NEWSLETTER OF THE INTERNATIONAL BUREAU FOR EPILEPSY - ISSUE 1 2016

INTERNATIONAL Epilepsy News

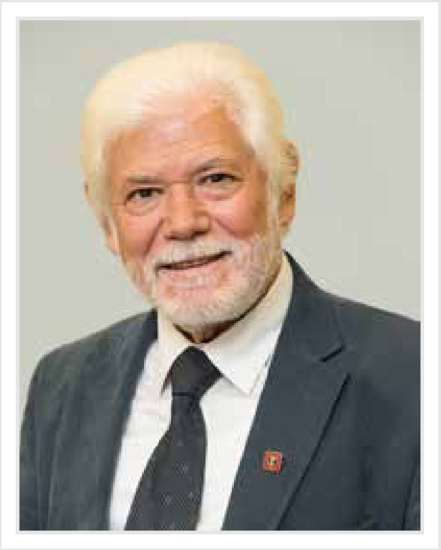
1963-2016

Reporting epilepsy news for 53 years

YES, I can!

International Epilepsy Day

PRESIDENT'S LETTER



A world day for epilepsy and other news!

Dear Friends

In January, the Scientific and Organising Committee (SOC) for the 32nd International Epilepsy Congress met in Dublin to choose topics and speakers.

Meetings of the IBE Management Committee and the IBE/ILAE Congress Finance Committee also took place, addressing budgetary issues related to various congresses and joint contracts.

International Epilepsy Day celebrations in Strasbourg on 2nd February was an excellent opportunity to communicate with Members of the European Parliament (MEP) on the need for improved treatment and services for people with epilepsy across Europe. Posters were displayed in the exhibition area, with stories of people with epilepsy and photographs from the 'Yes, I can!' photography competition!

During this very important event a group of us including Sari Tervonen, Philippe Ryvilin, Astrid Nehlig, Edouard Hirsch and two mothers (Antigoni Kallimachou from Cyprus and Francesca Sofia Francesca from taly), contributed to successfully meeting 36 MEPs. Our mission was to increase awareness of the need for improved services for people with epilepsy across Europe, and the world, including support for research projects. The result was an increase in membership of the European Advocates for Epilepsy group from 24 to 55 members.

In January, I was invited to participate in the 12th national Iranian epilepsy congress in Tehran, organized by the Iranian Epilepsy Association. My task was to give a welcome speech on behalf of IBE and a scientific speech. The meeting highlighted various scientific and educational issues related to epilepsy, including a session on epilepsy in resource-restricted settings.

In March, I was invited to the 3rd EMEC-UAE Epilepsy Congress to give a speech and chair a session on the social issues in CEMA region that included speeches on stigma, employment, treatment gap and driving. Two of the speakers were Najib Kissani, Vice President and Chahnez Triki, Chair, IBE Eastern Mediterranean Region. I also participated in the CEMA General Assembly.

Later that month I participated, on behalf of IBE, in a very interesting meeting in the Romanian Parliament regarding national epilepsy issues and how they could be solved. The meeting was under the auspices of Romania Health & Family Committee, Chamber of Deputies Romanian Parliament. An interesting meeting where the urgent need for evidence-based coordinated actions in improving epilepsy healthcare and treatment access were discussed. Special reference was made to the lack of most 3rd generation AEDS in Romania compared to most European countries.

We are, at present, in the second half of our term in office and the time has come to think about what we have achieved and, in addition, to new projects and activities. We should always be inspired by the patients' needs and deliver coordinated joint actions.

With best wishes to all,

Athanasios Covanis
President

International Epilepsy News
Issue 1 - 2016

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).

EPF

IBE is a member of the European Patients' Forum (EPF)

In this issue

Dear Readers

We had a tremendous reaction to the Yes, I can! photography competition with more than 300 entries from all corners of the world. Our cover for this issue features a happy image, the winning photo in the mobile phone/tablet category. You can find more winning images overleaf.

Joanna Burzec shares with us the story of her very rare form of epilepsy, which involves music, which you will find very interesting indeed. We are grateful to Joanna for sharing her experience with us.

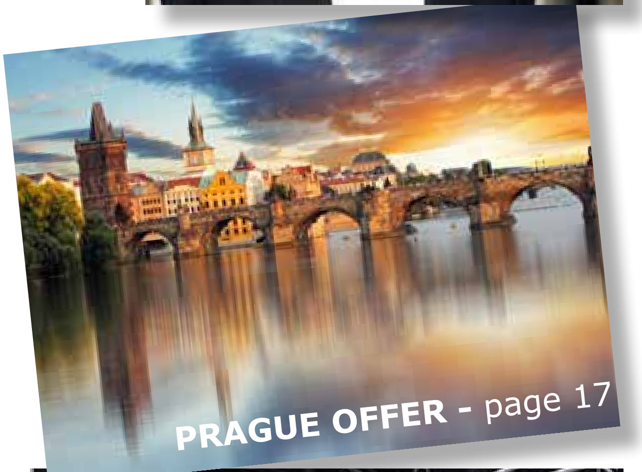
Ted Reynolds brings us the next episode of the fascinating story of ILAE, which had been held back from the last issue. Already I am looking forward to Part 10!

International Epilepsy Day was particularly successful in the European Parliament, where no less than 35 private meetings were held with Members of the European Parliament. By the end of the event, the membership of the European Advocates for Epilepsy ad hoc group had risen to 56. You can meet them all beginning on page 10.

Also in this issue is news of a very special offer on registration fees for the Epilepsy & Society Conference in Prague, news from Swaziland and Uruguay and much more besides.

Until next time - good reading,

Ann Little
Editor



Coming in the next issue

Kenneth Oakes, Meadvillw, PA, USA
"Three Months Seizure Free"

First Prize Camera Section

Kenneth Oakes was 19 years old when he started developing partial seizures during which he would lose the ability to talk or exchange even a few words. He was having five to 10 seizures a day.

At one point, after a night in hospital following a seizure at work, he returned to the studio to find his employer at his desk with his phone and computer who asked for his resignation. He was told because of his “condition” he was not permitted to hold the position any longer.

Fast forward, and at the age of 26 years, having undergone years of tests, a small benign tumor was found within his left front temporal lobe, believed to be the cause of his seizures. He was told that surgery would provide a 60% chance of becoming seizure free!

Now more than 4 months since surgery he remains seizure free, although recovery was difficult.

First Prize Phone/Tablet Section

Alessandra Seu, Italy:
"Enjoying the Ride".

The competition judges were greatly touched by the sheer delight shown on the faces of Alessandra's son Leonardo and her husband, Stefano, as they enjoyed a fairground ride at an amusement park in their home town of Lodi.

Leonardo, who is eight years old, is affected by Dravet Syndrome.

YES
I can!

PHOTOGRAPHY COMPETITION

The International Epilepsy Day photo competition attracted more than 300 powerful photographs from around the world. The winning photo in each category is awarded a prize of US$1,000.

HIGHLY COMMENDED

The judges also chose 6 photographs, which they considered should be deemed Highly Commended

Neenad Joseph Arul, Mumbai, India
"The Leap"

A little girl jumps with a steel glass as a red flag blows in wind. This young girls lives in the small hut on pavement.

Dipayan Bhar, Kolkata, India
"Playing"

Majda Dejlová, Prague, Czech Republic
"To Accomplish"

Lisa Cummings, Parkton NA, USA
"Finger-painting"

This is a photo of my 26 year-old daughter, Deborah, who has a rare disease called tuberous sclerosis and epilepsy. She suffered brain damage as the result of many seizures and functions at age 26 as a two year old. We love Deb immensely and priorities our day around doing what makes her happy. She is our hero. Brave beyond belief. This was her first experience finger-painting and her expression is wonderful.

Jérôme-Camphyn-Payelleville
"Laetitia and Célestine"

Laetitia was subject to significant discrimination. She was considered slow, lazy or even as being on drugs. Joining in a conversation was problematic; she didn't always understand, or quickly grasp, what was being said. The disability of her epilepsy is invisible, except when she is having a seizure.

Marriage and, especially, baby Célestine finally contributed to social recognition - that she is the same as everyone else. It's her epilepsy that is the difference.

Plabon Das, West Bengal, India
"Yes, I can fly!"

ROYAL SUPPORT IN SWAZILAND

Mbusomi Mahlalela, Swaziland Epilepsy Organization sent this report to International Epilepsy News

Similar to most royal households around the world, most Swazi royalty are engaged in different developmental and charitable initiatives. Prince Bandzile, who is the patron of Swaziland Epilepsy Organization, has demonstrated his great leadership qualities in addressing the plight of people living with epilepsy and other disabilities. It is unusual for a member of a Royal family to be associated with a cause that is fraught with stigma and discrimination. So, credit must go to Prince Bandzile for his effort and dedication in combating stigma and discrimination, thus ensuring that people with epilepsy in Swaziland live productive and fruitful lives, like other members of society.

The efforts of the Prince have improved the socio-economic welfare of those with epilepsy and have earned him the respect of the international community. He is the first and only youth in Africa to address numerous world forums about the plight of people living with epilepsy and other disabilities in the sub Saharan region, including a presentation at the 1st Eastern Mediterranean Regional Epilepsy Congress, Dubai 2009.

His efforts have been further compounded by invitations extended to him to address other forums of similar magnitude.

Locally, the Prince has called on the highest traditional public policy making structure, the Sibaya, advocating for access to farming land for people living with disabilities, since their exclusion from economic activity impacts negatively on national development programmes.

At organizational level, the Prince has mandated the Board and Management to lobby for a national policy on epilepsy so that people with the condition can have proper diagnosis and treatment.

Through the efforts of the Prince the Swaziland Epilepsy Organization was able to secure medical equipment and experts on neurology from Taiwan ROC.

Swaziland Epilepsy Organization had been operating on an ad hoc action plan basis until His Royal Highness commissioned the adoption of a Strategic Plan during the 2013/2014 financial year with the sole objective of driving the organization away from a donor dependency syndrome. Over the years we had heavily relied on donor funding and resources mobilized through fundraising campaigns. Due to the overwhelming demands from members, the organization had been unable to adequately address the needs of people living with epilepsy in the kingdom. However, through intense lobbying by the Prince, the organization received a substantial grant from the government under the Ministry of Health portfolio. This strategic plan entails the implementation of robust resource mobilization strategies aimed at maximizing income generating projects meant for vulnerable people with epilepsy, many of whom are unemployed and do not receive a disability grant. There have been contentions that epilepsy isn't a disability, hence their exclusion from the grant. However, this is a subject for another day.

His Royal Highness has seen it fit that the organization thrives to acquire its own assets in line with the road map towards financial independence and effective service delivery. Currently, the Prince is vigorously lobbying for the development of a state of the art Epilepsy Center and Clinic with strategic stakeholders.

It is because of such outstanding work that we can confidently say a rare gem has been unearthed in the Kingdom of eSwatini. The Prince has demonstrated a spirit of humanity few individuals of his status exhibit especially at such a tender age. Prince Bandzile has demonstrated how small initiatives, such as community based agribusiness, contribute to national goals and, by extension, His Majesty's vision 2022, through mutually beneficial partnerships.

We hope that the compassion and zeal he has extended to all people living with epilepsy may be emulated by other people of similar status.

JOANNA'S STORY

Musicogenic epilepsy - a rare syndrome from which Joanna Burzec suffers

It all began in 2008 when I was 16 years old. I was in a fitting room in a shop and had a strong déjà vu, very tired and excited at the same time. I heard people reciting a strange poem. I thought it was reality but then I "woke up" and realized that I was the only one who heard it. On the bus on my way home, I was listening to music on my headphones; the song was "Wonderwall" by Oasis was playing when I experienced the same strange feeling again. The vocalist was singing the words I had heard earlier as a poem and I had problems with breathing, I tried to save myself using my right hand for balance but I lost control. I woke up in the hospital and saw my mother crying. It was my first big, generalized seizure.

Seizures happened so fast: sudden fear and then voices. Sometimes I could avert my attention to something else, using deep breathing to avoid the seizure. But sometimes I could not stop it.

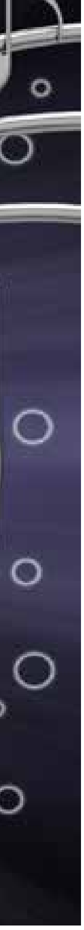
I am an emotional person. While listening to Coldplay I need to cry often, while listening to House Music I get this incredible energy and drive that lasts for hours. There is a general belief that music can help people with epilepsy – for me the opposite applies. It exists and it is called reflex epilepsy.

I still find it fascinating. Depending on the source of our epilepsy, different factors will trigger seizures. It can be reading, hot water, or flickering lights. In my case it was music and, often, specific songs. I knew, almost from the start, that a certain track sounded 'different' and could bring on a seizure. Also when I was playing sports, e.g. jogging, I always had a seizure.

> **I knew, almost from the start, that a certain track sounded 'different' and could bring on a seizure**

Recently I read about a rare kind of epilepsy - musicogenic epilepsy. My doctors did not make that diagnosis, I Googled it myself.

I once had a seizure that lasted about three days. I could not 'wake up' and get back to reality. I just heard a poem and some songs and wasn't able to speak normally for days. I had the impression that everyone around me was constantly reciting the poem. I was



convinced I was dying.

Another seizure, which was so painful and crucial in my life, happened in February 2014, around three months before my neurosurgery. It was this that made me decide 100% that I needed the surgery – something I haven't regretted.

My last big seizure happened while I was working in Germany. I was tired, hungry, in bad humour and it was raining. Usually I loved my job, but not in the last months before my surgery. And then I had a long, dangerous seizure in front of about 150 of the most important people in my company. I almost fell onto the busy road but I remember only the first minutes.

My great colleague from Poland and the projects supervisor from Italy saved my life. The Polish colleague was brilliant, but the Italian supervisor worried about his responsibility for me. While this was upsetting, it showed me that there is a need to educate people about epilepsy, so that they can offer support and not panic.

For the first three years I did not know that what I was experiencing were epileptic seizures. It was the problem in Poland. I think it is a miracle that I survived the last seven years, thanks to the help of some amazing people who were close to me when I was losing myself during seizures. Those I knew and those who just happened to be there when it happened – on the train, in the street, at the airport. Thank you all.

At first, Polish neurologists in Warsaw were unable to help me fully. I love thousands of things about my country, but Poland has a healthcare problem. My parents were spending thousands of Polish Zloty on visits to neurologists and psychiatrists. Some started a thorough examination, saw me twice, and then suddenly stopped responding to phone calls. Were they ashamed that they could not find the answer?

Some people think that after we triumph over illness everything in life is immediately perfect

I was well looked after in a children's hospital in Warsaw but when I turned 18 it became difficult to find an adult neurologist who could find a way to control my seizures.

Today I am a healthy successful businesswoman. How did I manage that? Despite hearing the poem at least once a month, I never stopped studying, and completed courses in seven foreign languages. I have to thank my family and friends for their great support. I studied International Business in Mannheim, while in full-time employment. My family was proud, but scared as well.

It was great in Mannheim. During the first months I had a few small seizures. I no longer remembered the bigger ones. The company helped me develop and nobody saw that I had any health problems.

Then on my 21st birthday, during a lecture with a professor, I had a seizure and ended up in Mannheim Universitätsklinikum. This is when I finally found out what was going on.

Today I feel amazing post surgery, with my little implants in my head. It was the team from Vienna General Hospital who saved me. Some people think that after we triumph over illness everything in life is immediately perfect and if that does not happen, they become depressed. But that's not the right approach! We need to be positive, because we will face problems along the way.

My grandmother died shortly after she found out I was well. On the day of my surgery, she said "Now I am happy and ready". And she was gone. What saved me is the power of positive thinking and my faith. I am confident, very stubborn, hardworking and, no matter what, have a smile on my face.

We need to increase awareness about epilepsy and educate people on epilepsy first aid, so that they can help someone, perhaps a stranger in the street, when they are having a seizure.

ANNUAL DUES 2016

Calling on all chapters to make your dues payment before the deadline of 30th April. The contributions of chapters is important in funding the activities of IBE and, for the first time in 11 years, there has been a small increase made to the dues levels.

Another major change is the option to make dues payments in Euro and we would encourage as many chapters as possible, in particular chapters based in Europe, to choose this option in order to reduce bank charges. The new dues levels are:

- Chapters: US$175/€160
- Associate Chapters: US$125/€115
- Subsidised rate: US$30/€28.

In addition, more than 30 chapters based in developing countries will continue to have their dues payments covered by the Solidarity Fund.

When settling your dues payment, we would earnestly ask that you consider a donation to the Solidarity Fund to help us to continue to support those chapters who have very limited financial means.

Please contact e: ibeexecdir@eircom.net with any queries on how to make your association's payment.

European Advocates for Epilepsy Group *grows in strength*

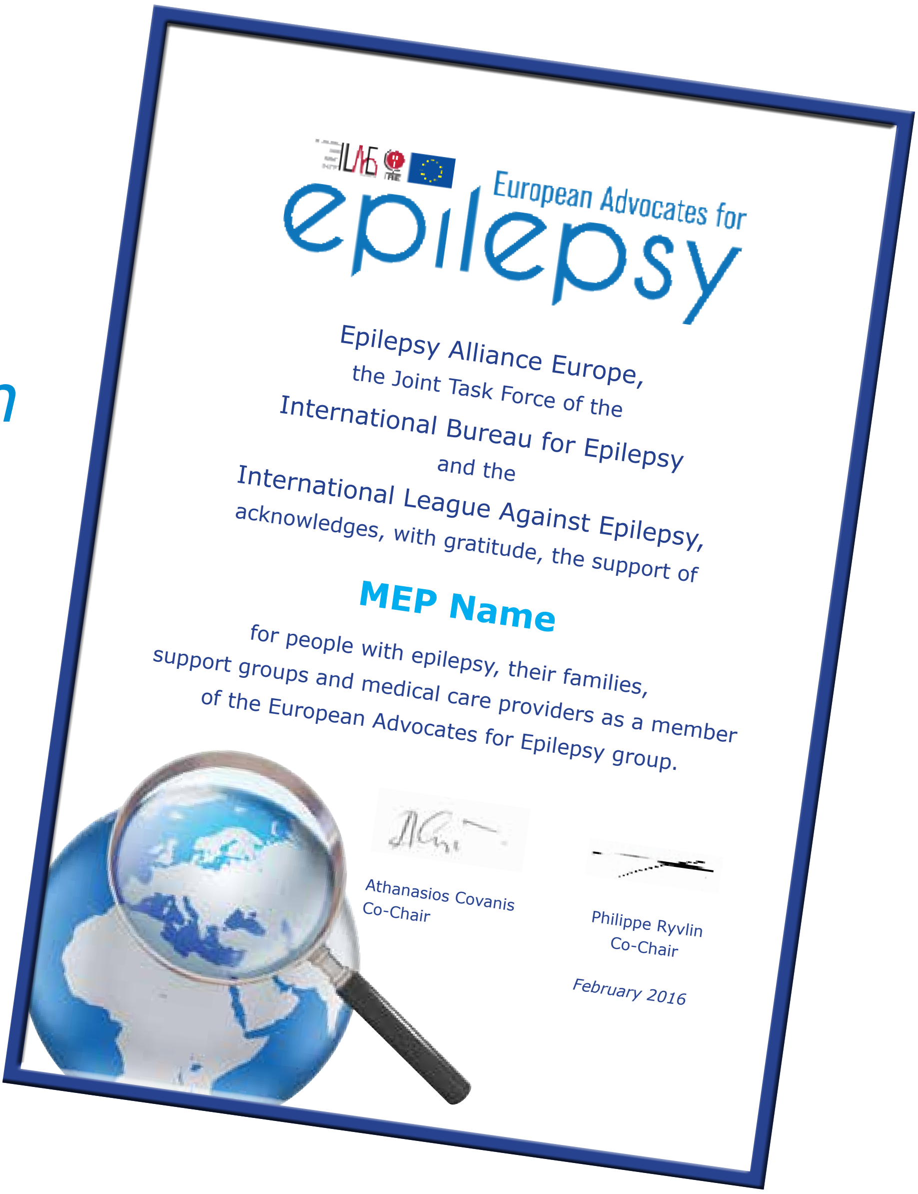
International Epilepsy Day celebrations in Strasbourg provided an excellent opportunity to communicate with Members of the European Parliament (MEP) on the need for improved treatment and services for people with epilepsy across Europe.

Hosted by the European Advocates for Epilepsy group in the parliament, the poster exhibitions of photographs from the Yes, I can! photo competition and the stories of people living with epilepsy, attracted the attention of a high number of MEPs and their assistants.

Even more important were the 36 private meetings with MEPs in their offices, all of which took place on Monday 2nd February. In addition to advocating for people with epilepsy and increasing awareness on the need for improved services and greater support for research, there was also the opportunity to encourage MEPs to demonstrate their support by becoming members of the European Advocates for Epilepsy group. The result was an astonishing increase in the group's membership from 24 to 55!

European Advocates for Epilepsy is a group of cross-party, cross-national MEPs with a particular interest in epilepsy that aims to improve the quality of life of all people with epilepsy, their families, care-givers and healthcare providers through European Union (EU) policy. One of the objective of the group is to support the epilepsy community in shaping policies that will impact positively on epilepsy by tabling amendments, oral or written questions and resolutions; by communicating with relevant Commissioners; and by organising targeted events on specific policy issues.

We are pleased to present all 55 members to you in this issue of IE News.



European Advocates for epilepsy

Epilepsy Alliance Europe,
the Joint Task Force of the
International Bureau for Epilepsy
and the
International League Against Epilepsy,
acknowledges, with gratitude, the support of

MEP Name

for people with epilepsy, their families,
support groups and medical care providers as a member
of the European Advocates for Epilepsy group.

Athanasios Covanis
Co-Chair

Philippe Ryvlin
Co-Chair

February 2016

Brian Hayes - Ireland
President

Nathalie Griesbeck - France
Vice President

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Austria

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Cyprus


Lefteris Christoforou
Cyprus


Tomáš Zdechovský
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Pavel Poc
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Bendt Bendtsen
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Christel Schaldemose
Denmark


Merja Kyllönen
Finland


Hannu Takkula
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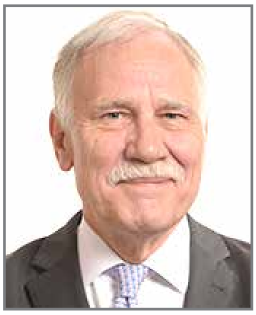
Anneli Jäätteenmäki
Finland


Miapetra Kumpula-Natri
Finland


Liisa Jaakonsaari
Finland


Sirpa Pietkäinen
Finland


Dominique Riquet
France


Jens Gieseke
Germany


Maria Spyraki
Greece


Theodoros Zagorakis
Greece


Eleftherios Synadinos
Greece


Lampros Fountoulis
Greece


Dimitiros Papadimoulis
Greece


Sofia Sakorafa
Greece


Kostas Chrysogonos
Greece


András Gyürk
Hungary


Seán Kelly
Ireland


Deirdre Clune
Ireland


Ness Childers
Ireland


Marian Harkin
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Mairead McGuinness
Ireland


Matt Carthy
Ireland


Giovanni La Via
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David Borrelli
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Miriam Dalli
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Portugal


Emilian Pavel
Romania


Marian-Jean Marinescu
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Romania


Claudiu C Tânăsescu
Romania


Jana Žitňanská
Slovakia


Alojz Peterle
Slovenia


Jytte Guteland
Sweden


Anna Hedh
Sweden


Theresa Griffin
UK


Jean Lambert
UK


Paul Brannen
UK


Julie Ward
UK

Help us to increase membership of the European Advocates for Epilepsy group even more by encouraging your national MEPs to come on board.
We would be happy to help you draft a message to send to your MEPs and can provide you with a copy of the Terms of Reference of the group. Every member of the group also receives a Certificate of Membership, which they can place on their websites.
For information e: ibeexecdir@eircom.net

EPILEPSY TRAINING FOR NURSES

Patricia Braga, President, Uruguayan League Against Epilepsy brings us this report

The Annual Meeting of the Uruguayan League Against Epilepsy 2015 took place in the city of Montevideo in the context of the activities under Strategic Area Number 3 of the Strategy and Plan of Action on Epilepsy in the Americas (ILAE/IBE/PAHO). In line with this important strategy, the first Training Course in Epilepsy for Nurses was organised.

The Chilean experience

The contribution of the Chilean experience was essential in achieving this objective, which has a model of great commitment, as demonstrated by the representatives from Chile - Dr Loreto Ríos and Nurse Francisca Serry - who travelled to the meeting from Chile. At the Liga Chilena Contra la Epilepsia nursing professionals have a significant role in the education of patients with epilepsy - much more so than in Uruguay.

The event was organized in coordination and with the support of the Epilepsy Section of the Neurology Institute and the Nursing Division of the Clinical Hospital. It also had the support of the Nursing Department of the Universidad de la República of Montevideo, Uruguay.

The topics varied from identification of seizures in children and adults, to pharmacological management and social aspects and support.

The meeting had 44 attendees, among them technical nursing auxiliaries, graduated nurses and advanced students of the University of Nursing. There was also the active participation of a group of 8 graduates of the Nursing of Hospital University and the Pediatrician Hospital (Hospital Pereyra Rossell), who prepared presentations aimed at sharing their experiences with their colleagues.

Participants included professionals based in Montevideo but also with the participation of of delegates from different medical departments from other cities around Uruguay - including delegates from San José, Durazno and Tacuarembó. The great majority of those professionals attending the meeting work in public hospitals (either university hospital, hospitals from the public health care network, or in the social security services) while others work in institutions affiliated to national health insurance.

Evaluation and outcome

An anonymous evaluation of the meeting was performed, with feedback provided by 37 of the delegates. All confirmed that the meeting gave them new knowledge and information that will help to improve their professional work. The evaluation average was 4.2 in a scale of 1 (insufficient) to 5 (excellent).

Future challenges

The balance of the activity by the organising team was really positive, defining at the same time challenges for the future, which will mark a work line in this strategic area, at a national level. The current challenges are:

1. Improve the resume of the Nursing degree.
2. Achieve a greater extension for future training activities, and
3. Evaluate the teaching strategy of future training, including more chances of interactive discussions or in workshops.

Finally, and due the active participation of several members of ALADE in this activity, there is the suggestion to extend the experience to other countries, with this or another modality.

THE HISTORY OF THE

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY
ILAE
ESTABLISHED 1909

Part 9: 1997 – 2001:
Professionalism and the Global Campaign

In part 8 (Issue 2, 2015) Ted Reynolds described the rapid growth and regional development of ILAE between 1993 and 1997, culminating in the launch of the ILAE/IBE/WHO Global Campaign. Delayed due to a special article in Issue 4, 2015, to mark the passing of Hanneke de Boer, we are now pleased to present the next instalment....

At the International Congress in Dublin in 1997 the new ILAE Executive included Jerome Engel Jr (Pete) (USA) as President, Peter Wolf (Germany) in his second term as Secretary General, and Guiliano Avanzini (Italy) as Treasurer.

The ILAE continued its rapid expansion. By 2001, 19 further chapters were added, - Albania, Armenia, Azerbaijan, Estonia, Honduras, Iraq, Jamaica, Kyrgistan, Lebanon, Malaysia, Malta, Nepal, Paraguay, Philippines, Qatar, Senegal, South Korea, Syria and Zimbabwe. In eight years the ILAE had doubled in size from 39 Chapters in 1993 to 81 in 2001.

Professional Management and Communication

Pete Engel and the new Executive realised that the increasing size of the ILAE and the scale of its proactive global commitments, some in collaboration with IBE and WHO, required a more professional approach to administration and financial management than could be provided by unpaid volunteer officers rotating every four years.

By 2001, the ILAE had scattered assets worth nearly three million dollars and an annual budget approaching one million dollars. Partly guided by Walt Schaw, a self-employed consultant in Leadership and Management, the Executive employed Peter Berry of Association Resources in the USA, where the ILAE is registered as a non-profit organisation, to establish a central accounting system and an investment policy to ensure the ILAE's financial security into the future. For the first time, annual audits were undertaken. A proposal to establish a permanent administrative office, perhaps in Europe, was discussed, but a decision was postponed for the 2001-2005 executive committee to consider.

In view of the growing size and financial importance of ILAE/IBE biennial International Epilepsy Congresses and the increased number of intervening ILAE and IBE Regional Congresses, Richard Holmes, based in Dublin, was appointed as International Director of Meetings to oversee financial, scientific and political control of these events for both the League and the Bureau. The international congresses continued in Prague in 1999 and Buenos Aires in 2001. The third and fourth European Regional Epilepsy Congresses were held in Warsaw in 1998 and Florence in 2000, respectively. The second and third Asian and Oceanian Regional Epilepsy Congresses were in Taipei in 1998 and New Delhi in 2000. The first official Latin American Epilepsy Congress was

Pete Engel, ILAE President 1997-2001

in Santiago de Chile in 2000. More local conferences continued or were initiated by Mediterranean, Pan Arab and Pacific Rim Chapters.

A new contract was signed with Blackwell for the publication of the highly successful *Epilepsia* journal under the continuing editorship of Tim Pedley (USA). This guaranteed a reliable source of income for ILAE for a further 5 years. Responsibility for *Epilepsia Digest* for developing countries passed to Blackwell to undertake in local countries.

Epigraph continued to be published twice or three times yearly, now in colour and later on-line, under the editorship of Simon Shorvon (UK). Plans for the ILAE-IBE website portal under Rajendra Kale (UK and India) continued but were delayed when the idea of a joint initiative with the British Medical Journal could not be agreed.

Regional Development and Commissions

The process of regional development, begun under the previous executive committee (see part 8), continued with the European Commission chaired by Martin Brodie (UK) and the Asian and Oceanian Commission chaired by Masukazu Seino (Japan). New commissions were established for Latin America, chaired by André Palmini (Brazil) and for the North American Continent chaired by William Theodore (USA). Plans were developed for an African Commission to be implemented by the next executive committee.

Peter Wolf (Germany), as Secretary General and chairman of the European Advisory Council, established Eurepa as an independent, but ILAE affiliated, educational organisation responsible for epilepsy education throughout Europe, but especially in the Eastern Europe, including educational activities during ILAE European Epilepsy Congresses.

Pete Engel reorganised the Scientific Commissions of ILAE into Resource Commissions, including Neurobiology, Psychobiology, Neurosurgery and Paediatrics; and Problem-orientated Commissions, including the Burden of Epilepsy, Developing Countries, the Search for Epilepsy Genes, Diagnostic Strategies and Therapeutic Strategies.

The goals and activities of these commissions were, to a large extent, relevant to and directed towards the flagship of almost all League activities i.e. the ILAE/IBE/WHO Global Campaign Against Epilepsy to improve the acceptability, treatment, services and prevention of epilepsy worldwide.

Launch of the Second Phase of the Global Campaign: Dr Ted Reynolds, ILAE Past President and Past Chairperson, Global Campaign; Dr Gro Harlem Brundtland, Director General WHO; Hanneke de Boer, IBE Past President and Past Chairperson Global Campaign; and Professor Pete Engel, ILAE President.

Global Campaign Takes Off

In part 8, I described the background, concept and objectives of the ILAE/IBE/WHO Global Campaign Against Epilepsy to bring epilepsy "*out of the shadows*", which was launched in Geneva and Dublin in June/July 1997. The strategic aims of the campaign included:

1. raising public and political awareness and understanding about epilepsy,
2. encouraging and supporting Departments of Health to address the needs, treatment, services and care of people with epilepsy nationally.

In phase 1, the first four years of the campaign, the emphasis was on the first aim by increasing awareness, creating acceptance, and improving education through global, regional and national activities.

Soon after, a new Director General of WHO, Dr Gro Harlem Brundtland, boosted the campaign by approving, in 1999, a so-called "Cabinet Paper", which raised the status of the campaign to the highest level within the new priorities of the reorganised WHO. Epilepsy is the first neurological disorder to be accorded this status and was at the forefront of WHO's 2001 World Health Day and Report on mental and brain disorders.

At the regional level in 1998 the German government sponsored a conference in Heidelberg of more than 100 professionals, patients/public, and politicians from all over Europe, which led to the publication and promotion of the European Declaration on Epilepsy. Similar regional declarations, based on the European format, were subsequently developed in Africa (Senegal), Latin America (Chile), Asia and Oceania (India) and North America (USA), all in 2000. More than 1,200 experts from more than 100 countries participated in these regional conferences and declarations. The European Declaration called for and led to the preparation of a "White Paper" on epilepsy for Europe, launched at the European Parliament by John Bowis MEP on March 22nd 2001. At the national level as many as 50 countries in all continents expressed a wish to join the campaign with their own "*out of the shadows*" initiatives.

All of these achievements led to a formal high profile launch of the second phase of the campaign in Geneva on February 12th 2001, led by the Director General, with the participation of senior WHO staff; the Regional Mental Health Officers of all six WHO regions; John Bowis MEP, representing the European Parliament; as well as the leadership of ILAE and IBE, representatives of national chapters and of other neuroscience NGO's, including some ambassadors to WHO. The objectives and outcome of phase 2 will be discussed in the next instalment. The speech of Dr Gro Harlem Brundtland, made at the launch, can be viewed as a milestone in the social history of epilepsy.

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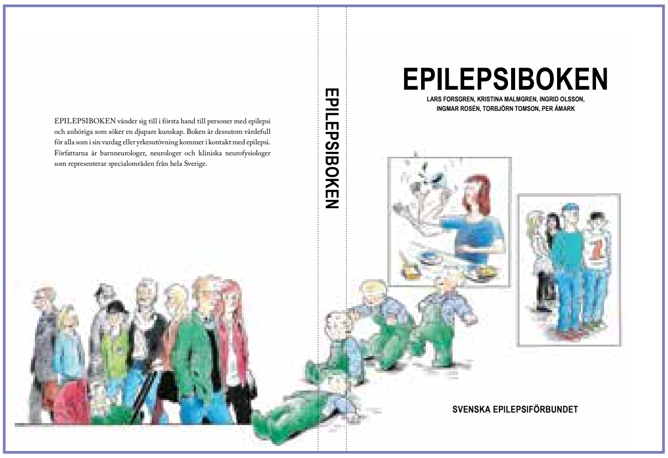
International Epilepsy Day SWEDEN


Photo: Mr Magnus Sandberg

International Epilepsy Day was celebrated in Sweden with an event in the Swedish Parliament, hosted by the Swedish Chapter of the IBE and its president MP Börje Vestlund. As part of the celebrations a new edition of a book on epilepsy (Epilepsiboken - “The Epilepsy Book”) was launched.

Written by a group of Swedish epileptologists, and including medical facts as well as patients’ own stories, the book targets patients, relatives, and health care staff. During the launch the authors gave examples of the positive development of epileptology and improvements in attitudes towards epilepsy over the 20 years since the first edition of the book was released.

The event attracted attention from the media and two specific topics were highlighted in the Swedish national public service radio, in conjunction with the International Epilepsy Day. Together with patients, Professors Malmgren and Tomson were interviewed on epilepsy surgery and pregnancy in epilepsy and this was broadcast at prime time on the radio channel 1. The program on epilepsy surgery was cited on the radio news several times during the day.


EPILEPSIBOKEN vänder sig till i första hand till personer med epilepsi och anhöriga som söker en djupare kunskap. Boken är dessutom värdefull för alla som i sin vardag eller yrkesutövning kommer i kontakt med epilepsi. Författarna är barnneurologer, neurologer och kliniska neurofysiologer som representerar specialområden från hela Sverige.

EPILEPSIBOKEN

EPILEPSIBOKEN

LARS FORSGREN, KRISTINA MALMGREN, INGRID OLSSON,
INGMAR ROSÉN, TORBJÖRN TOMSON, PER ÅMARK

SVENSKA EPILEPSIFÖRBUNDET

International Epilepsy Day - TOKYO

Japan Epilepsy Society (ILAE) and Japan Epilepsy Association (IBE) held a joint event to mark International Epilepsy Day.

The connection to St Valentine was explained by Amami Kato, Chair, Publicity Committee, Japan Epilepsy Society, while Makiko Osawa, President, Japan Epilepsy Society, focussed on the WHO/WHA Resolution.

Government official Katsushi Tahara, who is Director of the Mental Health and Disability Health Division, Ministry of Health, Labour and Welfare, reported on the policies for epilepsy in Japan and the designation of core hospitals for a medical service system for epilepsy.

Takaya Hara, a medical news reporter from Yomiuri Shinbum, spoke on “Living with Epilepsy”. Sae Sasajima, a professional calligrapher, performed big-brush calligraphy and wrote a large Japanese character for “wave” in purple ink, as an image of an EEG.

Mariko Yokoyama, from the Hand Stamp Art Project, introduced their project to collect the handprints of 100,000 children with disabilities, including epilepsy, to create a poster for the 2020 Tokyo Paralympic Games. The whole venue, lit up in purple, was full of emotion.

Keiji Tsurui, President, Japan Epilepsy Association, talked about a “Declaration on Epilepsy” to eliminate stigma and to provide proper understanding and medical and health care for people with epilepsy.

3 for 2!

PRAGUE
14th European Conference on
EPILEPSY & SOCIETY
15-16 September
2016
IBE
International
Bureau
for
Epilepsy

When registration for the IBE Epilepsy & Society Conference opens officially later this week, a special registration fee will be on offer that is sure to be popular with IBE chapters and other groups planning to attend.

The registration fee levels for the IBE regional congress have always been kept at an absolute minimum but for 2016 there will be a special 'three registrations for the price of two' offer that will allow chapters and associations to support even more of their members to participate in the congress.

Early registration will cost just €150 for a single delegate or €300 for three delegates and will close on 27th May. After that, the fee will increase to €200 for a single delegate or €400 for three.

Another major change is the timing and venue of the conference. Previously a stand-alone meeting, the conference will now begin immediately after the close of the ILAE European Congress on Epileptology and with a half-day joint session on 'Outcomes in Epilepsy'.

The conference will look at new developments in epilepsy treatment, associated cognitive dysfunction related to epilepsies and the psychosocial implications that derive from this common brain disease and, of course, to provide solutions. Above all, the aim is to facilitate communication and exchange of ideas among people with epilepsy and professionals in the field right across Europe.

The programme includes morning plenary sessions and afternoon discussion groups with as large as possible participation by delegates. The discussion group sessions will look at Epilepsy and Memory, Epilepsy and Employment and at Fundraising.

And all of this will happen in the beautiful city of Prague, Czech Republic. Located in the centre of Europe, Prague is very easily accessible from most countries in Europe and with many low-cost airlines offering frequent economic flights to the city.

For more information visit

www.epilepsyandsociety.org

14th IBE EUROPEAN CONFERENCE ON EPILEPSY & SOCIETY

Under the Umbrella

The European Federation of Neurological Associations [EFNA], of which IBE is a member, is launching a campaign to raise awareness in Europe of the prevalence of neurological disorders. This will be achieved by ‘branding the brain’- in other words, grouping brain disorders under a common symbol, creating a unified and identifiable brand.

During the month of March, EFNA is launching the Together Under the Umbrella campaign, with the aim to increase public, political and scientific support for all neurological disorders, which, it is hoped, will result in reduced stigma.

The campaign is asking the patient community, general public, and high profile figures to take a picture of themselves under an umbrella using the hashtag #UnderTheUmbrella, along with a link to the campaign’s online hub. The online hub will display key messages, interesting facts/statistics, campaign details, etc. alongside a list of supporting patient organisations and further information on the disease areas they represent.

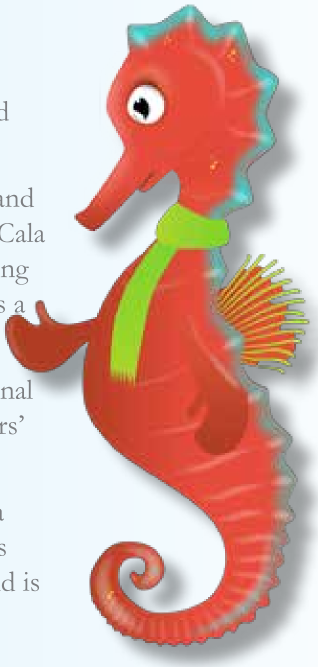
In addition to educating society on the wide range of neurological and other brain-related disorders and diseases, the campaign hopes to raise awareness on the impact and prevalence of these disease areas.

The Under the Umbrella campaign also hopes that by 'branding the brain' in grouping neurological disease areas under a common symbol, a unified and identifiable brand can be achieved.

If your association would like to take part in the campaign or use the Under the Umbrella campaign as a focus for an event already in planning, you can find out all about the campaign and access resource tools at www.undertheumbrella.eu.

TOGETHER UNDER
THE UMBRELLA

Have you met Campi?



Campi is a cute little seahorse who happens to have epilepsy. He is very gentle and kind and sometimes he is a little shy. Everyone is his friend.

For International Epilepsy Day, we launched a video on **epilepsy.org** to introduce Campi and his school friends - Cala the squid, Tuno the tuna and their teacher Mr W Hale, the whale. Cala loves ‘girlie’ things and having all those tentacles means that she has lots of room for wearing sparkling bracelets! Tuno is a bit of a tomboy – or maybe that should be tom-tuna! But he’s a bit of a softie behind all the bravado.

The video is a first introduction to epilepsy and is being developed it into a series of educational stories, specially suited to young children. Together with the video, we are creating a teachers’ pack to help educators to use the tool in the classroom.

So, you might ask, why did we choose a seahorse? We wanted to have a character that had a connection to epilepsy in some way and Campi just happened to fit the bill. The seahorse is genus Hippocampus and its shape resembles a part of the brain that has the same name and is important in producing seizures and epilepsy.

EpiMiRNA:
A 15 million euro epilepsy project

An EU-funded project, with the acronym EpiMiRNA, is hoping to improve our understanding of the underlying causes of epilepsy and to open up new diagnostic and therapeutic pathways focusing on the role of microRNAs.

The project has a budget of more than €15 million, with over €11 million provided in funding by the European Union. It started in 2013 and will run for five years and involves partners from Ireland, Netherlands, Germany, UK, Italy, Denmark, France and Finland, as well as further afield in the US and Brazil.

MicroRNA molecules are small messages hidden between genes that play a crucial role in regulating the gene expression process.

'To get from the DNA code to something that can function in the cell, the cell has to make a protein from the gene,' explains EpiMiRNA project coordinator David Henshall, who is based at the Royal College of Surgeons in Ireland. 'MicroRNA fine-tune and mainly work to slightly reduce the amount of protein in a cell.'

Discovered relatively recently, microRNAs have been shown to not only be critical for normal brain structure and function, but also to differ in the brain of patients with epilepsy compared to people without epilepsy.

One particular microRNA was also found to be a deciding factor in the excitability of the brain – and epilepsy is intrinsically linked to over-excitability of the brain. Once this microRNA was blocked in experimental models, seizures were strongly reduced.

But:

- How do microRNAs influence brain structure and function?
- How are microRNAs altered in patients with epilepsy?
- How can specific microRNAs be targeted, potentially, either to prevent epilepsy from developing following a brain injury, or to reverse epilepsy once it has been established?

These are the questions around which EpiMiRNA revolves.

In addition to understanding the 'ins and outs' of microRNAs in epilepsy, the large-scale project, with partners from academia and industry, is also hoping to find microRNAs that could be used as indicators to help diagnose epilepsy – a notoriously difficult task for this unpredictable and sporadic disease.

Since certain microRNAs are only produced within the brain, they could act as so-called biomarkers – their presence in the blood would imply that there is epileptic activity inside the brain.

'I think we will make great strides in the search for biomarkers,' says Henshall, looking to the future of the project, which will run until August 2018.

'MicroRNAs are really ideal biomarkers because of their cell specificity and their stability in the blood. I am optimistic we will come out with a panel of microRNAs which may be useful for diagnosing epilepsy and predicting treatment responses,' he explains.

Such predictive quality within biomarker microRNAs could be especially useful when it comes to non-pharmacological treatments for those whose epilepsy is resistant to drugs.

For several years now, certain patients with drug-resistant epilepsy have been fitted with a vagal nerve stimulator. While the underlying mechanism is still not fully understood, stimulating the vagus nerve – one of the cranial nerves – has been shown to reduce seizures in some patients who would not benefit from drug treatment or brain surgery.

'It doesn't cure them, but it can really make their lives more tolerable', Henshall points out.

New and improved drugs targeting and blocking the activity of specific microRNAs with the help of inhibitors could also contribute to a better quality of life for those suffering from epilepsy – another aspect of research into the disease covered by EpiMiRNA.

'Current microRNA inhibitors are quite large molecules and some of these will be very difficult to deliver to the brain,' Henshall explains. 'But if we can discover something much smaller, more similar to a normal-sized drug molecule, that would be a great advantage.'

In addition to the project's significant advances in identifying microRNA markers indicative of epileptic seizures, a promising 'hybrid' diagnostic device is being developed by a company partner in the project: it simultaneously serves as intracortical EEG depth-electrode and can take fluid samples by microdialysis, thus reducing the invasive diagnostic burden for patients.

Adapted from an article published by the EU.

FUTURE CONGRESSES

epilepsycongress.org