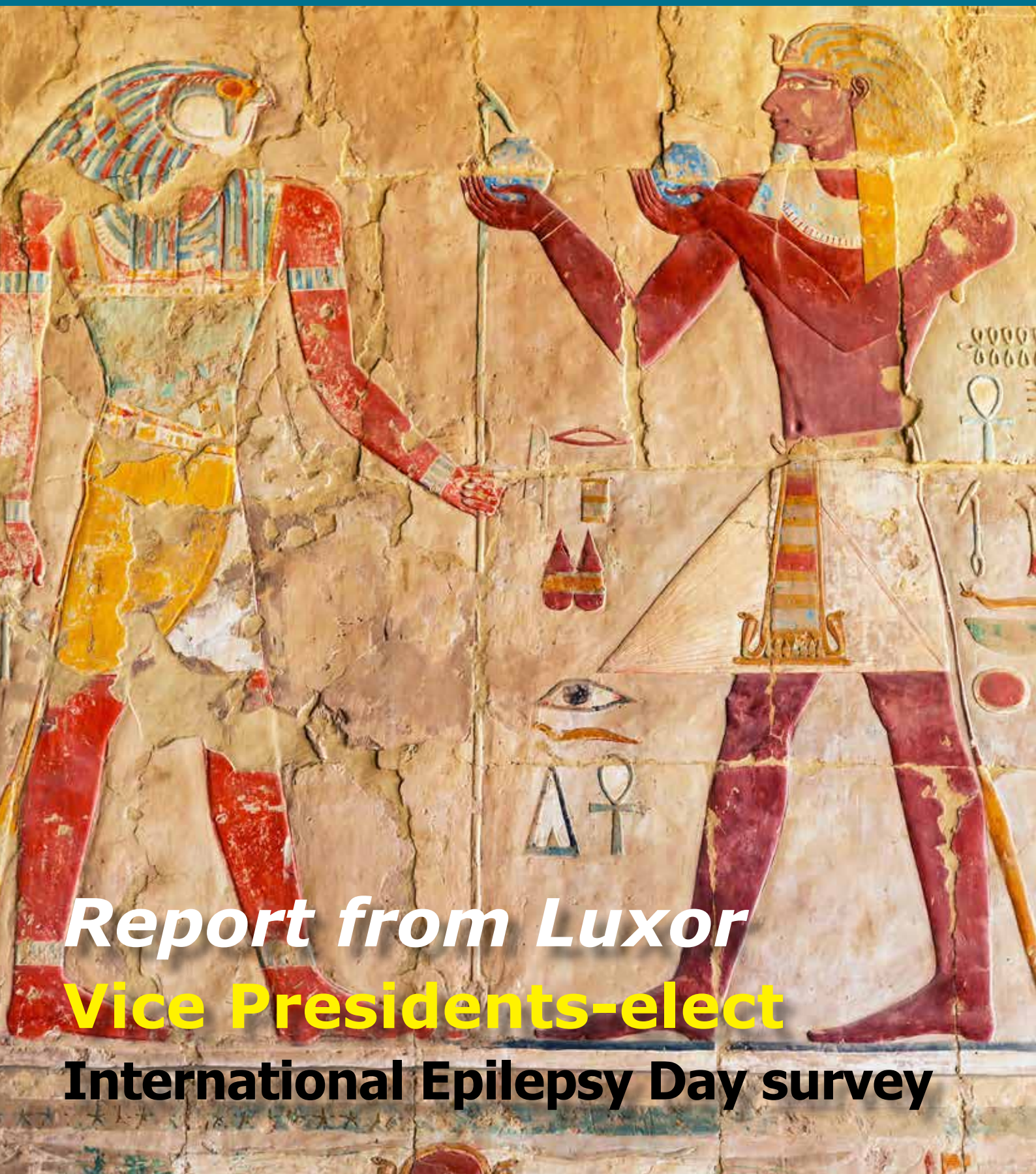


INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 54 years

1963-2017

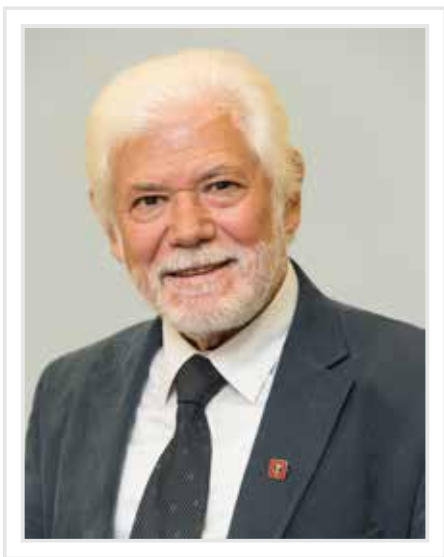


Report from Luxor

Vice Presidents-elect

International Epilepsy Day survey

PRESIDENT'S LETTER



Busy start to the year

Through the European Alliance for Epilepsy, we are involved in the Value of Treatment project of the European Brain Council which is due to complete its work in late June. This project is looking at the value of treatment and, in particular, early treatment, against non-treatment in nine disease areas.

Through the invitation of ILAE, we have been able to invite applications for the ILAE Leadership Development Program, which will take place during the congress in Barcelona. The deadline for applications has now closed and the first round of offers has been circulated to selected applicants. This program is a great opportunity for members of our chapters to increase their capacity to be the future leaders of their associations.

In February IBE and ILAE celebrated a very successful 4th Eastern Mediterranean Epilepsy Congress in Luxor, Egypt. The congress hosted more than 360 delegates from 30 countries. Most delegates came from neighbouring countries but some came from as far away as Argentina and Afghanistan! The 3rd African Epilepsy Regional Epilepsy Congress will take place in Dakar, Senegal and I hope to have the opportunity to meet some of you there.

I have also been busy representing IBE at national meetings and most recently was involved in the Russian Neurology Congress in Moscow, dedicated to the 25th Anniversary of the Russian-German Society of Neurologists and the 90th Anniversary of Professor BM Gekht.

Finally, IBE is preparing for the 32nd International Epilepsy Congress in Barcelona in September. But more about that in my next letter!

With best wishes to all,

Athanasios Covanis
President

Dear IBE Chapters, Dear Friends

As I prepare my message for this issue of IE News, I realise that my term in office as IBE President is slowly coming to a close. The next time I write, I will be bidding you goodbye as I step into the shoes of Immediate Past President.

During the last six months, you the chapters have been deciding on who you would like to lead the organisation for the next four years. In the last issue of the magazine you met with the President-elect, Martin Brodie, and the other newly elected members of the Management Committee - Mary Secco, Secretary General and Anthony Zimba, Treasurer. We have now just completed the election of the seven regional Vice Presidents, who were recently announced. There is still one more election to be completed in advance of the General Assembly in Barcelona, to fill the positions on the Regional Executive Committees and I hope that you will play an active role, either allowing your name to go forward to stand for election, or by nominating others.

Of course, the handover to the next committee is still some months away and, since I last wrote, the work and duties of the President have continued unabated.

The two projects to be supported under the 2017 round of Promising Strategies have been selected. This was a difficult decision, with almost 20 excellent projects submitted for consideration but with only a limited IBE budget available. The successful projects are in Colombia and China-Tibet and you can read about them in this issue of our newsletter.



International Epilepsy News
Issue 2- 2017

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- ⊙ Anastasia Vassou (Europe)
- ⊙ Tomás Mesa (Latin America)
- ⊙ Mary Secco (North America)
- ⊙ P Satishchandra (South East Asia)
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- ⊙ Janet Mifsud
- ⊙ Lilia Núñez-Orozco
- ⊙ Anthony Zimba
- ⊙ Emilio Perucca
- ⊙ Helen Cross
- ⊙ Sam Wiebe

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)

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In this issue



Dear Readers

In late January, at a meeting of the Joint Executive Committees of IBE and ILAE, all the nominations received for the Ambassador for Epilepsy, Social Accomplishment and Lifetime Achievement were carefully considered and discussed. In this issue of IE News, you can find out the names of those chosen to be awarded at the opening ceremony of the 32nd International Epilepsy

Congress in Barcelona in September.

Following the close of the Vice President elections, you can also meet the seven regional Vice Presidents who will serve on the IBE International Executive Committee for the term 2017-2019. You are also encouraged to play an active role in the Regional Executive Committee elections that are now underway.

After three very successful International Epilepsy Days, a survey of chapters was carried out to see how well we are doing and to find out how our chapters have been celebrating the day.

A major piece of work of the International League Against Epilepsy has been in introducing new classifications on epilepsy. There is a short report in this issue but a more detailed report will be published in the next magazine.

You can also read about the recent Eastern Mediterranean Epilepsy Congress in Luxor; an important project, supported by the IBE Promising Strategies Program, to eradicate neurocysticercosis in a rural town in Colombia; a survey on cannabidiol that took place in Australia, and other news from around the world.

Until next time - good reading,

Ann Little
Editor

Coming in the next issue





CANNABIDIOL CBD

AUSTRALIANS SURVEYED ON CANNABIS USE FOR EPILEPSY

Epilepsy Action Australia, an associate chapter of IBE, has played major role in a nationwide survey in Australia on the use of medicinal cannabis for epilepsy.

The online survey conducted by Epilepsy Action Australia asked participants their opinions and experiences in using cannabis-based products to treat epilepsy. Using social media platforms, the association's website and old-fashioned word-of-mouth to promote the survey and encourage participants, respondents were posed 39 questions on a range of topics from diagnosis and types of seizure to personal opinions on medicinal cannabis.

With around 30% of people with epilepsy drug-resistant, despite the high number of epilepsy drugs that are available today, more and more people are looking to non-medical options such as VNS, the ketogenic diet and, now, cannabidiol. So, it may not be such a surprise that the survey results showed that 15% of adults with epilepsy and 13% of parents or guardians of children with epilepsy were already using, or had used in the past, cannabis-based products to treat epilepsy. Of those figures, 90% of adults and 71% of parents reported a reduction in seizure frequency when cannabis products were introduced.

The survey report, published in *Epilepsy & Behavior*, stated that "*The main reasons for medicinal cannabis use were to manage treatment-resistant epilepsy and to obtain a*

more favorable side-effect profile compared to standard antiepileptic drugs. The number of past antiepileptic drugs tried was a significant predictor of medicinal cannabis use in both adults and children with epilepsy".

A total of 976 people responded to the survey over the 10-day period of its promotion. Of respondents, 60.1% were adults with epilepsy. In 46% of adults and 41% of children, the epilepsy syndrome was reported as being of 'unknown type'.

The report on the survey also highlighted the weaknesses of a survey of this type, carried out anonymously, online with open access, using Survey Monkey®. These include the potential for multiple responses e.g. both parents completing the survey on the same child. There was also potential for bias on the part of those who had benefited positively from the use of medicinal cannabis. Those who had experience of cannabis use for medicinal purposes were also more likely to take part in the survey in the first instance, resulting in an unrepresentative sample.

It is not surprising that 56% of adults with epilepsy and 62% of parents/guardians of children with epilepsy indicated a willingness to be involved in clinical trials of cannabinoids. The majority of those respondents who were unwilling to be involved in clinical trials of cannabidiol, stated uncertainty on the long-term (and short-term) side effects of cannabis products.

Mentioned in the report was the fact that the survey did not ask respondents about the types of cannabis that were, or had been, used; how they had been obtained; or how they were being taken. It further highlighted the need for proper regulation:

"Given the lack of regulation and quality assurance of artisanal cannabis products in the community, objective evaluation of standardized cannabis-based extracts is clearly warranted to relate efficacy, safety, and tolerability of these products to cannabinoid dose and concentration."

What remains clear is the growing interest in cannabidiol products for use in epilepsy and, in particular, in children with difficult to control epilepsy. The topic is also gaining traction globally and has no problem in drawing the attention of the media. Given the initial public ignorance of the difference between medicinal cannabis and its recreational relative, it's an attractive news story for journalists.

Nevertheless, while there have been a number of surveys and reports, there remains the problem of the absence of high quality data to draw conclusions on the effectiveness, or otherwise, of cannabidiol as an epilepsy treatment.

Suraev AS, et al, *An Australian nationwide survey on medicinal cannabis use for epilepsy: History of antiepileptic drug treatment predicts medicinal...*, *Epilepsy Behav* (2017), <http://dx.doi.org/10.1016/j.yebeh.2017.02.005>

The IBE/ILAE congress awards are presented biennially at the time of the International Epilepsy Congress, to honour individuals who have made significant contributions, over a long period of time and at international level, in the field of epilepsy. There are three categories: Ambassador for Epilepsy - presented to a maximum of 12 recipients; Social Accomplishment, presented to one individual; and the highest honour, Lifetime Achievement Award which, as its name implies, recognises a lifetime of achievement of an individual.



Lifetime Achievement Award

This is the highest award bestowed by IBE/ILAE and is given to an individual to recognise his or her exceptional and outstanding personal contribution over a long period of time to activities to advance the cause of epilepsy.

Presented to: Charlotte Dravet, France

Although especially known for the epilepsy syndrome that bears her name, Prof Dravet made impressive contributions to our understanding of the clinical and electrophysiological correlates of epilepsy syndromes of childhood. Her textbook *Epileptic Syndromes in Infancy, Childhood and Adolescence*, which she co-edited, has been updated many times over two decades and represents, to this day, a reference book for both students and epileptologists alike. She has mentored many trainees who have later become leading epileptologists, particularly

in Europe and Latin America.

In addition to her clinical expertise and research achievements, Prof Dravet is known worldwide for her humble attitude, tireless work and dedication to the epilepsy mission, including her support to the many lay associations, some made up of families of children with Dravet syndrome, which advocate for better care for children with epilepsy. She has produced many publications for the lay community, particularly parents of children with epilepsy, to help them cope with aspects of the disease.



Social Accomplishment Award

Every two years, one person who has carried out outstanding activities aimed at improving the social circumstances of people with epilepsy, over a long period of time, is recognised.

Presented to: Susan Axelrod, USA

In 1998, Axelrod and two other mothers, frustrated with their inability to protect their children from the devastation of seizures and side effects of medications, spearheaded the search for a cure for epilepsy. Axelrod launched a nonprofit organization that has established a national and international presence in epilepsy awareness and research.

Under Axelrod's leadership, CURE has led a dramatic shift in the epilepsy research community from simply treating seizures to enhancing understanding of underlying

mechanisms and causes, so that cures and preventative strategies can be found. CURE's research program is cutting-edge, dynamic and responsive to new scientific opportunities and directions through both investigator-initiated grants and unprecedented scientific programs and initiatives and the exploration of new areas in the quest to find answers.

CURE has also funded landmark conferences, including the 2000 National Institutes of Health (NIH) Conference, *Curing Epilepsy: Focus on the Future*.

Ambassador for Epilepsy Award

The Ambassador for Epilepsy Award is the oldest IBE/ILAE award, having been introduced in 1968. To date, a total of 312 worthy recipients have received an Ambassador pin to reflect international peer recognition and which is given for the lifetime of the recipient. Twelve Ambassadors will be presented with their awards in Barcelona.



Michel Baulac, France

Dr Baulac is Professor of Neurology and Neuroanatomy at Paris Sorbonne University; Director, Neurology Department at la Pitié-Salpêtrière Hospital, co-founder of the National Center for Rare Epileptic Diseases, and epilepsy research coordinator at the Brain and Spinal Cord Institute. A member of the ILAE Commission on European Affairs from 2001 (its Chair in 2005), he was elected ILAE Vice President in 2009.



Giuseppe Capovilla, Italy

Giuseppe Capovilla is currently serving as President of the Italian League Against Epilepsy. He served as a member of the ILAE Commission on Classification and Terminology from 2009 to 2013. He is the Chair of the Task Force on Sport and Epilepsy since 2011. He is the expert of both the European Medicine Agency and Italian Medicine Agency for antiepileptic drugs since 2011.



Nathalie Jetté, Canada

Dr Jetté is a Professor in the Departments of Neurology and Community Health Sciences at University of Calgary and Director of the Calgary Epilepsy Program. She served as President of the Canadian League Against Epilepsy, and chair of the ILAE Guidelines Task Force since 2012. She is current Chair of the ILAE Stigma Task Force, and is also Chair of the ILAE Global Burden Task Force.



Jaideep Kapur, USA

Dr Kapur collaborated with Sheryl Haut and Tina Budnitz to design and implement the successful ILAE Leadership Development Program. He is a member of the ILAE Education Task Force. He is also a member of the ILAE North American Commission since 2010. He was President of the American Epilepsy Society in 2010. Dr Kapur has also made substantial and ground breaking contributions in bench research in epilepsy.



Astrid Nehlig, France

Dr Nehlig is a premier basic scientist in the field of developmental epilepsy, based in Strasbourg, France, with outstanding achievements through translational research and effective collaborations with clinicians. She is very active in consumer affairs as it pertains to the rights and opportunities to deliver better care of patients with epilepsy. She is Co-editor-in-chief of *Epilepsia* and under her leadership, the journal has become the premier source of the epilepsy community.



Terence O'Brien, Australia

Dr O'Brien is the James Stewart Professor of Medicine, and consultant neurologist at The Royal Melbourne Hospital. He is a member of the ILAE Neurobiology Commission since 2009, member of the Task Force for the Development of Research Priorities, member of the ILAE-IBE Global Research Advocacy Task Force. He is one of four co-Chairs of the joint ILAE/AES Task Force on Recommendations for Pre-clinical Epilepsy Drug Discovery.

Presentation of Ambassador for Epilepsy Awards

The Ambassador for Epilepsy Awards, together with the Social Accomplishment and Lifetime Achievement Awards will be presented to these most deserving recipients during the Opening Ceremony of the congress in Barcelona on Saturday 2nd September 2017.



Makiko Osawa, Japan

Dr Osawa is Professor Emeritus, Tokyo Women's Medical University, Tokyo, Japan. She has contributed to medicine as a paediatric neurologist and has engaged in the care of children with epilepsy for 44 years. She was elected the first woman president of Japan Epilepsy Society. She has been a member of the ILAE Pediatric Commission, and established the Infantile Seizure Society with late Dr Yukio Fukuyama, of which she is Chair.



Galo Pesantez Cuesta, Ecuador

Dr Pesantez Cuesta is Director, National Center for Epilepsy, Ecuador. He is vice chair IBE Latin American Regional Committee. He was coordinator of the international project 'Neuropsychomotricity, an aid in the treatment of children with epilepsy', and current coordinator of 'Cannabidiol in the treatment of refractory epilepsies' project of the National Epilepsy Center, Ecuador Ministry of Health, and University of Madrid, Spain.



Parthasarthy Satishchandra, India

Dr P Satishchandra is Senior Professor of Neurology, National Institute of Mental Health & Neuro Science (NIMHANS), Bangalore and served as Director-Vice Chancellor from 2010 to 2016. His work led to NIMHANS achieving the status of 'Institute of National Importance' by the Indian Parliament. He is Chair, IBE South East Asia Regional Committee 2013-2017 and Past President of the Indian Epilepsy Society.



Ivan Rektor, Czech Republic

Dr Rektor founded the Brno Epilepsy Center in 1992. He introduced its epilepsy surgery program with almost 900 surgeries performed since the first SEEG recording in 1995. He served on the board of the ILAE Czech Chapter since 1986 (President 2003-2007), was a member of the ILAE Sub-committee on Epilepsy Surgery of the Commission of Therapeutic Strategies, and a member of the CEA Working Group on Epilepsy Surgery.



Eugen Trinkka, Austria

Prof Trinkka, neurologist and psychiatrist, is Chairman, Department of Neurology, Paracelsus Medical University, Salzburg. He is Past President, Austrian Chapter of ILAE and President Elect, Austrian Neurological Society. He is Treasurer of the ILAE Commission on European Affairs (2013-2017). He is a member of several task forces of ILAE and the ILAE CEA and is a dedicated speaker and educator. He is actively involved in European Reference Network activities.



Sameer Zuberi, UK

Dr Zuberi is an international specialist in chromosome disorders associated with epilepsy. He is a consultant paediatric neurologist at the Royal Hospital for Sick Children, Glasgow. His main focus is on identifying and arresting DNA mutations that can lead to epilepsy, and determining the best treatment for those affected by these genetic disorders. Dr Zuberi is involved in the work of the ILAE Classification Task Force which recently reported on completion of its work.



REGIONAL VICE PRESIDENTS 2017 - 2019



VICE PRESIDENT AFRICA

Jacob Mugumbate
Zimbabwe

Mr Mugumbate is a former Executive Director of the Epilepsy Support Foundation of Zimbabwe. He has also served on the IBE African Regional Committee as a co-opted member. He holds a Bachelor of Social Work and a Masters of Social Work from the University of Zimbabwe. Since 2011, he has been a lecturer and researcher at Bindura University in Zimbabwe. His current research is on epilepsy, disability, employment and social justice which is part of a PhD he is completing at the University of Newcastle, Australia. He has also published and presented on epilepsy stigma and management.

VICE PRESIDENT EUROPE

Mrs Morton has been working in the epilepsy field for more than 25 years. She was first employed as IBE Administrative Assistant when the IBE office was based in Heemstede and worked closely with the late Hanneke de Boer on the ILAE/IBE/WHO Global Campaign Against Epilepsy. Currently she is International Relations Officer at SEIN Epilepsy Centre. She holds a voluntary position as a representative to the UN for the World Federation of Mental Health (WFMH). She is also a member of the IBE Legislation Task Force.



Caroline Morton
Netherlands



Hassan Hosny
Egypt

VICE PRESIDENT EAST MEDITERRANEAN

Prof Hosny is Professor of Neurology at Cairo University. Trained at Cairo University Hospitals, he completed fellowships in Clinical Neurophysiology and Epilepsy at the University of Chicago and the Cleveland Clinic Foundation in the US. He is President of the Egyptian Epilepsy Association (IBE chapter), which he founded; he was elected twice as Chair of the ILAE Commission on East Mediterranean Affairs; sits on the board of the ILAE Educational and Epilepsy Care Commissions and is a member of the Editorial Board of the international journal of Epilepsy Research.



VICE PRESIDENT LATIN AMERICA

Tomás Mesa, Chile

Prof Mesa is Associate Professor at Pontificia Universidad Católica de Chile (PUC); Director of the Children's Section in a post-graduate training program for epilepsy; Director of Pediatric Sleep Training at the Sleep Medical Center and former Head of the Pediatric Neurology, Genetics and Metabolic Diseases Section. He is Past President of the Chilean League Against Epilepsy and the Association of Chilean Leagues Against Epilepsy (ANLICHE) - the Chilean chapter of IBE. He has served on the IBE Regional Committee for Latin America as Secretary (two terms) and Chair and was a member of the IBE Research Commission.

VICE PRESIDENT NORTH AMERICA

Phil Gattone, USA

Mr Gattone worked as Director of Education at Rush University Epilepsy Center and led the Epilepsy Foundation in Chicago for several years before joining the Epilepsy Foundation of America where he has served as President and CEO for the past five years, successfully increasing revenue and building relationships. He is currently IBE Vice President for North America and will serve for a second term. Personal experience as a father of a son who has endured thousands of seizures, multiple medications and two brain surgeries to control his seizures, which has driven him to become passionate about creating a movement for change.



VICE PRESIDENT WESTERN PACIFIC

Ding Ding
China

Dr Ding's career of epilepsy care started in 2002, as a co-investigator of a demonstration project in China: 'Epilepsy management at primary health level', carried out within the framework of the ILAE/IBE/WHO Global Campaign Against Epilepsy. She has been involved with the IBE chapter in China since 2005 and set up the Sea Horse art club for people with epilepsy. She has served on a number of task forces, including the ILAE/IBE Global Campaign Task Force and the ILAE Research Advocacy Task Force. She is currently serving a first term as IBE Vice President Western Pacific.



VICE PRESIDENT SOUTH EAST ASIA

Prof Satish Jain studied at the All India Institute of Medical Sciences (AIIMS), New Delhi; was awarded the WG Lennox International Clinical Research Fellowship of the Epilepsy Foundation of America and received advanced training in Epilepsy Research at Duke University Medical Centre, USA as a "Fulbright Scholar". He started the Comprehensive Epilepsy Care Facility at the AIIMS, New Delhi which today provides state of the art epilepsy care in our country. He is founder member and former President of the Indian Epilepsy Society (ILAE chapter) and is currently President of the Indian Epilepsy Association (IBE chapter).



Satish Jain
India

Introducing the seven recently elected IBE Vice Presidents, who will represent their regions on the International Executive Committee for the term 2017-2019.

Their terms of office will begin at the time of the IBE General Assembly, which takes place at the 32nd International Epilepsy Congress in Barcelona in September.

are so fundamental to the care of people with epilepsy. As knowledge grows and concepts evolve, classifications will change. However, this must be balanced against the requirement for consistency over time and a shared language for clinical practice and research. Clinical classifications need several years to become established, and although further fundamental changes to the 2017 classification of seizures and epilepsies are not planned in the short to medium term, the ILAE will continue to be responsive to feedback from the epilepsy community."

Explaining it all

Prof Martin Brodie, IBE President-elect together with Prof Zuberi are preparing an article that will explain in layman's language the details of the new classification, what the changes mean and how they will have a positive impact on the lives of people with epilepsy.

Articles:

Operational Classification of Seizure Types by the International League Against Epilepsy.
<http://onlinelibrary.wiley.com/doi/10.1111/epi.13670/full>

ILAE classification of the epilepsies. Position paper of the ILAE Commission for Classification and Terminology.
<http://onlinelibrary.wiley.com/doi/10.1111/epi.13709/full>

Instruction Manual for the ILAE 2017 Operational Classification of Seizure Types
<http://onlinelibrary.wiley.com/doi/10.1111/epi.13671/full>



Changes in seizure type classification from 1981 to 2017:

- | | | |
|--|--|---|
| 1. Change of "partial" to "focal" | 5. The terms dyscognitive, simple partial, complex partial, psychic, and secondarily generalized were eliminated | Atonic, clonic, epileptic spasms, myoclonic, and tonic seizures can be either focal or generalized |
| 2. Certain seizure types can be either of focal, generalized, or unknown onset | 6. New focal seizure types include automatisms, autonomic, behavior arrest, cognitive, emotional, hyperkinetic, sensory, and focal to bilateral tonic-clonic seizures. | 7. New generalized seizure types include absence with eyelid myoclonia, myoclonic absence, myoclonic-tonic-clonic, myoclonic-atonic, and epileptic spasms |
| 3. Seizures of unknown onset may have features that can still be classified | | |
| 4. Awareness is used as a classifier of focal seizures | | |

ANNUAL DUES 2017

The call for Chapter dues for 2017 was sent in early March. Dues payments are important in funding IBE activities and are also necessary to help us to introduce new activities and expand those that are already in place. Once again, this year we are encouraging those chapters based in Europe to make their payments in euro. This will reduce bank charges for both the sender and the receiver of dues funds. The dues levels are:

- Chapters: US\$175/€165
- Associate Chapters: US\$125/€115
- Subsidised rate: US\$30/€28.

In addition, more than 30 chapters based in developing countries have their dues payments covered by the Solidarity Fund. We would earnestly ask that you consider a donation to the Solidarity Fund, at any time, to help us to continue to support those chapters who have very limited financial means. Please contact ibeexecdir@eircom.net with any queries on how to make your association's payment.

International Epilepsy Day Survey

YOUR VIEWS MATTER!

BACKGROUND

Launched in February 2015, this year saw the third celebration of International Epilepsy Day on Monday 13th February.

The annual International Epilepsy Day is a joint initiative of the International Bureau for Epilepsy and the International League Against Epilepsy and is now celebrated on the 2nd Monday of February.

With IBE and ILAE having national chapters in more than 120 countries worldwide, it's a powerful opportunity to highlight the problems faced by people with epilepsy, their families and those who care for them.

OBJECTIVES

Developed in line with a strategy to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life, International Epilepsy Day aims to highlight that:

- epilepsy still remains a hidden disease due to the stigma attached;
- it is treatable, yet 40% of people living with epilepsy in wealthier countries do not receive appropriate treatment. Over 70% of those living in low income countries cannot even access epilepsy medication regularly;
- lack of treatment imposes a huge financial burden on national health systems;
- research and legislation remain key issues in improving the quality of life of persons with epilepsy.

2017

Over the past three years, we have strived to do so using a range of activities and initiatives which have gain public attention at a global level and have also been recognised by the World Health Organization (WHO). This year saw a continuation

of some of the activities that had proved successful in previous years, as well as some new ideas.

The theme 'Epilepsy is more than Seizures' continued as an underlying theme and many chapters continued to use the Epilepsy is more than Seizures poster, which was translated into almost 30 languages in 2016, to promote the day.

#EPILEPSYDAY

The hashtag #epilepsyday was again used on Social Media and we also asked people to adopt the Put Yourself in the Picture for International Epilepsy Day idea by uploading photos of themselves using frames.

The Putting Epilepsy in the Picture sub-theme was introduced to highlight how important it is for people to talk openly about epilepsy. In addition to photos on Social Media, a number of people with epilepsy provided moving videos in which they talked about what it was like to live with epilepsy. The videos are available to view on epilepsy.org. This was a particularly successful initiative and we will use the idea again in 2018.

CAMPI ANIMATIONS

Campi, the friendly International Epilepsy Day mascot that was introduced in 2016 was further developed with the second in a series of animated educational videos. This time Campi pays a visit to Dr Christina Langoustina at her surgery. But Campi also appeared on Facebook and Twitter helping to promoting International Epilepsy Day activities through a series of fun mini videos.

The Creating Artistic Waves art competition attracted a large number of entries in both the under-12 years and older categories. The standard of the entries was staggering and we were moved by the personal stories related to many of the artworks. These are now available to view



**International
Epilepsy Day**

on the epilepsy.org Gallery. We would like to thank all those to took part in the competition.

EUROPEAN PARLIAMENT

As in previous years, activities were organised in the European Parliament, using International Epilepsy Day as a platform from which to advocate for improved services for people with epilepsy across the European Union. Individual meetings were organised with MEPs and an evening reception also took place, hosted by Brian Hayes MEP, President of the European Advocates for Epilepsy MEP group. However, a highlight was the workshop on the need for a Global Alliance on Epilepsy Research, which was reported on in the last issue of IE News. The workshop brought together experts from North America and Europe to discuss how an alliance of European, North American and Asian agencies could provide a powerful group to address the need for increased research funding in epilepsy.

SURVEY

While there is no doubt that International Epilepsy Day is a great success, and now involves more than 40 countries worldwide, we wanted to see how well we were doing in the eyes of our member associations. It was on that basis that we carried out an online survey a month after International Epilepsy Day 2017. On the opposite page you can find out the results and it remains only to thank the 38 chapters who took the time to complete the survey. Your views are very important and will inform our plans for International Epilepsy Day 2018.



GENERAL STATISTICS

38 chapters responded to the survey

Repondents by region:

- Africa: 6 chapters
- East Mediterranean: 5 chapters
- Europe: 16 chapters
- Latin America: 6 chapters
- North America: 1 chapter
- South East Asia: 2 chapters
- Western Pacific: 2 chapters

Celebrated the day: 87.2%

Didn't celebrate the day: 12.8%

Those who had not celebrated the day, gave the following reasons:

- No budget: 86%
- Need more support: 50%
- Celebrate another day: 50%
- Date unsuitable: 35%
- Didn't like the theme: 12%

WHAT WERE YOUR OBJECTIVES FOR THE DAY?

- **Raise awareness in the general public: 94%**
- **Educate people with epilepsy: 53%**
- **Advocating for people with epilepsy: 50%**
- **Raise awareness in schools: 21%**
- **Fundraising: 18%**
- **Raise awareness in the workplace: 15%**

WHAT TYPE OF EVENT DID YOU ORGANISE?

- **Media campaign (print or online): 68%**
- **Public event or event in a public place: 50%**
- **Workshop for people with epilepsy: 47%**
- **Social media campaign: 47%**
- **Fundraising event: 17%**
- **Meeting with government: 8%**

DID YOU USE ANY EVENTS OR ACTIVITIES ORGANISED BY IBE/ILAE FOR THE DAY?

- Creating Artistic Waves Art Competition: 42%
- Put yourself in the Picture Selfie Campaign 42%
- Participated in International Epilepsy Day Facebook and Twitter campaigns: 42%
- Provided details of event for posting on the International Epilepsy Day website: 25%
- Provided personal story or video for the website: 11%
- None: 22%

Note that the responses include those who did not celebrate International Epilepsy Day.

DID YOU EVALUATE YOUR EVENTS?

Yes: 63%

No: 37%

Means of evaluation:

- A questionnaire at the event itself
- A post-event survey
- Noting increases in website and social media hits
- Pre- and post-tests at a workshop
- Asked branches/affiliates to report back on local events
- Through the level of media coverage obtained

DID YOU USE ANY MATERIALS PRODUCED BY IBE/ILAE FOR INTERNATIONAL EPILEPSY DAY?

- **Logo: 78%**
- **International Epilepsy Day Selfie Poster: 53%**
- **Theme Putting Epilepsy in the Picture: 47%**
- **Campi animated video: 31%**
- **Mini campi videos 25%**
- **Epilepsy general information postcard: 19%**

ANCIENT SETTING MODERN SCIENCE

HASSAN HOSNY AND CHAHNEZ TRIKI,
CO-CHAIRS OF THE CONGRESS SCIENTIFIC AND ORGANIZING REPORTING

The 4th East Mediterranean Epilepsy Congress (EMEC) was held on 16th-18th February 2017 in the city of Luxor on the east bank of the Nile River in Southern Egypt. It is on the site of ancient Thebes, the pharaohs' capital at the height of their power during the 16th to 11th centuries BC.

The congress took place in the beautifully located Steigenberger Nile Palace hotel, on the east bank of the Nile River, and hosted more than 360 delegates from 30 countries. The majority of participants came from the neighboring countries, as well as countries as far away as Argentina and Afghanistan.

CONGRESS PROGRAMME

The Welcome Ceremony was chaired by Hassan Hosny, Chair of the ILAE Commission on Eastern Mediterranean Affairs; Chahnez Triki, Chair of the IBE Eastern Mediterranean Regional Committee; Emilio Perucca, President

of the ILAE; Thanos Covanis, President of the IBE; and the Governor of Luxor, Mohamed Badr.

After the welcome speeches, the attendees joined a welcome reception by the east bank of the Nile River at the hotel.

CONGRESS THEMES

The four themes of the congress were:

1. Drug resistant epilepsy
2. Genetic generalized epilepsies
3. Auto-immune epilepsy
4. Status epilepticus

During the three congress days, epilepsy experts from the region and from the rest of the world presented exciting discoveries, novel fresh ideas, challenging projects and discussed many hot scientific and practical epileptological questions.

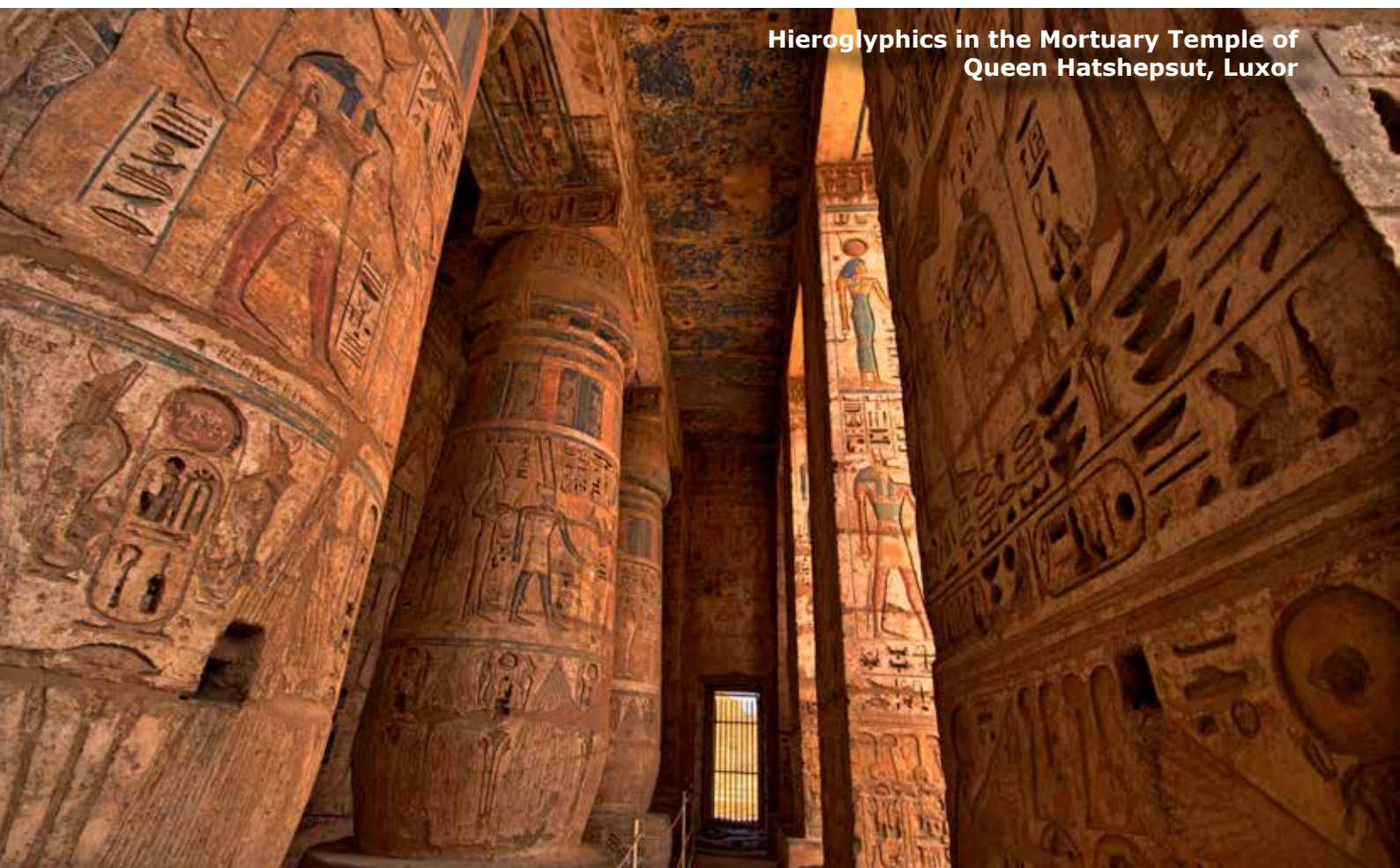
The scientific program consisted of a pre-congress EEG teaching course which was attended by over 100 delegates. The

next two days included numerous scientific sessions as well as four sponsored satellite symposia.

SPECIAL SESSION

A joint WFN/ILAE/CEMA special symposium was held on the second day, focusing on the collaboration between the two societies. The symposium was chaired by Emilio Perucca, ILAE and Raad Shakir, WFN (World Federation of Neurology). In addition, a guided poster tour included more than 30 posters.

Finally, the amazing stable sunny weather, the unique beauties of the river Nile, Karnak and Luxor temples, and the Valley of Kings and Valley of the Queens on the west bank of the river resulted in an unforgettable event for most of the delegates, and they left Luxor with positive experiences, warm impressions, and a lot of inspiring ideas in their minds.



Hieroglyphics in the Mortuary Temple of
Queen Hatshepsut, Luxor

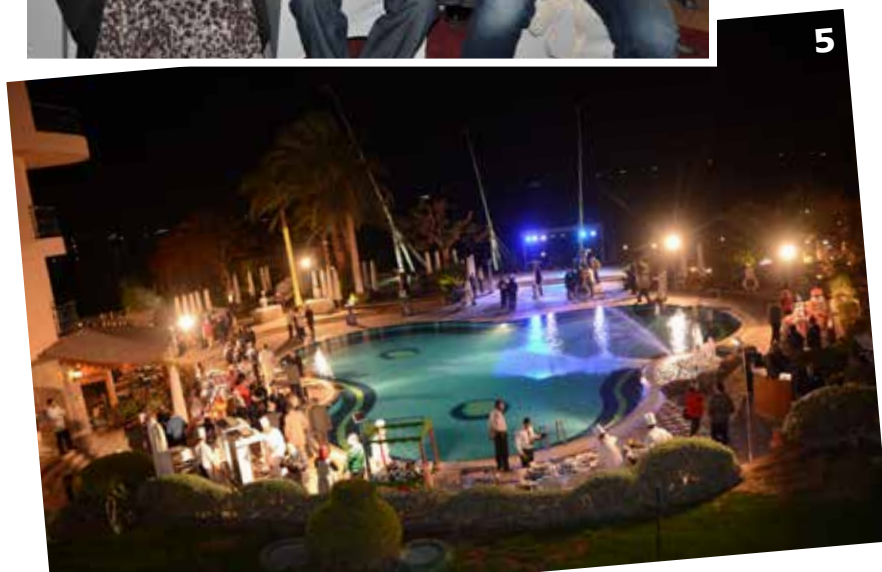


PHOTO CAPTIONS

1. Mohamed Badr, Governor of Luxor (left) with Hassan Hosny (centre)
2. Opening ceremony, from left: Hassan Hosny, Triki Chahnez, Mohamed Badr, Thanos Coavnis and Emilio Perucca
- 3., 6. and 7.: Congress delegates
4. IBE Exhibition Booth
5. Outdoor Opening Reception



REGIONAL EXECUTIVE COMMITTEES - ELECTIONS GET UNDERWAY

Following the close of the ballot period and the announcement of the seven elected Regional Vice Presidents (who you will meet elsewhere in this issue of IE News), the third and final election in the IBE International and Regional elections 2017, has now begun. From now until 27th May, voting chapters have the opportunity to nominate candidates to stand for election in their region.

The Election Task Force is encouraging all members to participate in the process.

Regional Structure

Every IBE chapters is a member of the Regional Committee in which they are located, in broad accordance with WHO regional boundaries. However, where regional affinity might be considered to be ambiguous, an IBE chapter can opt in or out of the region but may only be allowed to be a member of one Regional Committee at any one time.,

Following the change in the Constitution and Byelaws, approved by the General Assembly in Istanbul 2015, there are changes to the composition of the Regional Executive Committees, which are elected by the chapters in the region. Previously, the regional Vice President sat on the International Executive Committee and acted as the conduit between the, separately elected, Chair of the Regional Executive Committee and the International Executive Committee.

Constitutional change

This was not an ideal arrangement and introduced unnecessary complication to the structure. In the new Constitution and Bye-laws, the elected Vice President automatically becomes Chair of his or her Regional Executive Committee.

As a result, in six of the seven regional elections, the chapters will now elect the Vice Chair and Secretary, the exception being

Europe where there are also two Member positions. In additions, the President, Secretary General and Treasurer of the IBE are ex-officio non-voting members of each Regional Executive Committee.

Aims of the Regional Committee

Among the main aims of the Regional Executive Committee are the following:

- To provide a forum for IBE chapters within a defined geographical region.
- To pursue and co-ordinate at a regional level the implementation of the policies and plans of IBE.
- To identify regional issues of relevance and significance and to develop plans and policies to address these.

Role of the Regional Committee

Each Regional Committee works within the general policy and strategic framework set by the IBE and within these terms of reference reports to, and is accountable to, the International Executive Committee. A Regional Committee will:-

- Liaise with the Global Campaign Against Epilepsy and Global Outreach, IBE's other Regional Committees and other IBE and ILAE Commissions, Task Forces, Working Groups, and special initiatives on issues of common interest.
- Seek to encourage the development of new Full, Associate and Regional Chapters in the region in countries where no Full, Associate or Regional Chapters currently exist.
- Support existing chapters within the region by providing a forum for the exchange of information, expertise and experience.
- Provide a regional representative voice for IBE chapters within IBE and externally to other regional bodies like regional governments.

Responsibilities

Among the responsibilities of the Regional Executive Committee are:

- To promote IBE activities at regional level in order to increase the profile of IBE.
- To liaise with other NGOs, as appropriate, in order to promote IBE in the region and to improve services for people with epilepsy
- To work in close contact with the Global Campaign Against Epilepsy and Global Outreach and to promote their activities.
- To encourage the involvement of the WHO Regional Office in regional congresses.
- To work with the Secretary General in identifying new members in the region.
- To identify activities and actions to raise the profile of IBE at regional level.
- To promote the Promising Strategies Program within the region.
- To report to, and be accountable to, the chapters of the relevant Regional Committee and to the IBE International Executive Committee and to keep the International Executive Committee informed on all activities being carried out at a regional level.

Play your part

You, or your chapter nominee, can help to grow and promote the IBE by taking part in the regional elections. This is your chance to play a role in moulding IBE's future direction and taking an active role in its future focus. Remember, the deadline for submission of nomination papers is Saturday 27th May. Contact ibeexecdir@eircom.net if you need any information.

EUROPEAN REFERENCE NETWORKS

Official launch event in Vilnius



A video message of the President of the European Commissions, Jen-Claude Juncker, marked the opening of the 3rd European Reference Network (ERN) conference in Vilnius, Lithuania, on the 9th of March.

The conference, which was attended by 600 delegates representing healthcare providers, patient representatives, policy

makers and health experts, was the first opportunity for the 24 ERN Coordinators and their teams to come together and begin working on this new initiative of the European Union on rare and complex diseases

The conference was hosted by the Ministry of Health of Lithuania under the auspices

of the Maltese Presidency of the Council of the EU.

The EU Commissioner on Health and Food Safety, Vytenis Andriukaitis and the Ministers of Health of Lithuania (Aurelijus Veryga) and Malta (Christopher Fearne) attended in person and addressed the delegates. Members of the European Parliament Françoise Grosstête and Brian Hayes participated through video message. Brian Hayes MEP is President of the European Advocates for Epilepsy group in the parliament.

The conference included four roundtables, addressing the following topics: organisation and management of ERNs; EU policies and supporting actions to ERNs; ERNs and national healthcare systems; and the way forward for the new ERNs.

The conference was concluded by a ceremony where Commissioner Andriukaitis officially awarded certificates to the 24 ERN Coordinators, including Helen Cross, Coordinator of the ERN EpiCARE. Now the work begins!



RESEARCHING REMOTE TECHNOLOGY FOR A BETTER UNDERSTANDING OF EPILEPSY



KING'S COLLEGE LONDON



RESTRICTED TO PEOPLE LIVING IN THE UK

RADAR-CNS stands for Remote Assessment of Disease and Relapse in Central Nervous System Disorders.

RADAR-CNS is a new international research project which aims to improve healthcare provision by collecting information remotely through **smartphones and wearable devices** and in which IBE is involved as a member of the patient advisory board.

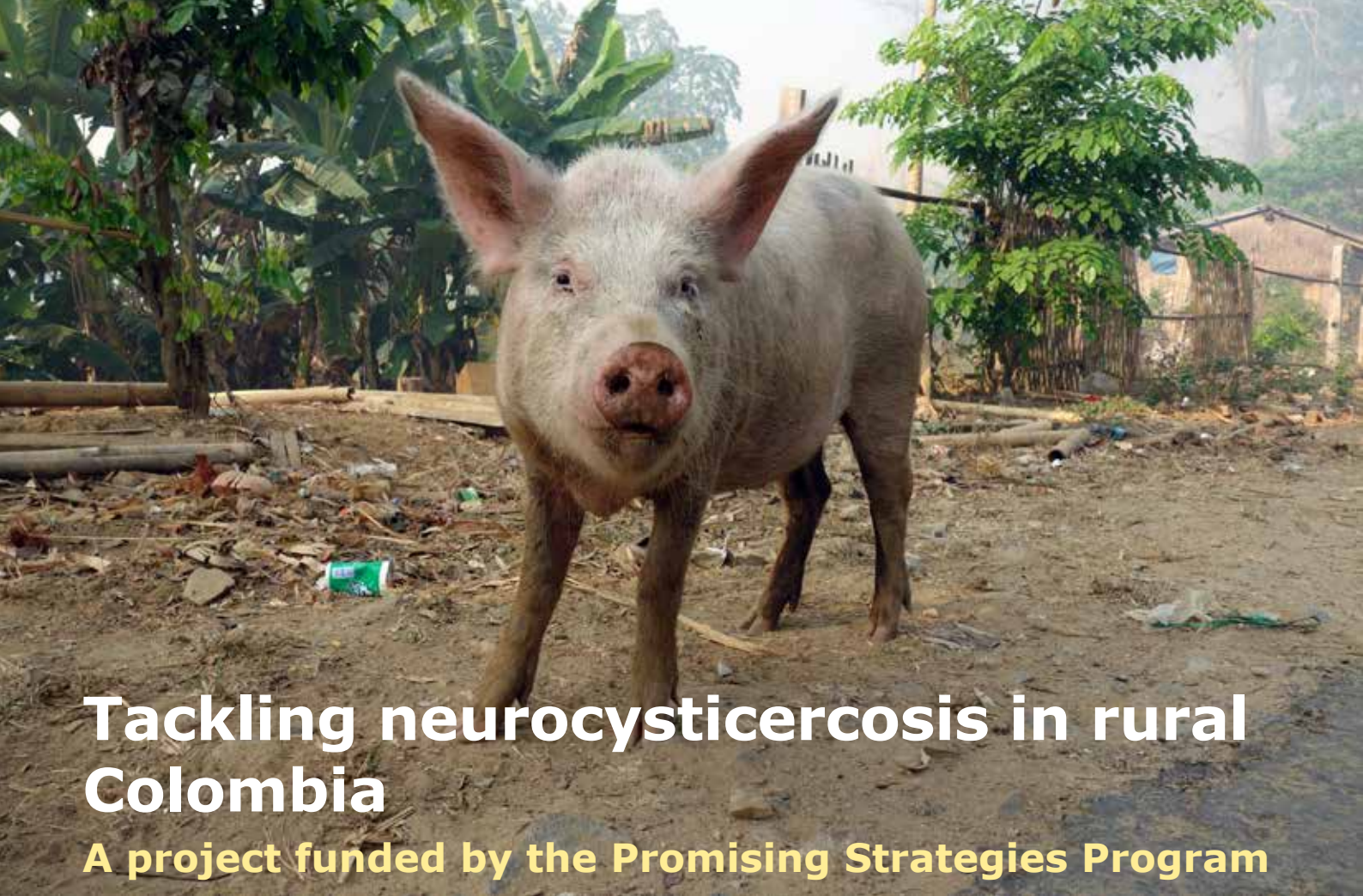
If you are living in the UK, your help would be welcome in the early stages of this project, to define what is important to people affected by **epilepsy or multiple sclerosis or depression**. One idea is to use smartphones and wearable devices as a **new way of measuring changes** in what someone does or how

they feel when they are experiencing symptoms. Identifying these changes could help with early detection of problems.

The project is interested in gathering information about the **experiences of using technology to help** measure these changes from people living in the UK affected by **epilepsy, multiple sclerosis or depression**.

You are invited to take part in an online survey via this web link: <https://www.surveymonkey.co.uk/r/PNYND7H>.

Please contact Sara Simblett at King's College London with any questions: Email: sara.simblett@kcl.ac.uk



Tackling neurocysticercosis in rural Colombia

A project funded by the Promising Strategies Program

The IBE Promising Strategies Program is now 11 years old and is one of the most successful of all IBE's initiatives. Set up in 2006, as a means of supporting IBE chapters through the provision of financial support for projects aimed at improving the quality of life of people with epilepsy, to date, 81 projects in 38 countries have received a total of US\$330,000 in support. Two new projects were selected by the International Executive Committee for funding in 2017. This issue of IE News features the project in Colombia. In the next issue we will present the second project, which is taking place in Tibet, China.

Neurocysticercosis is the first cause of epilepsy in the Caribbean region. How an epilepsy center in rehabilitation can help prevention in epilepsy along with the State **Health problem**

A common scene in poor towns is the lack of running water, sewage system and no faeces treatment at all, which are found everywhere in the streets or in appalling garbage collectors. The pigs roam on the streets, eating faeces and rubbish, that can have copious amounts of fertile eggs of the *taenia solium* (tapeworm). In the pigs' intestine, the eggs develop into moveable larvae that can pass through the intestine wall and reach the blood stream. Soon, these larvae reach the muscles and can stay there for a long time.

Humans can then eat this contaminated meat, and once consumed, the parasite follows the same cycle as in the pig. However, in this case, the larvae go directly through the blood stream to the brain, where they can remain as cysts for a long time until they are destroyed by the body's defenses.

When this happens, strange substances are emitted from the cysts that irritate the brain. A focal seizure occurs which can generalize to tonic clonic. But it can also lead to a cognitive deficit.

We know that about 40% of patients with neurocysticercosis will develop epilepsy

If seizures repeat, we have real epilepsy. We know that about 40% of patients with neurocysticercosis will develop epilepsy.

Why we fight this disease

It's easy to understand how an invasion of many cysts into the brain causes irritation and difficulties in mental faculties, which

can be permanent. When a child or an adolescent is attacked by the parasite, they are potentially going to suffer mental retardation and permanent epilepsy, especially when the cysts are situated in the meningeal space, producing hydrocephalus and dementia. These patients consult FIRE, the IBE chapter in Colombia, looking for special education because they are refused admission to normal schools.

These children, adolescents or young adults, could avoid these terrible problems by fighting the cause i.e. lack of sanitation and contamination of pork.

Due to the inability of the Colombian Government to tackle this task alone, we believe that we must initiate a campaign to get rid these ignominious and degrading conditions in which the poor people live and, at the same time, prevent cognitive problems arising, which is a significant financial burden to the Government and to their families. It's a three-part effort of the government (mayor of the town), private initiative (FIRE) and the community.

Situation in the Caribbean Coast

Colombia is a typical emerging country. There are regions with very good development and high per capita incomes, and other parts with very low income and a defective and precarious standard of living. It is in latter regions, especially on the Caribbean and Pacific Coast, where epilepsy has a higher prevalence and incidence, and where the mental and cognitive disturbances are frequently the consequence of cysticercosis.

The Government alone is incapable of solving the sanitation problem

The Government alone is incapable of solving the sanitation problem; the inhabitants are almost totally defenseless in organizing it themselves; so, it's necessary that entities such as FIRE provide assistance.

Project to eradicate cysticercosis

We have already planned the following work-schedule steps:

1. Introduction of the project with FIRE personnel (doctors, nurses, programmers, administrators) and local volunteers.
2. A survey in every home in the small town of Mahates, located about an hour from Cartagena, which has 7,000 dwellings and a population of approximately 23,000.
3. Meetings with community leaders to discuss the project.

4. Interviews with school directors to explain the project and to encourage them to involve 11th grade students, as they have an obligation to be involved in social activities in the community.
5. Door to door interviews carried out by the leadership of FIRE, and previously trained students, over two Sundays.
6. Analysis of results.
7. Provide 250 mgs. of Albendazole to the 23,000 inhabitants (the entire population - children and adults) with the collaboration of health authorities of the town (loudspeakers and pamphlets). We assume that the entire population will become free of *Taenia Solium*. This needs to be repeated every six months.
8. Construction of a communal herd of 150 piglets (purebred) in substitution for the vagrant pigs. This will be done, by agreement, with the owners of the old and contaminated pigs, who will receive pure-bred animals in exchange. Of course, the vet is central in destroying the infected animals.
9. Control by authorities.
10. Replication in every endemic region of Colombia.

Our results

Steps 1 to 6 have already been completed.

Step 7 has partially been completed, since it is necessary to obtain a further 23,000 pills of Albendazole.

Step 8 is extremely important and, to achieve this, we may need to obtain further funds which, added to finances provided by the municipality, would let us complete the project in Mahates.

It is of utmost importance to highlight completion of the project in Mahates,

since this will encourage neighbourhood towns to quickly copy the project. But to do so, we need to demonstrate its value.

Impact in the community

The main aim of this project is to demonstrate that FIRE, working together with the community, can make it possible to eradicate cysticercosis, the first cause of epilepsy in the Caribbean zone in Colombia, and so improve quality of life. But we also must encourage neighbouring countries to do the same.

Economically, the gain is enormous. We calculate that the incidence of neurocysticercosis in Colombia is about 8,928 new cases annually and that 35% of those infected develop epilepsy. The financial budget for these 3,125 people will cost approximately USD 3.125 million annually (excluding indirect costs and prescribing only first generation AEDs).*

**We have not got reliable statistics.*

Conclusions

1. One of the most important causes of epilepsy in Colombia is neurocysticercosis (NCC), especially in the Caribbean and Pacific coasts.
2. 35% of patients suffering NCC endure epilepsy and many of them cognitive disturbances that need rehabilitation.
3. Of course, they will be patients needing special education.
4. The life cost and catastrophic sequels are an enormous burden for the government, families and society in general.
5. Rehabilitation for cognitive sequelae of NCC is also a hard task for a developing country.
6. Our Project is feasible and necessary as we have already completed 50%; we need 50% for finishing it.

81 Projects in 38 countries around the world

ARGENTINA
BANGLADESH
BRAZIL
BULGARIA
CAMEROON
CHILE
CHINA
COLOMBIA
CZECH REPUBLIC
ECUADOR

GAMBIA
GEORGIA
GUATEMALA
HAITI
INDIA
INDONESIA
KENYA
LAOS
LEBANON
LITHUANIA

MAURITIUS
MALAYSIA
MONGOLIA
NAMIBIA
NEPAL
PHILIPPINES
ROMANIA
SIERRA LEONE
SOUTH AFRICA
SWAZILAND

TANZANIA
TIBET
TOGO
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URUGUAY
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ZAMBIA
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FUTURE CONGRESSES

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