by 175 international delegates.

Before departing for Mauritius, Mr Noormamode also met with Dr Gupta, Chairman of International Respect Age, based in Agra.

YES
I can!

PHOTOGRAPHY COMPETITION

YES, I can!

Announcing a photography competition for International Epilepsy Day 2016

Photography used to be regarded as a hobby, with cameras taken out of their cases to capture special occasions. In recent years taking a photo (or numerous photos) has become part of everyday life.

With the invention of the smartphone, photos of friends and family are taken at a frightening rate. With the Selfie came the immense explosion of photo-sharing on Facebook, Instagram, Twitter and Whatsapp (to name but a few). Today, photography has never been so prolific.

However, despite the 'point and click' ease of the smartphone, taking photographs using regular camera equipment has not disappeared. If anything, it has become even more popular. A growing number of people now are investing in expensive photographic equipment and joining classes and clubs to hone up on their skills. Flickr is their destination of choice for sharing prized images.

For International Epilepsy Day 2016, we are pleased to announce a photography competition with the theme 'Yes, I can', to demonstrate achievement in overcoming obstacles, or achievement despite obstacles. The best photographs will form the International Epilepsy Day exhibition, taking place in the European Parliament in Strasbourg from Monday 1st to Friday 5th February 2016.

All entries will also be placed in a gallery on the International Epilepsy Day website epilepsy.org.

Two prize categories:

1. Photos taken with smartphones or tablets
2. Photos taken using regular cameras

The prize winner in each category will receive US$1,000.

Competition rules

- Photos should reflect "the feeling of achievement"
- Photos must be include the hashtag #epilepsyday in some way (e.g. written or printed on a card or you might think of a far more artistic way to include the hashtag)
- Photos must be submitted by email to ibedublin@eircom.net
- Photos should be a minimum of 1MB and preferably 300dpi (in particular for photos taken using regular cameras)
- Photos may be taken using a regular camera, phone or tablet
- Entrants must provide their name, address, age (if under 21 years) and email address
- Each entry must be entirely the original work of the contestant, must have a title (in English) and indicate the location in which it was taken
- Any person included in a photo must have given their express permission to be photographed and for the photo to be shared
- By submitting a photograph to IBE the contestant agrees to grant IBE, free of charge, the right to publish the photograph online, in other IBE media, and as part of a photographic exhibition in the European Parliament in Strasbourg (1st – 5th February 2016)
- Closing deadline for entries is 10th January 2016 and all entries must be submitted electronically
- The winning entry will be announced on International Epilepsy Day – 8th February 2016
- Entrants under 16 years of age, must obtain your parent's or guardian's permission before entering the competition
- There is no limit on the number of entries a contestant may submit
- The judges' decision is final and no correspondence will be entered into
- IBE reserves the right to disqualify any entry which breaches any of these rules

DEADLINE FOR ENTRIES: 10th JANUARY 2016!

ESBACE Improving the life of people with epilepsy: A European Perspective

BACKGROUND

In 2013, Epilepsy Alliance Europe, a joint task force of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) held a workshop in the European Parliament in Brussels to highlight the need for a European-wide study on prevalence rates of epilepsy, using appropriate and standarised methodology.

It was reported that 66 studies on the prevalence of epilepsy in European countries had been published in English, which presented conflicting data, mostly likely due to methodological differences and shortcomings. Reliable cost estimates depended, among other things, on accurate data on the prevalence rates of epilepsy. The definition of epilepsy also varies across studies and the methods to ascertain epilepsy cases are also highly variable.

A sub-task force created by Epilepsy Alliance Europe pointed up that the prevalence and cost of epilepsy in Europe was a field with major knowledge gaps, which should be addressed urgently. Obtaining reliable information on the issue is essential for the rational allocation of resources to ensure adequate and cost-effective epilepsy care across Europe.

In response to a Call for proposals for a prevalence research project, issued in June 2014 by the European Commission Directorate-General for Health and Food Safety, the ESBACE project was successfully submitted.

ABOUT THE PROJECT

The general objective of the pan-European research project, **ESBACE** (European Study on the Burden and Care of Epilepsy), is to facilitate the development of high-quality epilepsy care at all stages of the disease, equitable across EU countries. **ESBACE** will provide data on the burden of epilepsy and on current provision and organization of care in selected EU member states.

ESBACE has established a consortium of 10 centres as associate partners, with a further 9 collaborating centres to drive this project.

The specific objectives of **ESBACE** are as follows:

1. Provide data on the prevalence of epilepsy in European countries
2. Provide information on the cost of epilepsy in European countries
3. Provide information on the stigma and quality of life of people with epilepsy
4. Provide information on the coordination of services for patients with seizures, through an audit that ascertains patients attending emergency services
5. Provide an update on provision and organization of epilepsy care in Europe
6. Disseminate to health care providers and decision makers information on the burden of epilepsy in Europe, and of deficiencies as well as examples of good quality care

In accordance with the tasks set in the by the Commission (Commission decision 4319), **ESBACE**'s first objective is to define appropriate standard methods for a population-based study of prevalence, cost and stigma of epilepsy, and also to survey organization and quality of epilepsy care.

As a second step **ESBACE** will apply the methods to assess prevalence, cost, and stigma of epilepsy in four member states, selected to represent different types of regions in Europe. To assess epilepsy care, **ESBACE** will study patients attending emergency services and assess their prior, acute and onward care pathways in these same countries.

Examples of good care will be identified. The project will also undertake a survey of the current epilepsy care, resources and organisation, across all member states. The data will inform appropriate resource allocations aiming at equity in access to good quality epilepsy care across the EU.

Methods and means

Ireland, Denmark, Austria, and Romania have been selected as representing different regions of the EU. In all, a population-based study to identify patients with epilepsy will be carried out in a representative region through systematic search at general practitioners, hospitals and other relevant institutions. Potential cases will have their epilepsy diagnosis validated by the research group, the type of epilepsy classified, and comorbidity recorded.

In Ireland and Denmark, the epilepsy prevalence will also be determined for the same study populations through utilization of National Drug Prescription and Health Care Registries.

For the cost study, the patients with epilepsy will be grouped into three categories:

1. recently diagnosed;
2. epilepsy in remission;
3. chronic epilepsy non seizure free.

Controls matched for age and sex will be selected from the general population, and epilepsy cases and controls followed for one year to determine direct and indirect costs. These data will be compared with cost estimates based on National Health Registers in Denmark.

Stigma and Quality of Life (QoL) will be assessed in every epilepsy patient using stigma and QoL inventories translated to the local language.

We will undertake an audit of the care of patients, ascertained following attendance at emergency departments at hospitals, in the four chosen regions. This will allow assessment of care pathways for patients with new and established epilepsy, and of the coordination of care across sectors including emergency services, neurology and primary care, using the same methods as the UK National Audit of Seizure Management in Hospitals *www.nash.org*, which collected data from around 150 hospitals.

An updated questionnaire, that was used 15 years ago to survey provision of epilepsy care in Europe, will be distributed to all ILAE chapters of the EU member states.

Expected outcome

ESBACE will deliver new information on the prevalence of epilepsy in four EU states from different regions and with different resources and health care. This will reveal if there are significant differences in the prevalence of epilepsy.

ESBACE will provide a comparison of prevalence estimates using different methods and thereby demonstrate if the burden of epilepsy can be assessed through data generated from national health registries, which in that case could be a recommendation for sustained monitoring.

- The seizure management audit will provide information on how services are coordinated and delivered, as well as comparative information on the quality of care.
- The data on stigma can be used for educational activities and public campaigns.
- The survey of epilepsy care will identify deficiencies to be corrected as well as good examples to be followed.

Project Partner

Aarhus University Hospital, Aarhus, Denmark

Associate Partners

1. University College Dublin, School of Psychology, Dublin, Ireland
2. Karolinska Institutet, Stockholm, Sweden
3. Christian Doppler Klinik, Salzburg, Austria
4. Universitatea de Medicina Si Farmacie "Carol Davila", Department of neurology, neurosurgery, psychiatry and child and adolescent psychiatry, Bucharest, Romania
5. Umea University, Umea, Sweden
6. Glostrup Hospital, Department of Clinical Neurophysiology, Glostrup, Denmark,
7. University of Liverpool, United Kingdom
8. University of Gothenburg, Gothenburg, Sweden
9. ILAE/IBE Congress Secretariat, Dublin, Ireland

Collaborating partners

1. Beaumont Hospital, Dublin, Ireland
2. St. James's Hospital, Dublin, Ireland
3. Cardiff University, School of Medicine, Cardiff, United Kingdom
4. Danish National Institute for Local and Regional Government Research, Copenhagen, Denmark
5. Dublin City University, Nursing and Human Sciences, Dublin, Ireland
6. The Children Hospital "Agia Sophia", Athens, Greece
7. University Hospital of Coimbra, Coimbra, Portugal
8. Dept of Neurology, Vilnius University Hospital, Vilnius, Lithuania
9. AstraZeneca AB, AstraZeneca Nordic-Baltic, Södertälje, Sweden

WWW.ESBACE.EU
European study on the burden and care of epilepsy
Funded by the European Commission Directorate-General for Health and Food Safety
Contract No. 2014/1/1995648

Think Tank on Epilepsy Research FIE workhop in Ferrara

Report by Francesca Sofia, Federazione Italiana Epilessie

Above: Francesca Sofia, FIE, Michele Simonato, University of Ferrara and Coordinator of EPIEXCHANGE and Philippe Ryvlin, Co-chair IBE/ILAE Task Force on Epilepsy in Europe
Below: Delegates attending the event in Ferrara (left) and Sari Tervonen, IBE Secretary General (right) speaking at the workshop

To mark the final meeting of the EU funded project EPIXCHANGE, Federazione Italiana Epilessie (FIE), organised a wide-ranging scientific meeting. In collaboration with Michele Simonato, coordinator of EPIXCHANGE, FIE created an innovative programme that took place in Ferrara, Italy in October 2015. The meeting entitled "Epilepsy Research in the EU: state of art and opportunities for the future", gathered together all the major EU-funded research projects specifically focused on epilepsy, advocacy organisations from Europe and beyond, professional societies, EU officers and pharmaceutical companies, becoming the first European-wide forum on epilepsy research of this kind. By putting together all pieces of the epilepsy research puzzle and involving all stakeholders in the discussion on its future, the organizers aimed to build a common framework for epilepsy research in the EU and to define the next strategic moves.

The combined total of funding granted to the projects represented in Ferrara was in excess of 70 million euro and involved dozens of laboratories in Europe and further afield, as well as biotech and pharmaceutical companies. The overall scientific picture that emerged was encouraging. Indeed, the EPIXCHANGE, EpiTARGET, EpiSTOP, EPImiRNA, DESIRE and EpiPGX projects cover all current major topics of epilepsy research.

From biomarker identification to the study of non-conventional strategies for therapy development, these projects are increasing our understanding of epileptogenesis and paving the way for new potential treatments, as demonstrated by the wealth of scientific papers being published.

However, during the meeting, it was argued there is still a huge gap to be filled between basic research results and their clinical applications; that we need to find new research methodologies and new measures of success - beyond papers - that enable the delivery of results to people with epilepsy.

Likewise, we need better support for epilepsy research as emphasized by Emilio Perucca, President of the International League Against Epilepsy, who pinpointed the paucity of current research funding as the most concerning hurdle along the path-to-the-cure of epilepsy.

Despite the fact that epilepsy is among the most prevalent neurological disorders, funds for research are dramatically inadequate with recent analyses that places epilepsy at the bottom of research funding in a comparison with many rarer CNS diseases, such as Parkinson's disease or Multiple Sclerosis.

Sari Tervonen, IBE Secretary General, also emphasised the need for better support for epilepsy research through increased funding and awareness. This is in line with IBE's Strategic Plan, one of the goals of which is to promote prevention and research focused on care and treatment of epilepsy and its consequences worldwide.

The need for greater long-term planning was also highlighted: many European consortia have built significant results and infrastructures (i.e. patient registries, biosample collections, research platforms, etc.) whose preservation and further development are impaired when funding is terminated. Finally, fragmentation of efforts and lack of collaboration are factors that diminish our capacity as a community to make a strong point for epilepsy research at public and policy levels.

In point of fact, the meeting in Ferrara provided a unique setting to begin harmonizing research efforts into a coherent framework on which public institutions and funders will be solicited to take action. In this process, the involvement of people with epilepsy would be crucial in order to reach policy-makers, funders and the general public.

Sharing the same vision, IBE and ILAE are speaking with one voice, stressing that epilepsy must be presented externally as one disease while, on the other hand, symptoms, etiology, syndromes and treatment options etc. should be addressed separately within the epilepsy community. It was recognized that people with epilepsy could provide the means for setting priorities, establishing new impact measures for research and, in general, promoting new methodologies; provided they are enabled to access information and acquire solid scientific citizenship. The meeting went exactly in this direction allowing people with epilepsy, not only to take part in its conception and design, but also, to bring some crucial questions into focus.

In this perspective, it was an opportune that pharmaceutical companies attended the meeting and were able to explain the reason for the shortage of investment in the development of new drugs for epilepsy, and to indicate what would be needed to achieve a new value proposition with a high likelihood for successful execution of research and development in epilepsy.

In summary, the take home messages all pertained to the strategies that would enable us to clear the hurdles on the path-to-the-cure of epilepsy.

TAKE HOME MESSAGES

1. Solicit increased and long-term support for epilepsy research
2. Improve research methodologies and measure of success to fill the gap between basic science and clinical development
3. Present epilepsy to the community at large as one disease
4. Make science accessible to patients: patient empowerment and scientific citizenship
5. Give voice to patients and involve them in the definition of the research agenda

FIE, an Associate Chapter of IBE, is an umbrella organization of 24 associations across Italy. Sharing goals with its member associations, FIE coordinates and addresses their activities and provides a common framework and vision. Recently, it has embraced a mission to become a strong advocate for epilepsy research.

In Memorium

Christoph Pachlatko

1956 - 2015

On 24 October, Christoph Pachlatko died suddenly at the age of 59 years. He was born in Basel, one of a family of five brothers. From a young age his vocation was to serve others without personal interest. He married Claudia, a university professor of music, and they adopted two Colombian children.

He studied both theology and business and received a doctorate in economics from the University of St. Galen with the intention of providing comprehensive care for people with epilepsy, based on ethics and economics.

Soon after he began working at the Swiss Epilepsy Centre in Zurich he was made General Director and devoted his, too short. career to caring for people with epilepsy. With an excellent group of collaborators, he managed to develop a world standard model institution.

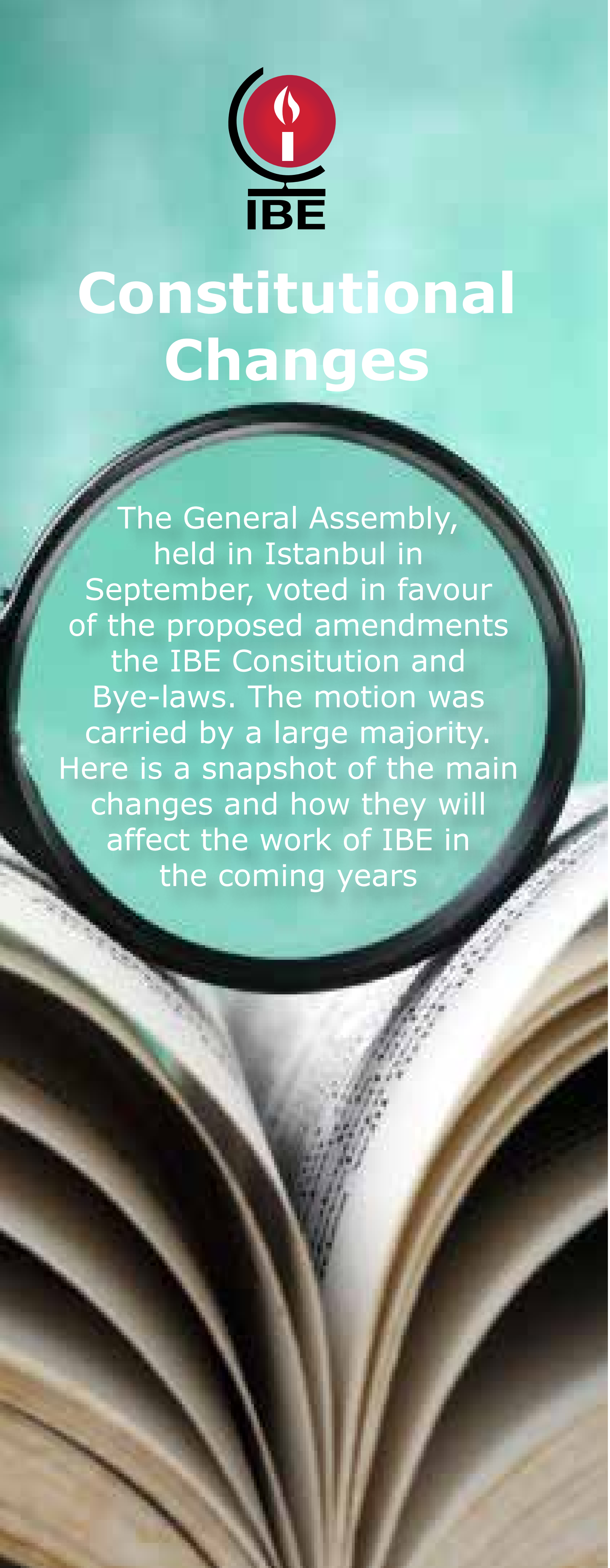
His greatest strength as a leader was to unite the two disciplines that he continuously cultivated - ethics and economics - for the benefit of the patient. "Economics and ethics complement each other. However, this will only be the case if economic and ethical considerations pursue the same goal: that of helping the patient." With this statement he leaves his main legacy for epilepsy: never be separated from the pure ethical traditions of the people.

But his work was not only dedicated to Switzerland. Together with John Annegers, Roy Beran, Richard Holmes, Birthe Pedersen, Anfré Perrot and Simon Shorvon, he founded the ILAE Commission on the Economic Aspects of Epilepsy. He published several books as editor on the costs and economic evaluation of epilepsy.

Chistoph soon realized that his work had no frontiers and with several visits to Colombia, found that the support of the Swiss centre should be directed to FIRE (Colombian Foundation Centre for Epilepsy and Neurological Diseases) in Cartagena, to link symbolically all of Latin America. For 15 years he aided the foundation with orientation, advice and economic help, seeing this as a way of following his ethical vision. Before long a young neurologist undertook an internship at the Swiss Epilepsy Centre. And so began his legacy at FIRE.

Elsewhere, this time in Togo, in Africa, his personal enthusiasm led to Swiss Epilepsy Centre support in the creation of an epilepsy centre in Lomé. There, he also turned his enthusiasm and life philosophy to create a model for Africa.

All men go, but their legacies remain. In Christoph's case, this was achieved in spades. We must strive to equal his example. *JFF*



IBE

Constitutional Changes

The General Assembly, held in Istanbul in September, voted in favour of the proposed amendments the IBE Consitution and Bye-laws. The motion was carried by a large majority. Here is a snapshot of the main changes and how they will affect the work of IBE in the coming years

Membership Title

- Full Members become Chapters - a reversion back to the title used prior to 2005.
- Associate Members become Associate Chapters.
- Applicant members, will become Full or Associate Chapters only at the time of the biennial General Assembly. In the interim applicant members will be called Provisional Chapters.

It will take some time for changes to be made to all documents to reflect this change.

International Executive Committee

- Beginning with the next elections, which will begin in mid-2016, the terms of office of the board will be staggered by two years.
- To begin the process, as a once off, the next elected Regional Vice Presidents will have a term of 2 years, instead of 4 years, with the President, Secretary General, Treasurer and Past President serving 4 years.
- To compensate the Vice Presidents for the shortened term of office, the once-off two-year term will not count as part of the total term for which a Vice President is allowed to serve.

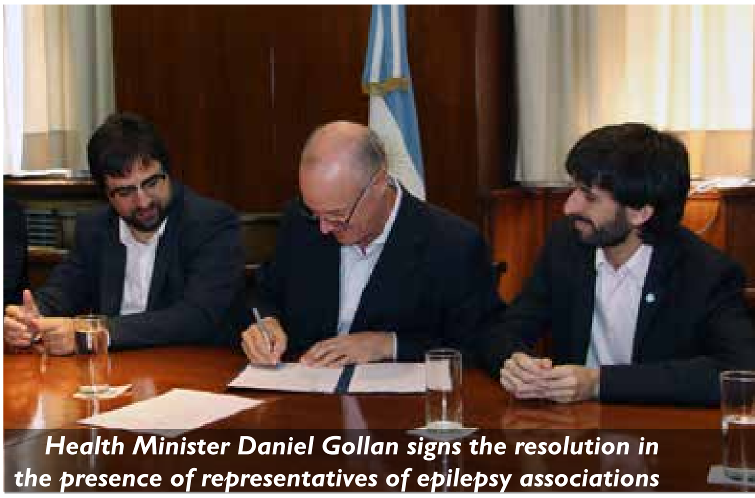
Regional Executive Committees

- The role of the Regional Vice President and that of the Chair of the Regional Executive Committee will be combined.
- The Regional elections will, therefore be limited to electing a Vice Chair and a Secretary (as well as two Members in the European region).
- This latter proposed change will serve to smoothen communication between the International and Regional Committees and clarify reporting duties.

Election Procedures

The revised procedures are covered in Byelaw III.

- The revised Byelaw allows for a much greater level of lobbying by candidates
- It also simplifies some of the procedures to encourage a higher level of participation in the election process by chapters - from the nomination process, to balloting and election.
- The nomination process, from the call for nominations to the end of the balloting process, has also be shortened from 120 days to 90 days.



Health Minister Daniel Gollan signs the resolution in the presence of representatives of epilepsy associations

ARGENTINEAN RESOLUTION ON EPILEPSY

On November 10th, 2015, the Ministry of Health of Argentina, Daniel Gollan, signed a resolution which results in the creation of a Cross Sector Work Force for epilepsy management with the objective to develop research, promote prevention, diagnosis and treatment for the aforementioned condition, with the collaboration of representatives of a number of epilepsy and neurology groups including two IBE Associate Chapters led by Silvia Kochen, who will play an important role in the Technical Advice Commission that will be created to provide advice to the work force.

The work force will establish regulations to protect people with epilepsy, undake statistical research and educational campaigns, and will provide technical collaboration for provincial authorities and for the city of Buenos Aires. The resolution also guarantees free drugs for those patients without access to medical assistance.

An cross sector work force on epilepsy management will be established within the Directorate of the Ministry of Health, and will involve a number of departments within the ministry of health including those on health promotion and control of non-transmissible diseases; community health; mother and child care; primary care health systems; and disease risk and prevention. The cross sectoral work force will be coordinated by the Secretary of Health Promotion and Programs and/or by whomever he/she may designate with a rank not lower than that of Vice-Secretary.

The work force with have the following objectives:

- A full understanding of investigation, teaching, prevention, diagnosis, treatment and follow up on all medical, social and employment aspects of the disease.
- Introduction of legislation, in the area of competence, in order to protect people with epilepsy.
- Perform nationwide statistical studies.
- Introduce educational campaigns for the general public and for specific groups to create awareness about the disease, to highlight the need for appropriate treatment and to avoid discrimination of patients.
- Provide scientific and technical support to provincial authorities and to the autonomous city of Buenos Aires to carry out regional programs.
- Guarantee to patients, who do not have medical assistance and are economically deprived, the provision of free drugs.

A Technical Advisory Commission will be created, with the objective of providing advice on issues related to epilepsy. In order to integrate the commission, it will be invited to designate one representative from each of the following organizations: The Pan American Health Organization, the Argentinean League Against Epilepsy, the Argentinean Neurological Society, the Association of Fight against Epilepsy (ALCE), the Argentinean Society of Child Neurology and the Foundation of Fight against Epilepsy. The coordinator of the aforementioned commission is authorized to invite afterwards experts on the topic. The decisions that the commission will take will not be binding.

The Technical Advice Commission will be coordinated by Dr Silvia Kochen. Its members will work ad-honorem and without prejudice to the specific functions of their office.

The Technical Advice Commission will give advice in the technical area on decisions that the working group will make on epilepsy management.

Costs related to the completion of the program will be funded by way of a charge on the designated budget of the Ministry of Health.

Recognising the statistics related to epilepsy, including hospital admissions and deaths due to the disease, the Minister stated that epilepsy would be recognised as a chronic disease. This means that it will continue to be considered as such even after the end of term of the current ministry.

EPILEPSY: *Treat it. Defeat it.*

Ghana Workshop on WHA Resolution. *Report by Marina Clarke*

Organised by WHO and attended by delegates from across Africa, a workshop in Accra in September considered the WHA Resolution on the global burden of epilepsy with a view to its implementation across the African continent. Marina Clarke, Vice Chair of the African Regional Executive Committee represented IBE at the meeting. This was the first in a series of planned workshops in response to the resolution.

In response to the call of the resolution for a coordinated effort, in opening the event, Dr Ebenezer Appiah-Denkyira, Director-General of the Ghana Health Services noted that Ghana was one of the few African countries where neurologists and psychiatrists worked together.

Outlining the objectives of the workshop, Dr Akwasi, Chief Psychiatrist, Ghana Ministry of Health, explained that the WHA Resolution would enable common understanding of future initiatives in epilepsy care and treatment, including scaling up programmes, national health insurance, capacity building and stigma reduction.

It was hoped that the workshop would achieve a better understanding of issues relating to epilepsy, particularly in terms of priority areas for epilepsy research and care, and a better understanding of the WHA resolution to ensure that delegates were better equipped to review epilepsy initiatives in the region.

Dr Prosper Tumusiime, Ghana WHO Representative, spelled out important statistics:

- Epilepsy represents 0.5% of the global burden of disease - only stroke has a larger impact
- 80% of the 50 million people worldwide who have epilepsy live in low- and middle-income countries.
- Treatment can cost as little as US$5 per annum
- Cost effective treatment can be provided through primary health care, with appropriate training
- Addressing the psycho-social aspects, such as stigma, is equally important as tackling the disease.

Ms Caty Forget, Sanofi Espoir Foundation, said that the workshop represented a starting point for networking and interaction to develop a sustainable model for the early detection of epilepsy and the reduction in the treatment gap. She also referred to the stories of persons with epilepsy, highlighting how they can become role models once they have accessed treatment.

In his keynote address, Ghana Minister of Health, Hon Alex Segbefia stated that Ghana fully supported the WHA resolution. He added that poor integration into healthcare systems, poor access to drug treatment, beliefs, attitudes and human rights abuses contributed to the struggle of persons with epilepsy whose mortality rates were three to six times higher than their peers.

Fight Against Epilepsy Initiative

This Ghana initiative, which had been introduced as a 4-year pilot plan (2012-2015) in 10 districts in five regions in Ghana had involved training 500 healthcare providers and 330 volunteers and this had resulted in a reduction in the treatment gap of 28%. Ghana was now ready to scale up the project in the African region, which implied that public education must be scaled up and the media integrated to banish myths and misconceptions.

Participants were asked to consider the initiative, discussing the challenges that had been encountered and how the project might be sustained.

Of interest was the fact that epilepsy aligned with the mental healthcare system in most African countries (South Africa being one exception). There was general consensus that all entry points should be used to reduce the treatment gap.

Some participants believed that stigma existed irrespective of whether or not treatment was offered via mental health facilities. It would seem that epilepsy is viewed as a health matter rather than a human rights issue in most African countries, which differs significantly from the principles inherent to the UN Convention on the Rights of Persons with Disabilities.

Global Burden and Response

Facilitated by Dr Tarun Dua (WHO), this session looked at the global burden with reference to current literature. The WHO Programme on Reducing the Epilepsy Treatment Gap was introduced, including current pilot demonstration projects in Ghana, Viet Nam, Mozambique and Myanmar.

Personal Testimonies

The moving story of Mrs Larbie, who spoke at the opening of the 2-day workshop, was followed by two further personal stories on the second day.

Mrs Grace Kumah told how she had had her first seizure at the age of 15; she is now 30 years old. She now knows what triggers her seizures and takes action to protect herself when she experiences a seizure. Her diagnosis of epilepsy was a shock to her family. Their prayers for a cure were not answered. She linked up with organisations, such as the Epilepsy Foundation of America, to get information about treatment options. She wears a wristband to remind herself to take her medication and understands the importance of keeping her treatment regime. Pregnancy was a challenge but her son, who is now 4 months old, is well. Like Mrs Larbie, Mrs Kumas's husband has stood by her.

Mr Eugene Doe lives with his father and siblings, who support traditional healther. His siblings prevent him from injuring himself during a seizure. He has also seen traditional healers and taken strange 'concoctions'. His friends don't know about his condition; he hasn't told them because he is ashamed and fears stigmatisation. This has made dating difficult and prevented him from proposing marriage to a woman. "Thus we look each other in the eyes, smile and carry on."

He says "other people have mental problems but because they don't fall down, people don't mind".

EPILEPSY: Treat it. Defeat it.

A video on the Programme on Reducing the Epilepsy Treatment Gap using the slogan *Epilepsy: Treat it. Defeat it.* was shown to delegates. The video, introducing basic concepts and providing information on how to reduce the treatment gap, uses eye-catching graphics and includes the important detail that epilepsy treatment can cost as little as US$5 a year.

Aba Larbie's Story

The patient perspective

Photo: Mrs and Mrs Larbie with Marina Clarke, National Director, Epilepsy South Africa

In considering epilepsy treatment and care, it is vital to include the voice of the patient. In Accra, Mrs Larbie, who was accompanied by her husband in a show of support, shared her emotional story.

She described her experiences of nocturnal seizures as a child and the interventions by traditional healers and priests. Mrs Larbie was diagnosed with epilepsy and her family was provided with information about the disease. In addition to antiepileptic drugs, she was also subjected to local remedies (including a mixture of head lice).

It was only once the correct drugs were used that Mrs Larbie gained control of her seizures. While she was frightened of disclosing her diagnosis, her husband accepted it and supported her by learning more about epilepsy.

When they were married in 2007, she was experiencing about 10 seizures every day. She has now been seizure free for two months and ascribes this to proper medical treatment and the antiepileptic drugs that enable her to live a fulfilling life.

The Larbies now have two children, including a daughter named after the Chief Neurologist of Ghana!

Mrs Larbie paid tribute to her husband and family, as well as to the medical care she received. She urged increased education about epilepsy.

Closing remarks

There was general consensus that a workshop such as this should be held regularly, perhaps linking to the IBE/ILAE African Epilepsy Congress, held every two to year years. This would provide both a cost effective element and a networking opportunity.

Attending the event was an enriching experience with opportunities to learn about the experiences of colleagues on the African continent and further abroad, as well as networking and developing friendships.

Central Repository of Educational Materials

During the final session of the workshop, delegates were questioned on whether IBE might create a central repository of all epilepsy awareness and educational material worldwide.

This has now begun in the African Region and all IBE chapters in Africa have been written to with a request to become involved in this initiative. It is hoped that all chapters in the region will participate.

FUTURE CONGRESSES

epilepsycongress.org

3rd Eastern Mediterranean Epilepsy Congress

DUBAI 2016

3 - 5 March

Intercontinental Hotel

Launching soon:

epilepsydubai2016.org

Hong Kong 2016

11th Asian & Oceanian Epilepsy Congress

13-16 May

CANCÚN 2016

20 - 23 de Agosto

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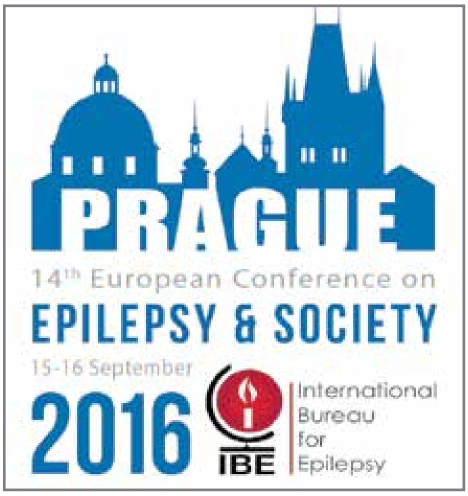
ILAE

IX CONGRESO LATINOAMERICANO DE EPILEPSIA



PRAGUE

14th European Conference on

EPILEPSY & SOCIETY

15-16 September

2016

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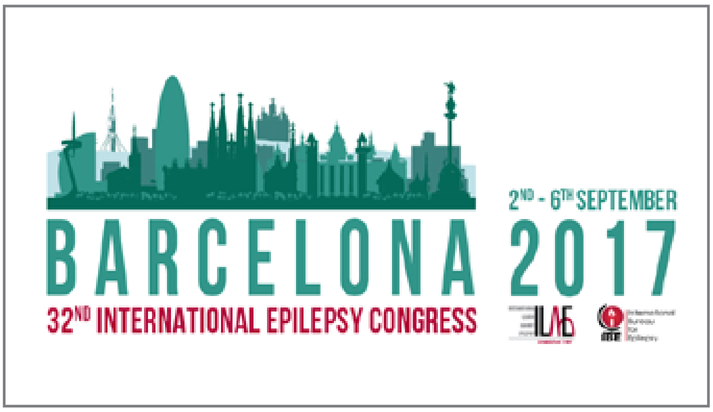
International Bureau for Epilepsy



2ND - 6TH SEPTEMBER

BARCELONA 2017

32ND INTERNATIONAL EPILEPSY CONGRESS