

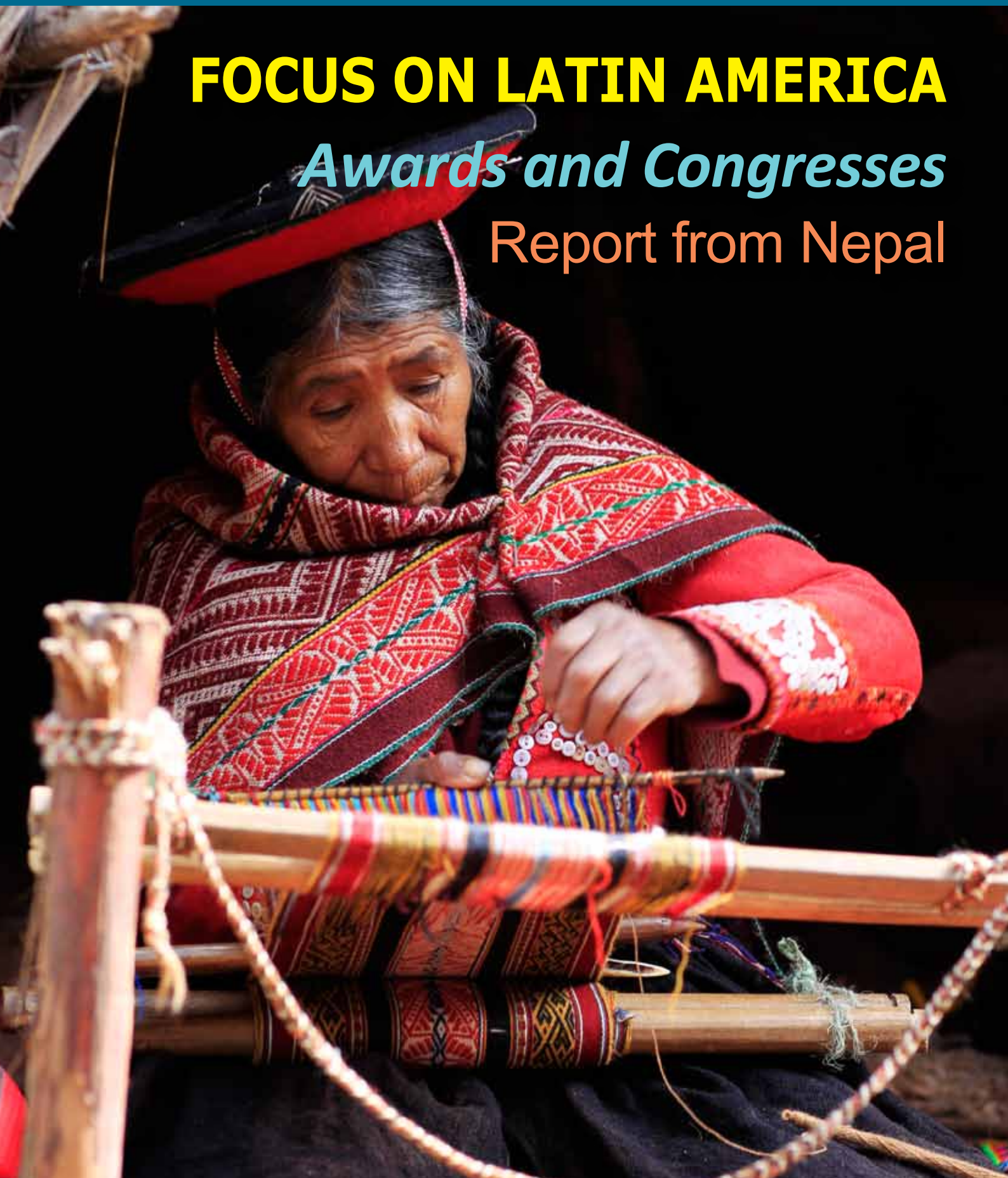
INTERNATIONAL

Epilepsy News

FOCUS ON LATIN AMERICA

Awards and Congresses

Report from Nepal





Continuing importance of Global Campaign!

Recently, three of IBE's Regional Vice Presidents took the opportunity to present the case for epilepsy in their region at WHO regional events and all felt that our message was well received.

I was reminded of this when I visited WHO's headquarters recently for my final visit there as IBE President. In the last four years I have observed a significant increase in the visibility of epilepsy on the world healthcare stage.

As we now prepare the ground for new Global Campaign Against Epilepsy projects in Ghana and Vietnam, it is timely to reflect on the success of the Global

Campaign over the past fifteen years.

The suspicion has to be that the GCAE will only be fully appreciated when it is gone. I do hope that that does not happen for a very long time as I am convinced that there is much more we can achieve with it.

Preparations are now at a very advanced stage for the 30th International Epilepsy Congress in Montreal. The current IBE International Executive Committee will meet early in the New Year to finalise these preparations and also work on the next round of Promising Strategies as well as all of its regular tasks.

2013 will also see another landmark reached when the 13th European Epilepsy & Society Congress is held in Ljubljana, Slovenia next August. This will be the first time that the congress has been held in a Central or Eastern European country which was part of the old Soviet system.

We believe that the conference will be a major success and would encourage all members to take the opportunity to attend and visit this lovely city at the same time.

With best wishes to all

Mike Glynn
President



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INTERNATIONAL RELATIONS

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WHO

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Celebrating IBE in Latin America!

The third issue of IE News 2012 celebrates the 7th Latin American Epilepsy Congress that will be held in November 2012 in the beautiful city of Quito, Ecuador. A report on some of the recent activities of our member associations in Latin American countries is a highlight of the magazine, with a specially extended version (in Spanish) for delegates attending the congress in Quito.

Also in this issue, we will continue with the ILAE and IBE history and now it is the turn for Ted Reynolds, who will provide us with the next chapter, just like a novel, of ILAE's history.

We are including reports about interesting

initiatives developed in Hong Kong and in Australia. After a break and due force majeure, we also will inform you about the redesigned IBE website; we invite you to visit it.

IBE President Mike Glynn's graduation with a Masters Degree in Epilepsy Services from Leeds Metropolitan University is a reason for pride, as is the Diploma in Epilepsy Care awarded to African Vice President Anthony Zimba, also in Leeds. We also congratulate our Executive Director, Ann Little on receiving an ILAE-CEA award in London

In addition we will inform you about the Joint Task Force activities developed in relation to an important Research Forum that will be held in Dublin next May during the Irish Presidency of the European Parliament. From Asia, comes a story of a support collaboration between Epilepsy Victoria in Australia and the Nepal Epilepsy

Association. Also from Australia, there is an article on a new Online Seizure Diary.

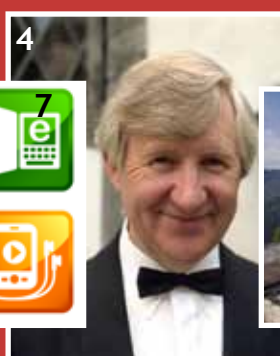
We would like to congratulate Emilio Perucca, Helen Cross and Samuel Wiebe on their elections as President, Secretary General and Treasurer, respectively, of the ILAE International Executive Committee 2013-2017. We wish success to all our good friends in their work.

Kind regards

Dr Carlos Acevedo
Editor

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THE ORIGINS OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

ESTABLISHED 1909

Part Four: The 50's and Early 60's

In the first part of his series on the history of ILAE, which was published in Issue 3-2010 of IE News, Ted Reynolds described the foundation of ILAE and its journal *Epilepsia* in 1909. Part 2 of the story recounted the period before and after World War II. Part 3 dealt with the period 1946 to 1957. Now the story continues, with the birth of IBE.

By the early 1950's ILAE had 10 chapters, including 4 in Europe - France, Great Britain, Netherlands and a non-functioning "Scandinavia"; 4 in South America - Argentina, Brazil, Chile and Peru; together with Japan and the USA.

The 1953 ILAE Constitution dropped any reference to a social objective and also stated: "The national branches should be primarily medical organisations, which may include in their membership laymen interested in the problems of epilepsy".

In the same year Bernard Ledebøer, who had been Medical Director in Heemstede in the Netherlands since 1930, and was now beginning his second term as Secretary General of ILAE, noted that three kinds of organisations in the "fight against epilepsy" had arisen in different countries:

1. Physicians
2. Lay-people
3. Mixed membership

He added: "Today it should be decided whether the League should restrict itself to the first group or whether it should be the uniting body for all the workers in the field of the fight against epilepsy. I can tell you that, personally, I am an advocate of the latter".

There is little doubt that tensions existed between scientifically and socially orientated physicians on the Executive in the 1950's, just as they had, periodically,

throughout the first 50 years of ILAE; this was a contributing factor to the founding of IBE in the early 1960's.

In the meanwhile there is a lack of documentation of the progress of ILAE between 1955 and 1961 for two reasons: ILAE's journal, *Epilepsia*, which in any case was only published annually, ceased publication from 1955. It was then revived in 1959 as a quarterly journal under a new editor, Sir Francis Walshe, a neurologist with a critical scientific track record as a former editor of the journal *Brain*. More seriously, with the death of Bernard Ledebøer in 1959 the archives of ILAE were mysteriously lost.

All we know for certain is that the quadrennial meeting of ILAE took place in Brussels in 1957 in conjunction with the 6th International Neurological Congress, the 4th International Congress of Electroencephalography, the 3rd International Congress of Neuropathology and the 1st International Congress of Neurological Surgery, an event which led to the foundation of the World Federation of Neurology.

The President of ILAE from 1953, Earl Walker, was a neurosurgeon and, surprisingly, he was re-elected in 1957 for a second term. This was something that has never happened subsequently, although there was a precedent with William Lennox. Even more surprisingly, Henri Gastaut, who was "President Elect" from

1953 to 1957, began the first of his two terms as Secretary General in place of Ledebøer, who died two years later, together with the archives. Although it would be interesting to know more about these political developments it seems clear that the medical and scientific approach was in the ascendency within ILAE, which is the backdrop to the initiation and development of IBE.

The details of the birth of IBE have been described by Harry Meinardi in an earlier article in this historical series (Issue 2-2010). In summary: As noted by Ledebøer, many countries had already established national associations of lay people in the post Second World War period.

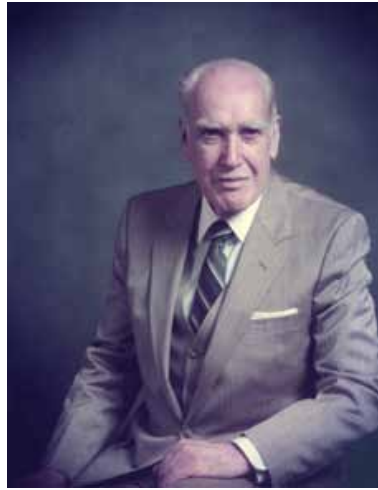
At the 1961 ILAE Congress in Rome, and on the initiative of the British Epilepsy Association, a Symposium was held on "The role of the lay organisation in the treatment of epilepsy". This led to the adoption of a formal proposal by Dr Mosovich (Argentina) to establish the IBE.

This was followed by discussions with the newly elected 1961-1965 ILAE Executive under its new President, Francis McNaughton, Head of the Montreal Neurological Institute in Canada, and including Henri Gastaut in his second term as the Secretary General. This initially led to the establishment of an informal IBE affiliated as the social arm of ILAE. It was run by a Board of Directors which included among

others, McNaughton and Gastaut as well as Ellen Grass (USA) and George Burden (UK), who later became President and Secretary General of IBE when it formally became an independent organisation with its own Constitution at the 10th World Congress of the International Society for Rehabilitation of the Disabled in Wiesbaden, Germany, in 1966.

Thus IBE evolved from ILAE, just as earlier in 1909 ILAE had evolved out of International Medicine.

In the meanwhile, by 1965, the number of ILAE Chapters had risen to 19 with the addition of Austria, Bolivia, Cuba, Germany, Israel, Italy, Poland, Sweden (in place of Scandinavia), Switzerland and Uruguay.



Notes:

A Earl Walker (1907-1995) - pictured above. The last to serve as President of

ILAE for two terms (1953-1961). A Neurosurgeon who represented the neuroscientific wing of ILAE.

Bernard Christian Ledebøer (1897-1959), served two terms as Secretary General of ILAE (1949-1957). As Medical Director of a special centre for epilepsy in Heemstede, The Netherlands, he represented the socially inclusive wing of ILAE.

Reference:

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

Solar Powered Victory

Brainwave's Brainbox



At Brainwave The Irish Epilepsy Association, they have always known that their Patron Rick O'Shea was a bit of a brainbox; now all of Ireland knows it as well, following Rick's runaway victory in the final of Ireland's TV Celebrity Mastermind competition.

Based on the well known and long-running BBC quiz series, *Mastermind*, where contenders sit under the spotlight in a black chair while facing two-minutes quizzing on their specialist subject and then two minutes of questions on general knowledge, the Irish celebrity version was all in the name of charity.

Rick O'Shea is a very well respected radio personality, who is not afraid to talk out about his epilepsy. As a contender in the competition, he had pledged any winnings to Brainwave.

Rick's general knowledge prowess and his in-depth understanding of his specialist subject, the Solar System, saw him survive the 4-minute grilling and storm to victory in the famous black chair, earning €7,500 for the work of Brainwave.

Rick also took the opportunity to raise epilepsy awareness by discussing his own life with epilepsy, and the work of Brainwave, with the show's presenter and master of ceremonies, former politician Nora Owens, before getting down to business to see off his opponents. He also won a special commemorative trophy and the respect of the Irish trivia-loving public for his outstanding performances in the series. Rick's great win put epilepsy very much in the spotlight and proved that a diagnosis of epilepsy doesn't have to be a barrier to achievement.

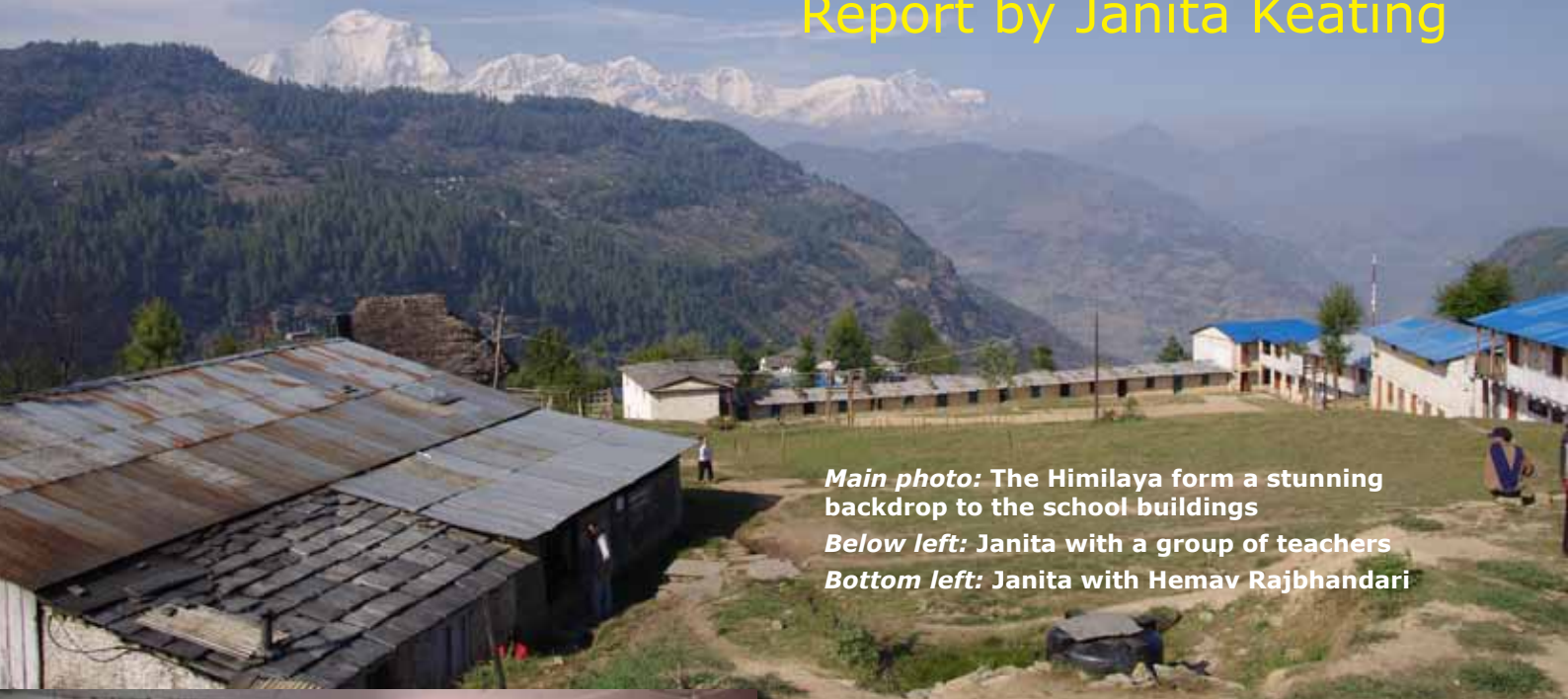
Need to pay dues for 2012?

The majority IBE member associations are up to date with annual membership dues and many have also donated to the Solidarity Fund. If you are one of the small number who have yet to settle dues for 2012, you will need to do so as quickly as possible to safeguard your IBE membership.

If you are a IBE Full Member, remember that only those in good standing are able to participate in the international and regional elections that are currently underway.

NEPAL Epilepsy education across continents

Report by Janita Keating



Main photo: The Himalaya form a stunning backdrop to the school buildings

Below left: Janita with a group of teachers

Bottom left: Janita with Hemav Rajbhandari



Nepal is a beautiful country, famous for its stunning Himalaya, rich culture and generous hospitality. In a country that is only 65% the size of Victoria, its population of about 27 million people is greater than all of Australia! Yet, there are fewer than 20 neurologists in the entire country.

Training is focused on emphasising:

- that epilepsy is a medical condition that should be treated by a doctor (not a shaman or witch doctor);
- that epilepsy is not contagious;
- that, when correctly diagnosed and treated by appropriate medications seizures can be well controlled in 70% of cases;
- that seizures are not the result of punishment or bad gods.

Those attending the training sessions also learned how to appropriately support the person during and after a seizure.

Five health workers and thirty teachers attended the sessions, with one health worker walking nine hours by foot to participate! Pictorial resources were distributed to the health workers to better enable them to continue the education process with newly diagnosed villagers. Linkages with NEA were established, so that any future questions or referrals can be addressed via telemedicine communications. Feedback from health workers and teachers was very positive.

The experience has highlighted how beneficial partnerships between international epilepsy organisations can be for both countries. Future joint EFV and NEA outreach epilepsy clinics in West Nepal are planned for September 2013.

A significant percentage of Nepalese people live in poverty, and are dependent on agriculture for a living. For those living with epilepsy, access to specialist support, medication and community understanding of this highly stigmatised condition is problematic and life can be very isolating and overwhelming.

A partnership between the Epilepsy Foundation of Victoria (EFV) in Australia and the Nepal Epilepsy Association (NEA) has recently seen Janita Keating, Education and Training Manager, EFV and Hemav Rajbhandari, Vice President NEA, IBE Full Member in Nepal, develop and deliver epilepsy education to teachers and health workers in the remote village of Nangi in the Myagdi District of West Nepal.



ONLINE SEIZURE DIARY



Epilepsy Action Australia recently introduced a new electronic seizure recording system to help people diary their seizures. Not only does a diary help people to recognise possible triggers or patterns and get clues to improving their situation based on what is really happening; the details can also be shared with close family members and, most importantly, with medical teams to help them provide the best and most informed care and advice.

Recognising the seizure management challenges facing people with epilepsy and the exciting potential of solutions found in technology, Epilepsy Action Australia took the plunge to launch an innovative online seizure diary. The online system, called 'My Epilepsy Diary' is being offered free of charge on its website www.epilepsy.org.au as part of a new integrated range of services available for people living with epilepsy. The organisation tells us that this is an Australian 'first'.

The seizure diary is a comprehensive clinical information organiser for people living with epilepsy. It was designed for use by people with epilepsy or their care givers,

to gather quality seizure data for better seizure management and control. Importantly people can choose to give clinicians direct access to their diary and in turn, to their seizure information, via an easy to use 'Clinician's Portal'.

To ensure privacy and security, the diary runs using Hypertext Transfer Protocol Secure, a connection that provides encrypted communication for better data protection. Once people have entered profile information, such as their medications, medical history and descriptions of seizures, the seizure diary is as easy to use as other online tools such as Facebook.

According to Carol Ireland, CEO of Epilepsy Action Australia, there are a range of pluses for people, their families and medical professionals. These include:

- A simple but comprehensive system to gather data using icons to represent seizures activity, side-effects, medications and dosages, making it straightforward to log important events and for later review at a glance.
- Creation of easy-to-follow reports and graphs mapping patterns. These can

then be taken to medical appointments as evidence of trends over time.

- Accessibility through the website via an easy secure log-in process. Users can update their diary on a desktop computer or mobile device (Android or Apple iPhone, iPod Touch and iPad) anywhere there is an internet connection.
- A note-making facility plus the ability to upload other relevant documents and photos that may prove valuable to know.
- Help to comply with medications through an SMS and email reminder system.
- Caregivers can log on and add data in the event a person is unable to do it themselves.
- Easy sharing by giving a doctor or nurse access to parts of the diary, or syncing with Google Health or Microsoft HealthVault.

Visit www.epilepsy.org.au to find out more. To watch a video on how the diary works, visit <http://my.epilepsy.com/node/989665>.



Congratulations!

Mike Glynn, IBE President and Anthony Zimba, IBE Vice President Africa, were recently conferred with a Masters Degree in Epilepsy Care and a Professional Diploma in Clinical Epilepsy Care respectively. Both graduated from Leeds Metropolitan University in the UK.

The Professional Diploma in Epilepsy Care, in which Anthony Zimba graduated, is an innovative distance learning course designed to meet the everyday practice and continuing professional development needs of health and social care professionals. The course has been written and developed in association with Epilepsy Action and York Teaching Hospital (NHS) Foundation Trust's specialist Neuro-Education unit.

Established in 1996, over 500 health, social care and voluntary sector professionals have now obtained this Diploma. The course is suitable for qualified health professionals working with people who have epilepsy and for those working in care support services and the voluntary sector.

Having completed the Diploma course some years ago, Mike went on to undertake more advanced studies in Epilepsy Practice, resulting in a Masters Degree.

EUROPEAN EPILEPSY FORUM

25th - 27th May 2013

Dublin - Ireland



Dublin 2013

Irish EU Presidency

European Forum on Epilepsy Research



Although the permanent offices of the European Union are based in Brussels, Belgium and Strasbourg, France, the Presidency moves around the 27 Member States, with each member country holding the role in rotation for a six-month period. From January to July 2013, it will be Ireland's turn to do so.

In conjunction with the Irish Presidency, a European Epilepsy Forum - a collaborative research conference funded by the 7th Framework Programme of the European Commission, and organised by the IBE/ILAE Joint Task Force *Epilepsy Advocacy Europe*, will take place at the end of May. The event also coincides with the European Month of the Brain in May 2013.

This will be the first conference on epilepsy research to be sponsored by the European Union and will, therefore, be a highly significant occasion. It will bring together, for the very first time, the key European stakeholders – including researchers, clinicians, epileptologists, neurologists, primary care physicians, basic neuroscientists, social workers, epilepsy specialist nurses, medical & post-graduate students, healthcare professionals, lay organisations, persons with epilepsy, health policy makers and government representatives.

The forum will have 3 key goals:

- more focused research funding
- the reduction of stigma associated with epilepsy
- pan-European access to optimal standards of care across Europe.

Six million people in Europe have epilepsy and approximately 300,000 new cases are diagnosed each year. This conference will build on the European Written Declara-



tion on Epilepsy, which was signed by 459 Members of the European Parliament in 2011, in the promotion and co-ordination of research in this still much misunderstood chronic condition.

With Horizon 2020 - the 8th European Union Framework Programme - due to be announced in 2013, the forum will present the opportunity to highlight the need for increased funding for epilepsy research in Europe.



Details of the programme are being finalised and further information will be available at www.epilepsyresearcheurope.org.



@EpilepsyCongress



Like us on Facebook



ILAE President 2013-2017

IBE sends best wishes to Prof Emilio Perucca (Italy), ILAE President-Elect. The new term of office will begin during the 30th International Epilepsy Congress in Montreal next June.

IBE's congratulations also go to Dr Helen Cross, UK (ILAE Secretary General-Elect) and Prof Samuel Wiebe, Canada (Treasurer-Elect). All three will also serve as ex-officio members of IBE's International Executive Committee.

Prof Perucca is currently ILAE Treasurer, while Prof Wiebe is ILAE Secretary General.

2013 MONTREAL

23rd - 27th JUNE, 2013

30th INTERNATIONAL EPILEPSY CONGRESS



MONTREAL CONGRESS AWARDS

IBE and ILAE member associations are invited to submit nominations for the awards of Ambassador for Epilepsy and Social Accomplishment, which will be presented during the congress in Montreal next year. The closing date for receipt of nominations is 31st December. Further information on these prestigious awards, including nomination forms, lists of previous recipients and award rules, are available on the IBE website or from the IBE office.

IBE Executive Director receives ILAE-CEA European Service Award



IBE Executive Director, Ann Little became the first recipient of the International League Against Epilepsy - Commission on European Affairs (ILAE-CEA) European Service Award when it was presented at the Opening Ceremony of the European Congress on Epileptology in London on 30th September.

The award is open to 'individuals in Europe of any profession who have made outstanding service contributions to European Epileptology and who have not received the Ambassador for Epilepsy Award'.

Pictured from left: Astrid Nebblig (France), Ann Little, Richard Holmes (IDM) and Pete Engel (USA).



13TH EUROPEAN CONFERENCE ON

Epilepsy & Society

LJUBLJANA, SLOVENIA
28TH - 30TH AUGUST 2013



Besides having everything that all the other modern capitals have, Ljubljana succeeds in maintaining the relaxed atmosphere of a small city. This picturesque, compact and very vibrant city is full of surprises for the visitor.

Ljubljana is classified as a mid-sized European city, but it has preserved its small-town friendliness and relaxed atmosphere while providing all the facilities of a modern capital. It is a very unique city dotted with pleasant picturesque places where you can expect all kinds of surprises.

Those who attend the 13th European Conference on Epilepsy & Society will not be disappointed, either with the city or with the conference itself. Already the European Regional Executive Committee (EREC) has spent a considerable amount of time discussing the congress - which will have the theme of Stand Up for Epilepsy to Break Down Barriers. Speakers have been identified and the official programme is almost ready.

The conference aims to inform people with epilepsy and their families, as well as those working in the field of epilepsy, about new developments in epilepsy treatment, associated cognitive dysfunction related to epilepsies, and the psychosocial implications that derive from this common brain disorder and, of course, to provide solutions.

But, more importantly for people with epilepsy and their families, the meeting

will 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.

A new introduction is a Train-the-trainers workshop, which is currently being outlined. Further information will be available on the conference website as details are finalised.

As is becoming a custom for the Epilepsy & Society meeting, a special Youth Session and a Karaoke evening are also on the cards!

The end of August is a great time to visit Ljubljana. The intense heat of summer will have subsided and pleasant temperatures of around 20 degrees can be expected. There is a range of accommodation available from 4* hotels to self-catering apartments and friendly bed & breakfast accommodation.

Within Ljubljana city there is much to see and a boat trip on the Ljubljanica river is a must. If you have time to spare, take the opportunity to move outside the city to enjoy the magnificent scenery that Slovenia has to offer. Who could fail to be enchanted by the town of Bled, one of Slovenia's most popular resort towns, famous



for its alpine lake with an island in the middle on which is perched the beautiful Bled Castle? Or how about a tour of the picturesque towns and villages along the Mediterranean coast?

Ljubljana and EREC look forward to welcoming you to the 13th Epilepsy & Society Conference next year, for what is going to be an excellent gathering of wonderful people. See you there!



www.epilepsyandsociety.org

PROMISING STRATEGIES 2013

Call for Letters of Intent

Introduction

IBE is committed to finding new and innovative solutions to the problems impacting people with epilepsy and their families worldwide. As part of this commitment, IBE provides financial support to IBE member organizations on a competitive basis for initiatives aimed at improving the quality of life for people with epilepsy in emerging nations through its Promising Strategies Program 2013.

Definition of a Promising Strategy

A promising strategy is one that will foster effective and innovative public health practice with regard to epilepsy. Ideally, a promising strategy contains many of the following:

- is based on measurable, realistic, and time specific objectives and is need-based and data-driven
- is innovative and represents the development of new solutions to common problems
- establishes a strategy that makes a difference in improving accessibility to accurate, timely, and culturally appropriate information or services
- demonstrates a sustainable effect in the community where it is being introduced
- has the potential for replication of positive results if the program is implemented in a similar environment, with a similar target population, as its original pilot demonstration
- is likely to be implemented in collaboration with other partners
- has a mechanism to evaluate results and get feedback to continue to improve the program.

Since its introduction in 2006, IBE has supported 70 initiatives, with a total of US\$300,000 provided to date. The total sponsorship fund for 2013 will be US\$50,000.

How to apply

To have your project selected for further consideration, the first step is to submit a short letter of intent, no more than one to two pages in length, giving an outline of the proposed project. The outline should include the likely total cost of the project and the level of funding being requested from IBE.

- The letter must be received at the IBE office no later than Monday 26th November 2012.
- Please note that applications from member associations that are not in good standing will only be considered in exceptional circumstances.
- Associations who have received funding to support projects in previous rounds will not be considered if the procedures financial and reporting procedures have not been adhered to.

Guidelines

Your association should be located in a country where the gross national income (GNI) is less than US\$10,000 according to World Bank figures. Exceptions may be considered.

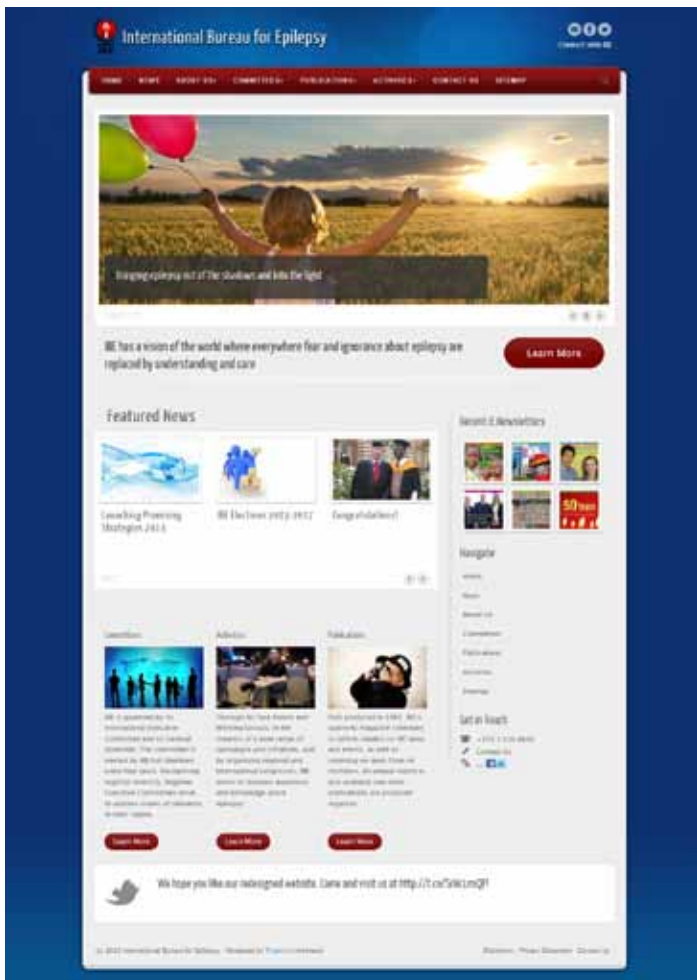
The project must be new; funding will not be provided to support an existing program or ongoing work of an association.

The initiative should:

- be sustainable after the end of the funding period and, ideally, be a program that could be copied by members in other countries.
- have a definite time line and a specific objective.
- be a program that can make a real difference to the lives of people with epilepsy and those who care for them.

How to Submit

Letters of intent must be submitted by email to the IBE office ibedublin@eircom.net, to arrive by 26th November 2012:



IBE Website has a New Look!

After some months of hard work, the new design of the IBE website has been launched! This is the first redesign since 2007 and brings the site up to date with the technological innovations that have been introduced since then.

Facebook and Twitter have been added and, in time, further social networks may be included.

Using the more traditional means of communication, you can now access any one of the six latest issues of IE News by a single click on the homepage.

We will use videos more widely and navigating your way around the site will also be more user friendly.

For members, the private member's section provides an easy access to forms, reports and a range of downloads.

Pay us a visit and see for yourself!

www.ibe-epilepsy.org



News from Rose Club Korea Korean Member of IBE



Professor Kyoon Huh (President) and Dr Chong Cheul Park (Honorary President and Advisory Board Member and former Vice President of IBE) have been working closely together since 2008 in developing many important activities for the Rose Club, the Korea Bureau of Epilepsy. Prof Huh tells us that the Korea Bureau of Epilepsy is driven by the

goal of promoting better socio-cultural status for the people with epilepsy and their families. Government funding has allowed the organization to offer training camps for 20 to 30 families of epilepsy patients once or twice a year. For 3 or 4 days, families are trained in epilepsy patient care and ways to encourage engagement in social activities.

Chronic, uncontrolled, or deteriorated epilepsy patients are offered monthly meetings in groups of between 40 and 100 for worship, discussion, counseling, and clinical supervision.

Severely ill patients are eligible to receive the government funding.

Currently, there are 20,000 people with epilepsy registered and monthly meetings are being held regionally, gathering 4,000 people with epilepsy each time.

The Nepal Thimi City Hospital (Korea-Nepal Friendship Hospital) was founded by KOICA (Korea International Cooperation Agency) and is under the manage-

ment of the Korea Bureau of Epilepsy (Rose Club Korea). Seven Members of the Rose Club Korea, including Korean doctors and nurses, serve as volunteers on the Advisory Management Board.

The hospital is equipped with a digital EEG machine and provides educational opportunities for hospital staff. Nepali doctors and nurses have been invited to Korea for the training in medical treatment of epilepsy, EEG technician training, and training for nursing.

Information booklets on various aspects of epilepsy in cartoon book format and quarterly Epilepsy News are published for patients, patient's families, educators, and the public to enhance the proper understanding of epilepsy.

Top photo: Dr Park (wearing yellow scarf) with Nepali colleagues.

Lower photo: People with epilepsy enjoy a recreational event, organised by the Rose Club Korea.



Epilepsi – uten ord

Epilepsy – without words

During the northern hemisphere summer, which has just finished, Norsk Epilepsiforbund - the Norwegian Epilepsy Association - organised a photography competition to raise awareness on epilepsy in Norway. The theme of the competition was inspired by the IBE Jubilee Photography Competition Epilepsy Without Words. Supported by an article in Norway's leading photography magazine 'Fotografi', the competition was judged by a panel of photography professionals, including the director of the magazine, a photographer and a designer as well as a representative from the Norwegian Epilepsy Association.

A total of 106 entries were received of which the best 40 were selected to form an exhibition to be mounted in a number of cities in Norway. The four winning photos received prizes ranging from 300 to 2,000 euro.

It is interesting to note that none of the winning images were submitted by people with epilepsy or related to a person with epilepsy. This means that the competition has reached out to the wider population, to people who had to research epilepsy in order to find out how to represent epilepsy visually.

Pictured is the winning entry 'Absence' by Berit Solstad, reproduced by kind permission of Norsk Epilepsiforbund.

The Ultimate in Doctor-Patient Trust

This photograph may not mean very much to you but, when you hear the story behind it, it becomes a very special image that shows a bond based on trust between a doctor and his patient. It was provided to us by Dr Shunglon Lai, from Taiwan - IBE Vice President Western Pacific, who happens to be the doctor pictured in the photo.

During the time the IBE Jubilee Photography Competition in 2011, he was asked by one of his patients, who was expecting a baby, to support her during labour. He was proud to be asked and, afterwards he thought how a photograph of the occasion would have been very special.

Recently, another patient asked Shunglon to support her during delivery and this time he took along a camera! The expectant mother had herpetic encephalitis at 16 years old. She had status epilepticus and was in a coma for more than one month at that time and she spent three months in hospital. After discharge, she had intractable seizures, but she still managed to graduate from high school and then university, and later worked for a tour agency.

She married when she was 26 years old and, despite taking four kinds of antiepileptic drugs, she still decided to have a baby. When the delivery date approached, she asked Shunglon if he would hold her hand during her labour.

'I want you to witness this joyous moment for me, which was a thank you for having taken care of her for so long', Shunglon said. You will be pleased to know that a beautiful baby girl was born and mother and child are doing well.



EUROPEAN EPILEPSY DAY

Monday 11th February 2013

11 FEBRUARY 2013
eed
EUROPEAN EPILEPSY DAY



STAND UP FOR EPILEPSY

NO Seizures Side-effects

Epilepsy
Advocacy
Europe



ILAE-CEA
IEREC
IBE

The 3rd annual European Epilepsy Day will be celebrated across Europe by IBE and ILAE member associations on Monday 11th February 2013. The IBE/ILAE Joint Task Force *Epilepsy Advocacy Europe* is organising a week of celebrations in the European Parliament in Brussels, starting on Monday 18th February. Events planned include an exhibition of the photography initiative *Stand Up For Epilepsy*, featuring international athletes

pictured with people with epilepsy; as well as a reception to launch the exhibition. It is also hoped to organise an significant workshop on the Prevalence and Cost of Epilepsy. Further details will be available as plans progress. Is your association planning anything special for European Epilepsy Day? If so, we would love to hear from you so that we can share your great idea with other members.



Journalism that reaches out and grabs you!

When a story is well researched and carefully written, it can jump off the page and grab your undivided attention. News reports or informative articles that are well written have an instant impact and remain in the public memory for a long time. Now it is time to reward such high standards!

Excellence in Epilepsy Journalism Award

The Excellence in Epilepsy Journalism Award is a joint initiative between the International Bureau for Epilepsy (IBE) and the biopharmaceutical company UCB, which recognises journalists who have excelled in reporting on epilepsy.

As the closing date for the Excellence in Epilepsy Journalism Award 2012 fast approaches, we are sending a last reminder to submit entries for this year's awards.

Consumer, health and medical journalists writing for print, broadcast or online outlets are invited to enter. Freelance journalists are also eligible.

Now in its fourth year, the annual Excellence in Epilepsy Journalism Award is attracting a growing number of high-quality entries from around the world, with 49 entries from 24 countries received last year.

Know someone who deserves the award?

The 2012 award is open to journalists around the globe, who can either submit their own work or be nominated by a third party. Do you know a journalist from your country who has written or broadcast on epilepsy in the past year and who you believe deserves recognition? Then why not seek their permission to submit their work for consideration?

There are four categories for entries:

- print
- online
- broadcast TV
- broadcast radio

One prize of €3,000 travel vouchers will be awarded for each category. It is encouraged that these travel vouchers could be used to defray travel costs related to further journalistic research and publications about epilepsy in an international context.

All entries must be the original work of the applicant that does not violate another party's copyright. Joint applications will be accepted and collaborators must give their consent and co-sign the entry form. Entries can be about any aspect of epilepsy but must have been published or broadcast between 30th November 2011 and 30th November 2012.

Journalists can enter no more than one article or broadcast item in the same category. Journalists may enter an article in both the online and print category if published in both categories and provided that a separate entry form accompanies each entry.

The independent judging panel will select articles or reports that are responsible, informative, original and support the aim of raising awareness and understanding of epilepsy.

How to enter

Full information on the award, together with the Entry Form, is available on the IBE website: <http://www.ibe-epilepsy.org/announcing-the-excellence-in-journalism-awards-2012/>. A copy of the rules and Entry Form can also be requested by email from the IBE office ibedublin@eircom.net. The deadline is 30th November so, don't leave it too late!

LATIN AMERICA

Special report marking
the 7th Latin American
Epilepsy Congress,
Quito 2012



A Region of Rich Historic, Geographic and Cultural Diversity

Many people are confused between the countries that comprise the continent of South America and the group of countries that make up the Latin American region. However, if we consider whence the term Latin America originated, the situation becomes much clearer.

Latin America designates those countries (or territories) in the larger Americas region where a language derived from Latin - that is, Spanish, Portuguese and, to a lesser extent French - are spoken. So, in addition to the Spanish, Portuguese and French speaking countries in the South American continent, the Latin American Region also includes Belize, Cuba, Dominica, Dominican Republic, El Salvador, Guatemala, Honduras, Mexico, Nicaragua and Panama (which are geographically in the North American continent).

It should be mentioned that Belize, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, and Panama form the Central America sub-continent of North America! And, to complicate matters even further, there are two countries in South America

were non-Romance languages are spoken: English in Guyana and Dutch in Suriname!

With extremely sophisticated and enormous empires that stretch back centuries before Christopher Columbus first dipped his toe in the water and set sail in the early 16th century - think Maya, Aztec, Inca - no single characteristic can possibly typify this vast area. It has tremendous diversity, not only in its landscapes and climates, but also in its architecture, music, art and people.

The geography of South America contains many diverse regions and climates. Peru, east of the Andes, is regarded as the most important biodiversity hotspot in the world with its unique forests that form the western edge of the world's largest rainforest, the Amazon Rainforest.

South America can also lay claim to three of the world's highest capitals: Bogotá, Colombia; Quito, Ecuador; and highest of all, La Paz, Bolivia.

In terms of tourism, Machu Picchu in Peru, the Galapagos Islands of Ecuador,

Iguazu Falls on the Brazil/Argentina border; Easter Island, Chile and the Mayan sites in Mexico are among the places on earth most people would rank high on their *Must Visit* wish-lists.

Yet despite its rich cultural history and breathtaking scenery, in much of the Latin American region a significant number of people live in poverty. In World Bank rankings, Guatemala lies in 113th place, with Bolivia, Honduras and Nicaragua all lying lower down the scale. Looking at Latin American nations, Argentina and Chile appear highest on the list, ranked 51st and 53rd respectively.

Despite difficulties caused by financial problems, epilepsy associations in Latin America have made tremendous strides in introducing and implementing new services and initiatives for people with epilepsy in recent years. Selfless efforts have also seen improvements in the legislation that affects people with epilepsy. More recently, with the approval of the PAHO Strategic Plan for Epilepsy that will see epilepsy as a priority for the next 10 years, there is cause for celebration and optimism that the next decade will see even greater strides forward for people with epilepsy throughout the Americas.

Countries in the IBE Latin American Region

(extracted from the listing of countries in the WHO region of The Americas)



In addition to the 12 countries that comprise the geographic landmass of South America (Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Guyana, Paraguay, Peru, Suriname, Uruguay and Venezuela), the IBE Latin American Region also includes those countries from North America and Central America where Spanish is the spoken language and where cultural traditions are similar to those of South American nations. Countries in which IBE is represented are highlighted in blue.

1. Argentina
2. Belize
3. Bolivia
4. Brazil
5. Chile
6. Colombia
7. Costa Rica
8. Cuba
9. Dominica
10. Dominican Republic
11. Ecuador
12. El Salvador
13. Guatemala
14. Guyana
15. Haiti
16. Honduras
17. Mexico
18. Nicaragua
19. Panama
20. Paraguay
21. Peru
22. Suriname
23. Uruguay
24. Venezuela



spearheading problems in Latin America

PROMISING STRATEGIES PROGRAM

Now beginning its seventh round, the IBE Promising Strategies Program is one of the most successful of all IBE's initiatives.

In the Latin American region, 13 projects have been supported to a total of US\$46,000. This represents almost 20% of the total 70 projects in 37 countries to have received support and almost one sixth

of the total funding figure of US\$300,000.

A Promising Strategy is one that fosters effective public health practice with regard to epilepsy, based on measurable objectives, that develop innovative solutions to common problems impacting people with epilepsy and their families. True to the focus of the program, strategies developed

in Latin America have made a real and tangible difference, with a sustainable effect in the community. Many have the potential to be used elsewhere in similar environments.

Here are some of the Latin American programs, which have been successfully completed.



Guidelines for Driving for People with Epilepsy

With a total ban on driving for people with epilepsy in Argentina, FUNDEPI undertook research to determine the optimal seizure-free interval for driving licence provision and to support measures to improve driving laws. The association produced a consensus proposal for driving for people with epilepsy and worked with the regulatory government department to encourage adoption into law.

GUATEMALA: Epilepsy information on CD

Guatemala is a large nation with great diversity of ethnic groups and languages. Although Spanish is the official language of the country, less than half the population speaks it. In addition, in particular in rural and isolated areas, the incidence of illiteracy is very high. To overcome this difficulty, audio cassettes and CDs were

produced in a range of languages spoken in Guatemala to explain epilepsy. The CDs can be played on mass transmission radios, on personal CD players or can be used by community groups to educate both people with epilepsy and members of the community at large on the true facts about epilepsy.



Epilepsy at School: Teaching the Teachers

Children with epilepsy suffer prejudice at school and this is responsible for much of the stigma in adult life. The program, introduced by the Associação Brasileira de Epilepsia in Brazil, was a teaching model about epilepsy to promote basic education about the disease directed at the biggest group of elementary school teachers in Latin America as well as in other Portuguese speaking countries.

The program was developed in two steps:

- A CD about epilepsy directed at Elementary School Teachers
- Introduction of an intervention program for Sao Paulo State.

Meet Juanito - the puppet who has epilepsy!

Puppetry is known to be successful in helping young people deal with issues that can be difficult to confront. ANLICHE, in Chile, introduced us to Juanito and his puppet family in videos aimed at 7 to 12 years-olds. The stories started with the diagnosis of epilepsy and looked at how the family confronts and then accepts the diagnosis. It was shown to more than

5,000 students in 20 primary schools in the Metropolitan Area of Chile, to eliminate stigma and improve the self-esteem and self-confidence of children with epilepsy. After screening, a social worker was in attendance for discussion. In addition, the Chilean Ministry of Education agreed to make more than 200 copies of the video available to schools throughout Chile.





Training for PERManent Employment in Chile!

The ANLICHE hairdressing workshop trained people with epilepsy in hair-dressing techniques for ladies, gents and children. The participants also took a course on running a small business, so that they could set up their own micro enterprises once trained. The workshop

was aimed primarily at housewives whose epilepsy was now well controlled. The women would have had little chance to study or work while still having seizures and had neither social benefits nor healthcare assistance within the normal parameters of a national health system.

ECUADOR: Provision of Medication

In providing free medication, Centro Nacional de Epilepsia APNE believes that people with epilepsy receive not only economic support but, also, moral support, in realising they are not abandoned.

Delivery of the medication happens at support meetings, so people with epilepsy are encouraged to become involved in finding out more about their condition and there

is the opportunity to talk about problems encountered.

Benefits that have been witnessed since the project began include increase in compliance, reduction in the number of seizures, improved self esteem, better employment opportunities which, in some cases, have allowed people to begin buying their own medication.



Home Clinic: COLOMBIA

The aim of the HomeClinic project of the Foundation for the Rehabilitation of People with Epilepsy (FIRE) is to help people with epilepsy and their families through the creation of a welcoming space, where pupils can develop basic life skills such as independence in dressing, feeding, bathing and other everyday activities. The general purpose is to educate with dignity,

regardless of physical or mental health, using individual and group activities, involving the family and the community. HomeClinic hopes to improve the quality of life of those attending the course, and their families.

The program is for young children with epilepsy and associated syndromes in the age group of 4 to 10 years of age.

Strategic Plan on Epilepsy

The Pan American Health Organization (PAHO) has approved a strategic plan that will see epilepsy as a priority in every country in Latin America for the next 10 years - the first time this has happened in the 100 year history of the organization.

Participants attending a special workshop in Honduras, September 2011, at which the plan was launched





7^{mo} Congreso Latinoamericano de Epilepsia QUITO, ECUADOR

Entre los días 14 y 17 de Noviembre 2012, se llevará a cabo, el 7^{mo} Congreso Latinoamericano de Epilepsia, en Quito, Ecuador. Hermosa ciudad, como sabemos, declarada Patrimonio Cultural de la Humanidad.

En este congreso, el primer día se dará inicio al curso de ALADE, en el cual se tratarán tópicos como los mecanismos básicos de las epilepsias, un curso de farmacología y otro de Electroencefalografía, siguiendo con sesiones de semiología y genética.

Ese mismo día estará la clásica Jornada del IBE, organizada por el capítulo local y los temas serán sobre escolarización y epilepsia además de la ayuda de la neuro-psicomotricidad, en el manejo de las epilepsias.

La sesión plenaria presidencial, tratará el tema de las Epilepsias para las Américas, con la participación de IBE, ILAE, OMS y OPS. Tema trascendental para el desarrollo

de políticas en epilepsias para los próximos diez años, con la contribución activa de cada uno de los estamentos enumerados.

Entre los temas a discutir, estarán desde el diagnóstico, etiología y tratamiento de las epilepsias de los niños y adultos. Por otro lado, se discutirán, epilepsia y sueño, epilepsia y mujer y simposios que contarán las experiencias de los planes nacionales de epilepsia y las guías clínicas y consensos.

El día 13 de Noviembre, habrá una reunión para los representantes IBE e ILAE de los capítulos de cada país, con la participación de representantes de OMS, OPS para evaluar lo realizado y proyectar el trabajo futuro, sobre el desarrollo del Plan Estratégico para la epilepsia en las Américas.

El Centro Nacional de Epilepsia y la Asociación de Padres de Niños con Epilepsia

(Capítulo Ecuador del International Bureau for Epilepsy) consecuentes con sus objetivos de ampliar conocimientos sobre las complejidades de la Epilepsia en el niño, ha diseñado una programación que atañe a profesionales de la salud, de la educación y familiares, que se realizará el día 14 de noviembre de 2012 dentro de la programación establecida en el Congreso Latinoamericano de Epilepsia.

Durante este día se desarrollarán el Simposio Internacional: *Escolarización y Epilepsia; y, el Seminario: Neuropsicomotricidad*, una ayuda en el tratamiento del niño con Epilepsia, en los que intervendrán prestigiosos científicos e investigadores nacionales e internacionales.

Noticias de los Miembros del IBE en Latinoamerica



FUNDEPI ARGENTINA

La Dra Silvia Kochen, reciente Directora Ejecutiva de ALAE, nos envía la resolución y estatutos, de la formación de esta nueva institución integrada por pacientes y profesionales: ALAE - Asociación de Lucha Argentina contra la Epilepsia, una organización sin fines de lucro, de conformidad con las leyes de la Argentina.

Entre los miembros fundadores son:

- Sr Jorge Loventó, Presidente Fundador
- Dra Veronica Campanille, Vice-Presidente
- Dr Jacobo Mesri, Vice-Presidente

- Dr Adrián Muñoz, Vice-Presidente
- Dra Silvia Kochen, Director Ejecutivo
- Dra Estela Centurion, Tesorero
- Lic Daniela Franceschetti, Secretario
- Sra Daniella Puñales, Vocal
- Dra Agustina Roel, Vocal
- Dra Laura de Viñas, Vocal
- Nicolás Lombardi, Vocal
- Dr Jorge Florida, Vocal
- Dra Maria Taboada, Vocal
- Dr Luis Pasteris, Vocal
- Dra Silvia Oddo, Secretario - Actas.

BRASIL

En la edición de International Epilepsy News, numero 4, del 2011, aparece El Lado D de las EPILEPSIAS.

Los autores, Paula Fernández y Li Min Li, conocidos investigadores en nuestro medio, ganaron el IE News Jubilee Award.



La Dra Lilia Morales Chacón, presidenta de la Liga Cubana contra la Epilepsia, nos informó sobre la página Web de la liga Cubana, donde aparecen noticias tanto del Capítulo del IBE, como de la ILAE. El coordinador del capítulo IBE, es el Dr Justo Reinaldo Fabelo Roche.

CUBA

CHILE

Se realizó el lanzamiento oficial del Manual sobre el Consenso Chileno de Manejo de Fármacos Antiepilepticos en algunos síndromes electroclínicos y otras epilepsias en niños y adolescentes, el día 9 de Septiembre 2011.

Entre los días 27 y 29 de Abril 2012, se realizó en la Ciudad de Los Ángeles, Chile, el XV Encuentro Nacional de Asociación de Ligas Chilenas contra la Epilepsia. Invitado internacional fue el Sr Mauricio Olave, quien expuso sobre las Características y Organización de FIRE. Por otra parte, se entregó el Premio Anual de Periodismo, a Diario La Tribuna, de la Ciudad de Los Ángeles, por su constante contribución al conocimiento y des estigmatización de las epilepsias.



FOTO: Los días 19 a 21 de Abril 2012, se llevó a cabo, en Santiago de Chile, el V Simposio Internacional de Epilepsia, organizado por la Liga Chilena contra la Epilepsia (IBE). Los conferencistas internacionales fueron: Michel Baulac, Jacqueline French, Hans Luders, Soheyl Noachtar y Jorge Rodríguez (OPS).



GUATEMALA

Representante IBE para Guatemala:

- Dr Henry B. Stokes
- Dra Arla Cinderella Stokes Brackett

Comité

- Presidente: Lic Elizabeth Stokes
- Vice presidente: Dr William R Sánchez
- Secretaria: Lic Waleska Yoc
- Secretaria adjunta: Señora Josefina Godínez
- Tesorero Dr Migda Herrera
- Tesorero adjunto: Lic Silvia López
- Vocales: Lic Federico Álvarez, Señora Silvia Vernon, Lic Mirna Pérez, Lic Valeska Camposeco, Lic María Lemus, Lic Arely Rodríguez, Lic Ana Fajardo, Lic Estela Rivas, Lic Isis Marroquín, Srita Yaneth Ortega

Objetivos Generales:

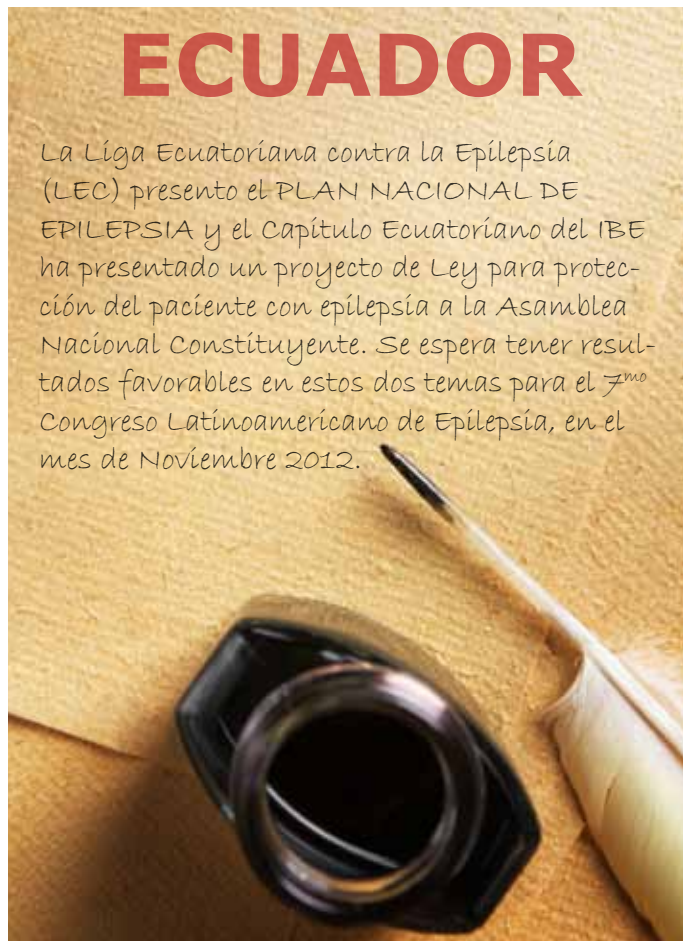
- Sacar la epilepsia fuera de las sombras del desconocimiento, miedo y represión social
- Enfrentar el temor y la vergüenza de pacientes con epilepsia y familiares con educación, asesoría y medicina

Objetivos Específicos:

- Planificación y Organización de Actividades de información para la población general acerca de la condición médica de la epilepsia.
- Informar al paciente y familiares acerca de:
- Planificación y Organización de Actividades en grupos de apoyo con el fin de facilitar comunicación, conocimientos; e intercambio de opiniones y experiencias personales entre los pacientes y familiares.
- Planificación y Organización de talleres para brindar herramientas útiles para los pacientes y familiares.

ECUADOR

La Liga Ecuatoriana contra la Epilepsia (LEC) presento el PLAN NACIONAL DE EPILEPSIA y el Capítulo Ecuatoriano del IBE ha presentado un proyecto de Ley para protección del paciente con epilepsia a la Asamblea Nacional Constituyente. Se espera tener resultados favorables en estos dos temas para el 7^{mo} Congreso Latinoamericano de Epilepsia, en el mes de Noviembre 2012.



HONDURAS



FUNDAHEP

*Juntos en la búsqueda de ayuda,
salud y esperanza.*

Desde Julio 2012, la Fundación Hondureña de Epilepsia, es Miembro Pleno del IBE, siendo su capítulo presidido por el Sr Eduardo Rodas.



URUGUAY

El 22 de Junio tuvieron la celebración de los 10 años del Programa de cirugía de Epilepsia. En ella participaron pacientes y familiares. Son un grupo muy activo y tuvieron la iniciativa de presentar una encuesta organizada por ellos, sobre algunos aspectos de conocimiento sobre epilepsia entre la población general.

Foto: Celebración de los 10 años del Programa Uruguayo de Cirugía de la Epilepsia



VENEZUELA

Los miembros de la Junta Directiva principal realizaron en Noviembre 2011 en Caracas un Simposio divulgativo, abierto a profesionales, interesados y público en general denominado "Alternativas Terapéuticas en la Epilepsia" tal como fue acordado en reunión del Bureau Latinoamericano de Epilepsia, en Roma, presidido por la Dra Lila Nuñez, en el marco del Congreso Internacional.



OTROS PROYECTOS

Sr Mike Glynn, presidente del IBE, nombró al Sr Mauricio Olave, de Colombia, como director del Comité Latinoamericano del IBE. Fue felicitado y bienvenido al Comité. El es Fonoaudiólogo y es Subdirector de FIRE.

ALADE: En la reunión en Roma, se decidió que el IBE, se integrase a ALADE, y en general como comisiones regionales hermanas, íbamos a evaluar la posibilidad de presentar patrocinios entre ambas para actividades comunes. Dr Tomás Mesa, quedó como representante del IBE para comité de educación de la comisión Latinoamericano de la ILAE.

Comisión Internacional de Investigación del IBE (Research Task Force), ha estado trabajando activamente. Hizo en primer lugar una encuesta a investigadores de todas las latitudes, teniendo una buena respuesta nuestra región. Además, se ha llevado a cabo reuniones en Roma y conferencia telefónica, con el fin de estimular la investigación y la comunicación entre los autores. El próximo encuentro será a fines de Septiembre en Londres.

Día Latinoamericano de Epilepsia: el 9 de Septiembre, es la fecha de celebración, en la cual cada país realiza actividades con la comunidad y pacientes. En algunos lugares, se extiende las actividades a toda la semana.



Estrategias y Plan de Acción en Epilepsias para las Américas

OPS/ILAE/IBE

los miembros de la ILAE y la PAHO, así como la comunidad de epilepsia puedan reunirse y trabajar con sus gobiernos para mejorar la atención de la epilepsia y la investigación en cada país. Instamos a todos a trabajar con sus organizaciones y gobiernos nacionales a elaborar planes de acción que cumpla con las metas en sus respectivos países.

Diez años no es mucho tiempo y el logro de los objetivos esenciales no será posible sin planes claros y bien considerados. Para la región de América Latina, se ha solicitado a Carlos Acevedo y Marco Medina que cada país tenga un plan en marcha por la reunión regional celebrada en Quito, y nosotros apoyamos ese objetivo.

Por favor, comience. El acuerdo es una oportunidad sin precedentes que no podemos permitir que nos pase de largo.

La Liga a través de sus comisiones regionales, y la Oficina a través de sus comités ejecutivos regionales, ayudará en todo lo posible para desarrollar los planes nacionales. Esperamos poder aprender los enfoques creativos de cada país toma en la creación de un plan nacional para la epilepsia.

Damos las gracias a todos por su dedicación a la causa de la epilepsia.

Atentamente,
Nico and Mike

Nico Moshé, MD
President
International League Against Epilepsy

Mike Glynn
President
International Bureau for Epilepsy

Charles Frost
Professor of Neurosurgery and Neurology
Albert Einstein College of Medicine

Plan que fue lanzado en Honduras en el mes de Octubre del 2011 y se estableció una alianza con la Secretaría de Salud (la Vice Ministra estuvo allí), OPS/OMS, IBE, ILAE, Universidad Nacional.

Carta de los Presidentes

A todos nuestros colegas de la epilepsia en las Américas,

Como ustedes saben, en septiembre de este año, la Dirección General de la Organización Panamericana de la Salud aprobó una resolución de apoyo a la Estrategia y Plan de Acción para la Epilepsia en las Américas. Esta resolución se ha comprometido con todos los países miembros de la OPS para la elaboración de planes nacionales para la epilepsia. Se trata de un desarrollo sin precedentes que da esperanza

a las personas con epilepsia, así como a aquellos que cuidan de ellos. También es un hecho que nos obliga a tomar la iniciativa para asegurarse de que esta oportunidad no se pierda.

Hemos escrito a los dirigentes de los organismos nacionales de salud dándoles las gracias por su apoyo a la epilepsia, y presentándoles a los líderes de los capítulos nacionales de la Liga y las asociaciones nacionales miembros de la Mesa. Les hemos pedido que trabajen con la comunidad de la epilepsia en su país para cumplir con los objetivos del Plan de Acción.

La resolución y el Plan de Acción <http://www.ilae-epilepsy.org/Visitors/News/paho.cfm> están en vigor para los próximos diez años, y aún queda mucho por hacer para alcanzar los objetivos. Es hora de que

ASAMBLEA GENERAL COMITÉ LATINOAMERICANO DEL IBE

Agosto 2010

Cartagena de Indias



Asistentes: Dr Carlos Acevedo (Chile), Sra Norma Bragunde (Uruguay), Dra Alicia Bogacz (Uruguay), Dra Verónica Campanille (Argentina), Sr Mike Glynn (Irlanda), Dr Laura Guilhoto (Brasil), Ann Little (Irlanda), Dr Tomás Mesa (Chile), Dr Franklin Montero (República Dominicana), Dra Lilia Nuñez (México), Sr Mauricio Olave (Colombia), Dr Henry Stokes (Guatemala), Dr Ernesto Triana (Panamá).

Directiva:

- Dra Lilia Nuñez, Presidenta. (México)
- Dra Elza Marcia Yacubián, Vicepresidenta. (Brasil)
- Dr Tomás Mesa, Secretario. (Chile)
- Dr Carlos Acevedo, Vicepresidente Regional LA (Chile)

Tabla:

Dra Nuñez da la Bienvenido a todos los asistentes y presenta la tabla a tratar.

Dr Mesa da lectura Acta Anterior (de reunión realizada en Budapest), la que se aprueba.

Sr Mike Glynn, Presidente del IBE: manifiesta su agrado de participar en esta asamblea, recalando que el Comité LA del IBE, es uno de los mejores grupos de trabajo regionales. Está muy interesado en escuchar el avance los proyectos educativos de estrategias promisorias que se presentaran en el congreso. Por otro lado, le gustaría saber la posición de los países de la región, en relación a otra alternativa de sede para el próximo congreso LA, cuya primera candidatura la tiene Ecuador. Manifiesta que se está en plena organización para el congreso de Roma 2011, momento que se celebraran los 50 años de

la creación del IBE. Espera que en Europa se celebre el día Europeo de la Epilepsia, teniendo como modelo lo que se realiza en LA.

Congreso ROMA 2011: se comenta sobre la posible participación del IBE LA en dicho congreso. El comité organizador se reunirá próximamente en Portugal, para los planes a seguir. Se expondrán los mismos posters que se presentaron en este congreso de Cartagena. Por otro lado hay un concurso de fotos, cuyas bases se han distribuido ampliamente.

Congreso LA 2012: se manifiesta la preocupación por el posible resultado económico de la realización el congreso en Ecuador. Sr Holmes, explica que es muy importante contar con una o dos posibles sedes extras, para así poder negociar tarifas, precios de hoteles etc. Bolivia estaría interesada, pero no es posible, ya que no cuenta con capítulo de IBE. Se propone por decisión de la asamblea: aparte de Ecuador, como otras posibles sedes a México y Argentina. La decisión final la tomará el comité ejecutivo, antes de Marzo 2011. Reporte del Vicepresidente Regional: Dr C Acevedo:

Campaña Global: se modifica la presidencia de esta campaña, quedando a cargo ambos presidentes de IBE e ILAE. Para Latinoamérica, se nombra por IBE al Dr Li Li Min (Brasil) y por ILAE, al Dr A Scarameli (Uruguay). La idea es trabajar en tópicos como leyes, tratamiento, día latinoamericano, libro de situación regional, educación etc.

OPS: se ha establecido contactos con

el Dr Jorge Rodríguez, para crear planes de impacto LA en tópicos de epilepsia a diferentes niveles, en particular con los ministerios de salud.

Agradece a Susanne Lund y Mike Glynn, por el apoyo que le han brindado en las distintas iniciativas.

El programa de proyectos de estrategias promisorias ha tenido bastante éxito y la idea es que continúen.

Epilepsy News: sigue con artículos de todas las regiones y una sección en español. Se abre la iniciativa de establecer premios para profesionales y no profesionales.

Reunión IBE-ILAE: se realizó el día 31 de Julio 2010, la tercera reunión de los comités ejecutivos LA de ambas instituciones. Se planea continuar con estrechos lazos, trabajando en educación y epilepsia, compartir materiales de ILAE, organización de congresos, utilizar sitios WEB, participación en ALADE. En ALADE (comisión de educación de ILAE), se acuerda incorporar a 3 representantes del IBE.

SitioWEB: Existe una sección latinoamericana en la página del IBE. Se suben noticias, reportes, actas, fotos.etc. Se plantea la posibilidad de hacer algo más ágil, más activo, con un estrecho lazo entre nuestros capítulos y que recolecte material de divulgación para no médicos y material para médicos. Para esto, se nombra a la Dra. Alicia Bogacz (Uruguay), para que presente un proyecto.

Le cooperaran: Dr Franklin Montero (R Dominicana) y Sr Mauricio Olave (Colombia). La traducción al portugués estará a cargo Dra Laura Guilhoto (Brasil).

Se hará un catastro de las páginas web existentes actualmente, para asociarlos.

Nuevos Capítulos: se comenta de los posibles nuevos capítulos IBE. Los contactos actuales son: Panamá: Dr E Triana, Bolivia: Dr F Fortun, Paraguay: Dr C Oliveira.

Se sugieren pasos a seguir al Dr Triana, quién expone la gran demora que toman los aspectos legales en su país.

Otros países pendientes: Belize, Costa Rica, Honduras, Nicaragua, San Salvador

Presentación de Países: se presentan los representantes de los países asistentes a la asamblea y comentan algunas novedades. Quedan de enviar reportes anuales a la secretaria:

ARGENTINA: Dra V Campanille, quien pertenece a FUNDEPI, expone la situación de ALCE, organización que representa el capítulo del IBE en Argentina. No es operativa, ya que no informa de sus actividades ni asiste a congresos. Se solicita apoyo al Comité LA del IBE, para solucionar situación. Dra Campanille nos enviará fono, dirección y persona a cargo, para ubicarla y conversar.

BRASIL: Dra Guilhoto cuenta que el Dr Luis Otavio Caboclo fue elegido nuevo presidente de la Asociación Brasileña de Epilepsia (ABE).

Enviaran el reporte de actividades.

Colombia: Sr Olave, manifiesta que están trabajando temas de Calidad de Vida y realizando talleres.

CHILE se comentan las actividades que se realizan, entre ellas cursos mensuales para diferentes profesionales, curso internacional para médicos, trabajos de investigación y proyectos de estrategias promisorias.

Actividades septiembre '09 – septiembre '10:

2009

04 al 12 Septiembre:

- Semana de la Epilepsia: Campaña "Juntos le ganamos a la Epilepsia"
- Taller de pintura para niños "Ponte la camiseta por la Epilepsia"
- Taller para Padres "Juntos le ganamos a la Epilepsia"
- Voluntariado visita Instituto de Neurocirugía
- Actividades voluntariado CEDEI

05 Septiembre:

- I Curso de Epilepsias para Técnicos Paramédicos – Santiago

09 Septiembre:

- Ceremonia Día Latinoamericano de la Epilepsia
- Curso Básico de Epilepsia en 33ª Comisaría de Carabineros
- Charla sobre Epilepsia Colegio Orlando Letelier

12 Septiembre:

- Fiesta en familia "Juntos le ganamos a la Epilepsia"
- Voluntariado difusión con folletos "Que hacer ante una crisis de Epilepsia".

26 Septiembre:

- IX Curso de Capacitación en Epilepsia – La Serena

03 Octubre:

- Repetición Curso de Epilepsias para Técnicos Paramédicos – Santiago

23 Octubre:

- II Curso Básico de Epilepsias - Santiago

05 Noviembre:

- Cena Bingo

07 Noviembre:

- X Curso de Capacitación en Epilepsia

– Talca

14 Noviembre:

- XI Curso de Capacitación en Epilepsia – Curicó

11 Diciembre:

- Finalización Año CEDEI

16 Diciembre:

- Ceremonia finalización Talleres Autoayuda y Valoración Personal

18 Diciembre:

- Ceremonia finalización actividades Taller Diferencial Dr Alfonso Asenjo Gómez

Enero a Septiembre 2010

11 al 29 Enero:

- Proyecto "Disfrutando Mi Verano" Actividad para niños y jóvenes con Epilepsia – CEDEI - Santiago

19 Marzo:

- Curso Básico de Epilepsia- Santiago

9-10 Abril:

- Simposio Internacional de Epilepsia - Santiago

30 Abril:

- Inauguración Sede Las Condes, Liga Chilena contra la Epilepsia – Santiago

8 Mayo:

- Simposio Epilepsia Adolescencia – Santiago

14 Mayo:

- Curso de Capacitación en Epilepsias para Técnicos en Electroencefalografía – Santiago

15 Mayo:

- Curso de Capacitación en Epilepsias para Profesores- Santiago

19 Junio:

- Curso de Capacitación en Epilepsias para Alumnos de Pedagogías- Santiago

24 Julio:

- Curso de Capacitación en Epilepsias para Enfermeras – Santiago

14 Agosto:

- II Curso de Capacitación en Epilepsias para Enfermeras – Santiago

28 Agosto:

- Curso de Capacitación en Epilepsias – La Serena

4 al 11 Septiembre :

- Semana de la Epilepsia

4 Septiembre:

- Simposio Epilepsia y Mujer- Santiago

09 Septiembre:

- Ceremonia Día Latinoamericano de la Epilepsia

11 Septiembre:

- Fiesta en familia: Actividad que reúne a la Familia

REPUBLICA DOMINICANA: Siguen trabajando en la organización llamada: Sociedad Dominicana Unidos por la Epilepsia.

Guatemala: continúan con actividades en



la página WEB y con las audio-lecturas.

Mexico: grupo Aceptación de la Epilepsia sigue trabajando en forma habitual.

URUGUAY: presente en esta reunión con dos representantes: Sra Norma Bragunde y Dra A Bogacz

El capitulo uruguayo del IBE, AUCLE, continua a la búsqueda de un local propio que le posibilite la realización de sus proyectos de apoyo a la educación de las personas con epilepsia.

Mientras tanto, se están reorganizando los grupos de autoayuda en conjunto con el capitulo uruguayo de la ILAE, LUCE, para que funcionen en Hospital universitario, que actualmente facilita un lugar de reunión a otros grupos de pacientes o sus familiares.

Se trabajó en conjunto con la Dra Patricia Braga en la validación de cuestionarios de calidad de vida y su adaptación a nuestra cultura.

Con el apoyo de un grupo formado por pacientes operados en el Programa de Cirugía de Epilepsia y sus familiares el capitulo ha tomado nueva energía para la realización de sus proyectos. En especial la Ley de protección de los derechos de las personas con epilepsia, que recibió aprobación de la comisión parlamentaria en el ejercicio anterior y que debería pasar para su aprobación por las Cámaras en este nuevo ejercicio.

Se realizó una función de cine a beneficio del capitulo en la cual se pasó un video informativo, en conjunto con LUCE.

Esperamos que el 2010-2011 nos permita mayores logros.

VENEZUELA: Las siguientes fueron las actividades del Buró Venezolano Contra la Epilepsia – BUNACE, durante el año 2009:

- Planificación y realización de Cursos sobre epilepsia abiertos a profesores, maestros de primaria y público general, realizados en la Ciudad Capital, participando como conferencistas.
- Incorporación en Programas de tipo informativo de radio y televisión como parte de la Responsabilidad Social de dichos medios de comunicación social.
- Trabajo y Diseño de Seguro de Vida por medio de una empresa aseguradora que acepta incluir a personas con epilepsia en coberturas de Cirugía, Maternidad y Hospitalización
- Se adelantan gestiones para lograr la implementación de Capítulos del Buró a escala nacional
- Se integra el Buró y el GAPE (Grupo de Amigos de Personas con Epilepsia)
- El Buró implementa alternativas para recabar fondos a ser utilizados en la Campaña de Despistaje de Epilepsia en Niños y Adultos que se realizara el próximo año en el mes de Mayo 2010 en locales de cadenas de farmacias a escala nacional.
- Participa en charlas a escala nacional dirigidas a maestros y profesores escolares centrada en el tema de Calidad de Vida de las personas con epilepsia.
- El Buró y GAPE han realizado entrevistas en la sede de LIVECE para identificar a aquellas personas de escasos recursos económicos que no cumplen el tratamiento a fin de proveerles los medicamentos a través de donaciones de la Industria Farmacéutica.
- Se discute el Ante Proyecto de la Ley de Protección al Epiléptico presentado por La Liga Venezolana Contra la Epilepsia - (LIVECE) encaminado a mejorar la Calidad de vida de personas con epilepsia. Este Proyecto

de Ley se introducirá en la Asamblea Nacional de la República de Venezuela para el año 2010 una vez cubiertos los aspectos legales.

- Participa con LIVECE en la programación y ejecución de Trabajos de Investigación así como en Jornadas para medir incidencia y prevalencia de epilepsia en el país.
- Elección, escogencia y designación del nuevo Presidente del Buró, resultando el periodista y Lic René Scull Mederos.

SUIZA: El Sr Pachlatko, representante de EPISUISSE, institución que tiene 125 años y que desde 2003 es capítulo Suizo de IBE, agradece la invitación a esta asamblea, informando que el comité ejecutivo IBE-ILAE en suiza, trabajan juntos. Además dice que el 5 de Octubre es el día de la epilepsia en su país.

Informe Asamblea General Comité Latino Americano Del IBE, Cartagena 2010

Nombre de los asistentes:

- Carlos Acevedo
- Norma Bragunde
- Alicia Bocagz
- Verónica Campanille
- Mike Glynn
- Beatriz González del Castillo
- Laura Guilhoto
- Ann Little
- Tomás Mesa Latorre
- Franklin Montero
- Mauricio Olave
- Christoph Pachlatko
- Henry Stokes
- Ernesto Triana

Tomás Mesa

Secretario Comisión LA del IBE

Futuros Capítulos IBE en Latinoamérica

BOLIVIA

El curso del XIII congreso Panamericano de Neurología, (Marzo 2012) llevado a cabo en la ciudad de La Paz, Bolivia, el Secretario del Comité L.A. del IBE, tuvo la oportunidad de junto con el Dr. Federico Fortún y con el voluntariado Boliviano contra la epilepsia, que tiene cerca de 50 años de existencia y han contribuido a construir las dependencias y edificio de Neurología y neurofisiología del Hospital Público de la Paz. Se mostraron muy interesados en pertenecer al IBE, por lo que comenzarán con los trámites pertinentes.

PARAGUAY

Pendientes están los trámites para postular a ser miembro del IBE.



Grupo de Voluntarias de la Paz, Bolivia, junto con los Dr Tomás Mesa y Dr Federico Fortún

FUTURE CONGRESSES



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