

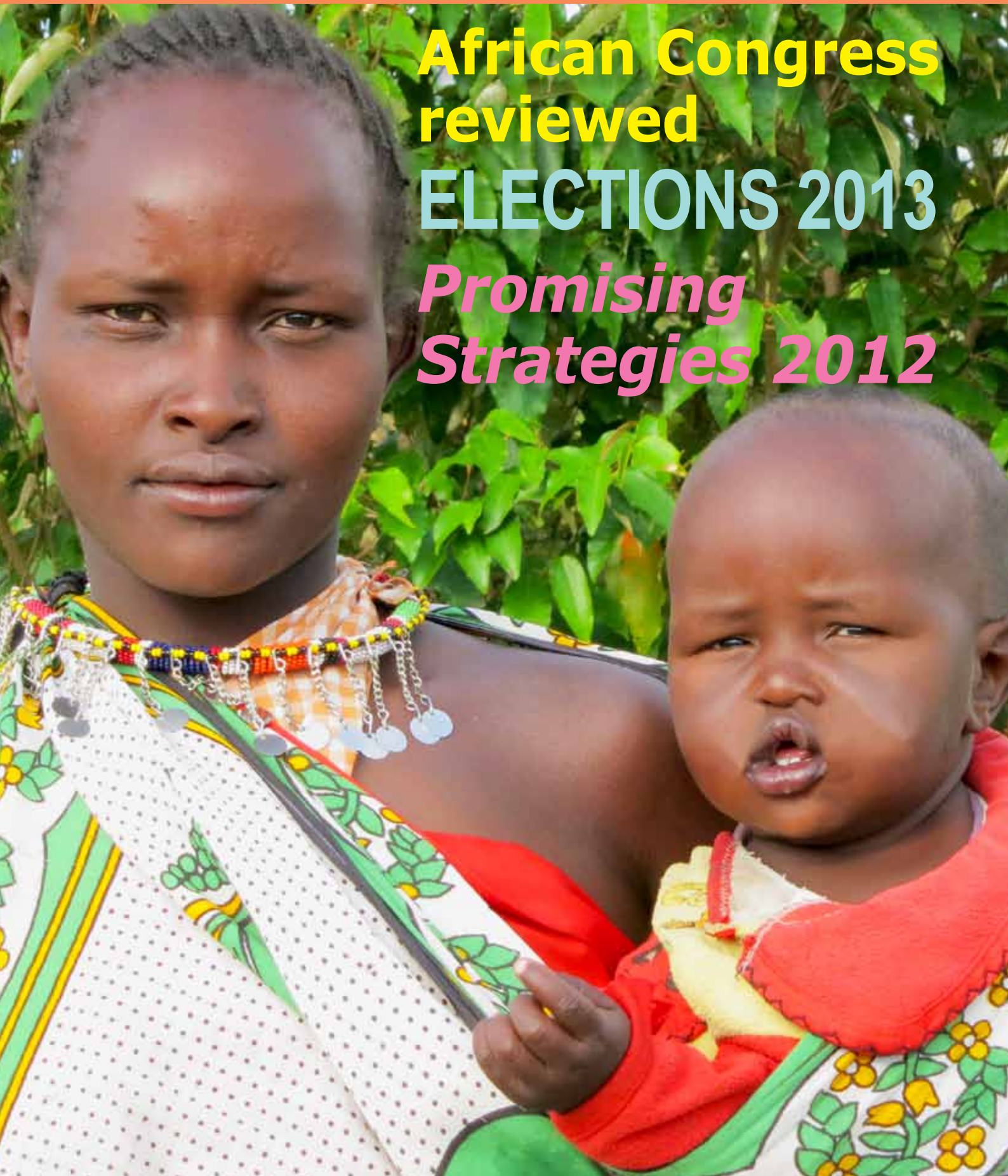
INTERNATIONAL

Epilepsy News

**African Congress
reviewed**

ELECTIONS 2013

***Promising
Strategies 2012***





An exciting year of congress successes!

At last, the 1st ever African Epilepsy Congress has now been held and a real success story it was too with delegates coming from all over Africa to take part in this historic event. Everything ran very smoothly in Nairobi and huge congratulations for this must go to Anthony Zimba and Gallo Diop and all the other local organisers and especially Sam Wiebe who co-ordinated everything.

Preparations are already underway for the 2nd AEC and it is hoped that more delegates from French and Portuguese speaking countries will be persuaded to take part in it.

Earlier in June I had the privilege to take

part in the ceremonies and celebrations to mark the replacement of the old, inappropriate, symbols for epilepsy in Korea with new, positive image symbols. The greater significance in this is that the symbols have been officially recognised and legislated for by the Korean parliament. The celebrations took place during the 2012 Korean Epilepsy Congress which is now a very important epilepsy conference throughout Asia.

The Korean success, together with the legislation change made possible by our colleagues in Colombia, provide tremendous examples of how the epilepsy community can make huge positive changes for all people with epilepsy.

We can now begin to look forward to the very important 7th Latin American Epilepsy Congress, which will take place in Quito, Ecuador in November. Doubtless the success of IBE and ILAE in putting epilepsy on the map in PAHO, led by

Carlos Acevedo, will be a major talking point there.

Next month in Paris, the International Executive Committee of IBE will meet for the first time since Rome for what promises to be a very busy meeting with much to catch up on.

With best wishes to all

Mike Glynn
President



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Exciting reports from around the world!

The second issue of IE News 2012 presents us with information on nine of the Promising Strategy projects funded this year. These are in the Latin American, South East Asian and Western Pacific regions. The last issue reported on the 11 initiatives to receive funding in Africa, Eastern Mediterranean and European regions. The Promising Strategy Program is one of the most successful IBE initiatives of the last five years.

Also in this number, Harry Meinardi will delight us with his IBE historical viewpoint, bringing us closer to the current time as he reviews the period 180-1981.

From Korea we have an interesting report

on the work undertaken by epilepsy associations to change the epilepsy term. Dr Byung-In Lee writes about what has been carried out to date in Korea and opens an interesting controversy.

Shung-Lon Lai, IBE Vice President in the Western Pacific Region will tell us his news about his trip to Laos. We are also happy to present you with a report on the 1st African Epilepsy Congress, which was held in late June in Nairobi, with a great success and attendance.

We have news stories from Canada, Italy and Malta and Dr Ichiro Tatsumi writes about his visit to the IBE office.

We are glad to bid welcome to six new members of the International Bureau for Epilepsy and we look forward to working with them over the coming years.

As a final word - and in this case I am also wearing my hat as Secretary General - I

would like to bring to your attention the elections for the next IBE international and regional committees, which will begin at the end of August. If your association has yet to settle outstanding dues, I would like to encourage you to do so as soon as possible, so that you can participate in these important elections.

Kind regards

Dr Carlos Acevedo
Editor

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PROMISING STRATEGIES 2012

The IBE Promising Strategies Program is now 6 years old and is one of the most successful and innovative of all IBE's initiatives. Set up in 2006, as a means of supporting IBE members through the provision of financial support for projects aimed at improving the quality of life of people with epilepsy, to date 70 projects in 37 countries have received a total of US\$300,000 in support.

A Promising Strategy is one that has the potential to 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, time specific objectives and is need-based and data-driven
- Is innovative in developing new solutions to common problems impacting people with epilepsy and their families
- Establishes a strategy that makes a difference in improving accessibility to accurate, timely, necessary and culturally appropriate information or services
- Demonstrates a sustainable effect in the community where it is being implemented and has the potential for replication elsewhere in similar environments

- Is a strategy that can be used to generate policies and initiatives to address systems issues and common problems impacting people with epilepsy and their families
- Is likely to be implemented in collaboration with other strategic partners and has a mechanism to evaluate results and get feedback to continue to improve the program.

More than fifty applications were received following the latest call for letters of intent. The applications were reviewed by the relevant Regional Executive Committee, with their recommendations presented to the International Executive Committee. A total of 20 new projects, in 19 countries, were then selected by the International Executive Committee for funding this year.

In the last issue we introduced the projects funded in the African, Eastern Mediterranean and European regions. In this issue we feature the projects in the Latin American, South East Asian and Western Pacific regions. Information on all 70 projects, funded to date, can be found on the IBE website. The next call, for projects to be considered for funding in 2013, will be circulated to IBE member associations later this year.

ALCE Club - ARGENTINA

Young people with epilepsy in Argentina experience significant stigma, which can significantly reduce their self-confidence and, as a result, their quality of life.

The Asociación de Lucha Contra la Epilepsia (ALCE) is developing a social club for young people with epilepsy - the ALCE Club. The aim of the club is to improve the quality of life of persons with epilepsy by providing a range of leisure and learning activities in a social context. Activities will include:

- Film screenings, with follow up discussions;
- DVD and a book libraries, which the young people will help to create themselves;
- Artistic workshops to encourage an interest in music and art;
- A toy library for the younger members of the club to enjoy.

The objectives of the ALCE Club, which will take place twice weekly, are:

- To encourage interaction among people with epilepsy attending the Club and to provide a link for their peers and families
- To increase the young people's confidence so that they can discuss the problems they face because of their epilepsy, both with other people with epilepsy and with the public and general.



Since 2006, assisting **70 projects**, in **37 countries**, through **US\$300,000** of financial support, to improve the quality of life of people with epilepsy



Fruit and Vegetable Dehydration Project

People with epilepsy unable to find work, due to poor qualifications or discrimination, will have the chance to undertake training on this project in Curicó City, which will provide them with the skills to work independently, raising family income and, at the same time, improving self-esteem and quality of life. The project will consist of one year's training in dehydration techniques for 10 people with epilepsy. Specific objectives are:

- To develop a fruit and vegetable dehydration workshop with commercial potential to enable the participants to achieve financial independence and to strengthen their personal autonomy.

- To provide the opportunity for the workshop participants to exchange their experience on living with epilepsy. The products sold will, in turn, provide the necessary funds to support further development of the project so that more people can be trained in the future. The students will have training during 3-hour lessons once a week, where a farming technician will teach them the correct techniques in dehydration. Other professionals will also help to complement the training process, including a food-handling technician and a business administrator to assist in marketing plans.



REMOTE REHABILITATION PROGRAM

In Colombia it is common for children with epilepsy and learning difficulties not to attend school. They live in remote rural areas and parents often cannot afford transport to school. As a result, the children grow up without rehabilitation care and become a severe burden on the family and society. The FIRE 5-step education program is trying to improve things for these children.

1. Using Latin American Rehabilitation guidelines (GLARE), FIRE meets with the child's parents. The group consists of a psychologist, a special educator, a speech therapist, a physiotherapist and a social worker.
2. The child is evaluated and an agreed diagnosis is made, evaluating the stage of knowledge at which the child currently is (for example 30%).
3. The group then estimates the percentage of knowledge to be reached in 30 months and this is explained to the parents.
4. The program, which is simple but with a defined progress and in which the parents are trained, runs for the 30 months, with check-ups every three months.
5. At the 3 months' evaluation, if the child has passed the exam, he or she will progress to Level 2 and so on for 10 periods, after which the goal will have been reached.

The program has been running for 10 years, and

approximately 150 children have enrolled. 70% have completed the course and 30% have dropped out for many reasons, the prominent reason being lack of money for the trip to FIRE every three months.

The Promising Strategy support will be used to cover the cost of stationery and financial aid to parents for transportation to FIRE. With this support, FIRE expects to have 100% success.

COLOMBIA



Information Program - on the move!

Arica is a fishing port located in the north of Chile. The Arica chapter of ANLICHE is organising a novel way, through a range of initiatives, to raise epilepsy awareness. Using mobile information exhibitions, the association is going out into the community to encourage discussion about epilepsy. The association will visit 10 public services, 33 schools, 14 centres for people with a disability as well as the community at large. The program will be promoted on TV and on radio, as well as in the printed press.

Materials will include posters, CDs and information brochures as well as the use of audiovisual materials. The information will be provided by a social worker, a neurologist, and a social technician. People with epilepsy will also talk about what life is like when you are living with the disease.

Support from the Promising Strategies Program will enable the association to purchase the necessary equipment for the project.



Arica City CHILE

Cell phone repairs



INDIA Nellore Calling

Epilepsy is engulfed by social stigma and misunderstanding in India. With a view to dispelling misconceptions about the disease, the Indian Epilepsy Association was established in 1970 and has been actively involved in educational activities and awareness raising since then.

Nellore is a city, with several connecting neighbouring villages, from which people with epilepsy come for regular follow up care. Cell (mobile) phones are a very useful commodity used by almost everyone, even in the villages. However for any minor or major repairs one needs to visit the neighbouring city.

Persons with epilepsy face problems that affect their higher education. This further creates problems in finding employment. With the help of the mobile phone repair project, the association will be able to help 5 selected persons with epilepsy. Initially they will be trained in cell phone repair techniques by qualified persons with training continuing for a period of 6 months. Subsequently, since they have finished their training, they will be given the infrastructure to establish an outlet in their villages where they can continue with this work.

This training will make them independent, self-sufficient and will build self confidence through the provision of a trade and employment.

Lithuania Mauritius Mongolia Namibia Nepal The Philippines
Romania Sierra Leone South Africa Swaziland Tanzania Tibet
Togo Uganda Western Pacific Islands Zambia Zimbabwe

Information & Support

The population of Indonesia is around 240 million, who live in 30 provinces on 13,000 islands, with the majority on low economic, social and education levels. While there are no data on prevalence of epilepsy in Indonesia, based on worldwide figures, it is estimated that 2.4 million people in Indonesia will have epilepsy. Not all of them have the opportunity to have good medical services because there are a lot of problems that come from one source, i.e. stigma in the community. Many people with epilepsy are being kept at home. Children don't have a proper education and adults become dependent on other people, and jobless.

The project, proposed by PERPEI (Indonesian Society against Epilepsy), will last 5 years, with the following activities:

- Preparation of posters, booklets, leaflets and magazines telling the true facts about epilepsy
- Training healthcare providers through seminars in 16 provinces
- Providing low cost anti epileptic drugs to those on low income
- Helping families of people with epilepsy to have good economic income through skills training
- Supporting and encouraging people with epilepsy to create a self help group and to have meetings once a month to share their experiences so they can support each other.



Indonesia

Tackling a 90% treatment gap in LAO PDR

Lao PDR is a low income, multi-ethnic, landlocked country of 6 million inhabitants. Approximately 52,000 people have epilepsy, with a treatment gap of over 90%. Misconceptions, false beliefs, fear and stigmatization are common. Since 2008 the ICTE program has been working to improve healthcare and living conditions for people with epilepsy. A major objective is to increase awareness in the general public, including health authorities, so that a national policy for epilepsy care can be set up. Three radio programs on epilepsy have been broadcast daily in the capital over a two year period and 12 to 15 doctors have been trained on a 3-day basis every two months in the province.

As a first step, the radio spot and leaflets on epilepsy will be

distributed in all 38 schools in the capital, Vientiane. Pupils and teachers will hear about the new outpatients' clinic in Sethathirat hospital with possible treatment for epilepsy available. As a second step, epilepsy awareness will be raised in teachers and pupils in 24 schools in 6 provinces, once every two months, over a 3-day period, taking advantage of the training of doctors in the same cities. In this way, it is hoped to trace more people with epilepsy and to help them contact their local trained doctor. Radio spots will be translated into three of the major ethnic group languages and sent to all local stations.

Those involved in the project say that health education must play a prominent role in the consultation process for people with epilepsy.



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MONGOLIA



Mongolia is the 17th largest country in the world with a population of just 2.7 million, divided into 22 major administrative units - 21 provinces and the capital city of Ulaanbaatar.

Population density is very low and many herdsmen still follow a nomadic style of life making them even more scattered and difficult to reach. Because of their way of life, riding horses as a principal means of transport, there is the probability that trauma-based epilepsy is higher than in other countries and this makes the occurrence of partial epilepsy in Mongolia particularly high.

Mongolia has huge territories of desert, steppes and mountains but with a very low level of infrastructural development, making it very difficult to deliver epilepsy care. As a result, very few people with epilepsy will receive regular care from doctors. Due to their nomadic lifestyle, it is economically difficult to deliver adequate medical services. People with epilepsy have to travel to

the capital Ulaanbaatar for diagnosis and treatment and those from remote areas will spend between US\$500 and US\$800 for transportation, accommodation and meals for themselves and a caregiver who will accompany them to the city.

In 2006, Mongolia Epilepsy Association started a “Quality of life” program to improve health education on epilepsy among the population, including people with epilepsy, their family members, family doctors and young neurologists. This program has been very successful and the hope is to roll the program out to cover all 21 rural provinces of Mongolia.

In the last few years the association has been working with IBE and has organized a series of “Quality of life” programs, thanks to Promising Strategies Program support, in seven rural areas and cities. Mongolia Epilepsy Association is now ready and eager to go to the remaining 14 provinces to achieve its objective.



Tibet Epilepsy Patient Center

Project Objectives:

- Raise awareness about epilepsy among people with epilepsy and their families;
- Offer an alternative means to access medical advisers for people living in rural areas;
- Offer a platform for building self-help networks.

Methods:

- Set up the Tibet Epilepsy Patient Center in the Department of Neurology of the First People's Hospital in Tibet;
- Invite epilepsy patients in the department to join the center;
- Conduct a monthly lecture for patients and their families;
- Using QQ, the popular instant online messaging program, to set up an online Tibet Epilepsy Patients Group;
- Invite people with epilepsy and their family members to talk about their lives in schools and communities.

Perspective results:

- An increased awareness about epilepsy among people with epilepsy, their family members and medical workers;
- Successful online access to medical carers through QQ group;
- Increased knowledge in the general public on living with epilepsy;
- Improved self-confidence in people with epilepsy through the peer support of the self-help networks.

IBE Welcomes 6 New Members

We are very pleased to report that in recent months the following six associations have been ratified as IBE members by an electronic ballot of the General Assembly:

Full Members

- Albanian Association of Epilepsy, Albania
- Fundación Hondureña de Epilepsia, Honduras

Associate Members

- Community Development & Epilepsy Foundation (CODEF), Cameroon
- Epilepsy Association Doctors for Support, Serbia
- LGS Foundation (Lennox-Gastaut Syndrome), USA
- MHCD Centre for Prevention and Treatment of Epilepsy, DR Congo

IBE is now represented in **95** countries by **92** Full and **34** Associate Members.

For information on how to apply for membership, please contact the IBE office ibedublin@eircom.net.

National Conference MALTA

More than 100 delegates attended the National Epilepsy Conference organised by Caritas Malta Epilepsy Association and Dr Janet Mifsud, IBE Vice President Europe from the Dept of Clinical Pharmacology and Therapeutics, University of Malta. The meeting was opened by Monsignor Dun Victor Grech, Director, and Mr Mario Dimech, President, Caritas Malta Epilepsy Association. The European Union Health Commissioner, John Dalli spoke about the initiatives being taken by the Commission, which has recognised the importance of prioritising epilepsy as a major disease since it affects about 6 million people in Europe and 20 million family members. This follows approval of the EU Written Declaration on Epilepsy late last year. The key note speeches were made by Prof Mike Kerr, Dept of Psychological Medicine & Neurology, University of Cardiff and Ms Hanneke de Boer, Coordinator, ILAE/IBE/WHO Global Campaign Against Epilepsy. The conference presented an innovative way of understanding epilepsy through an

interactive session which consisted of a play written by Giovanni Attard, with Bernardo Riolo and Daniela Micallef in the main roles. This was followed by a panel discussion. The conference highlighted how epilepsy presents a global problem affecting all ages, social classes, groups and countries. Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows". The most significant problems people with epilepsy encounter in daily life often are not related to the severity of the condition, but stem from misconceptions held by the general public. The impact of epilepsy on social functioning, or the ability to participate in a broad range of social activities and interpersonal relationships, can be quite varied. People with epilepsy have a higher prevalence of social problems than those

from the general population. Children and adolescents often suffer from overprotection within the families and at school. In adult life problems are reported concerning obtaining and retaining employment, which is confirmed by research findings. Older people like younger ones suffer a loss of confidence. They may lose their functional independence. All chronic conditions have an impact on quality of life; however, the impact of epilepsy may be greater partly because of the unpredictability of the seizures and partly because of the associated stigma.





Flying the Kite for Epilepsy

"In the kite I have always seen freedom and joy, a message of peace carried on by a wind knowing no bounds."

These are the words of Jane Parker-Ambrose, a kite maker from Colorado, USA and founder of One Sky One World (OSOW). The organisational purpose of OSOW is to develop awareness of and respect for human and cultural diversity, nature and the environment at home and around the world.

The spirit of OSOW is evident in an Italian National Event - 'Let's Colour the Skies' - which has been celebrated every year in Umbria since 1982, with people of all ages flying kites or taking off in hot-air balloons. This year, for the second year running, the Italian League Against Epilepsy (LICE) used the event to raise awareness about epilepsy.

This year, besides flying a big kite, children made small kites onto which they stuck the logo of Italian National Epilepsy Day. The event provided LICE the opportunity to circulate information on epilepsy and to promote the LICE Foundation.

The association received very positive feedback to the message it was trying to get across: "epilepsy kites must fly together just like the other kites".



Canadians with epilepsy face serious health and social problems



Results from The Impact of Epilepsy on Canadians survey, released at the end of February 2012, shows that Canadian adults struggling to control their epilepsy face serious health obstacles, including access to specialized care and treatment options, as well as numerous social impacts. They listed stigma, independence, and social and work barriers among the top challenges that need to be addressed.

Conducted in late 2011, The Impact of Epilepsy on Canadians survey is the first of its kind in Canada to explore the impact on life and health among adults living with the disease.

"We are grateful to the many Canadians from St. John's to Victoria who shared their experiences living with epilepsy through this important survey," says Gail Dempsey, President of the Canadian Epilepsy Alliance (CEA), IBE's Full Member in Canada. "Their insights confirm that many are still struggling to live well with epilepsy, and importantly, they point to where changes are needed most across the country to improve lives."

Stigma & discrimination

Over half of respondents (56 %) said that restricted independence due to epilepsy is their number one challenge. Stigma, discrimination and a lack of awareness about epilepsy is cited by 38% as the number two challenge, along with the

impact of the disorder on their social life. The third biggest challenge is maintaining employment, with half saying their job choices are restricted, and just under 40% unable to get a job if they disclosed their epilepsy during interviews.

"Since I was diagnosed with epilepsy more than 28 years ago, I have learned to cope with the many challenges of this disorder, including the effects of seizures and the feeling of isolation which comes as a result of stigma and discrimination," says Terri Beaton, who lives in Victoria, British Columbia.

"This survey, as well as connecting with my local epilepsy society, has given me a voice - a way to share my experiences with epilepsy, in the hopes of overcoming the obstacles faced by all those who are touched by it, including our family, friends and colleagues," she added.

Access to services

Beginning at the point of diagnosis and continuing throughout their lives, the survey indicates that Canadians living with epilepsy need improved access to specialized medical care. On average, respondents waited nearly four years to be diagnosed with epilepsy, and almost one year to be seen for the first time by an epilepsy specialist. About 60% of respondents who were candidates for surgery waited up to five years for their surgery. For ongoing treatment of epilepsy, 40% reported seeing their GP or family doctor regularly, and only 30% had ever seen an epileptologist. The survey findings also show that access to community-based government sup-

port services and disability programs is lacking, according to some respondents. Although social services exist for people with epilepsy, two out of every ten Canadians living with epilepsy reported that the services were not available in their communities. With 77% of respondents believing that uncontrolled epilepsy should be classified as a disability, 41% reported that government disability programs were not available to them.

Seizure frequency & treatment

The Impact of Epilepsy on Canadians survey confirmed that the majority of adults living with epilepsy continued to have seizures with profound physical, psychological and emotional consequences. Nearly all (96%) of those who answered a question on seizure frequency indicated that they suffered from seizures, with only 4% reporting being seizure free.

The survey also highlights the need for new and better treatment options in order to minimize the impact of epilepsy felt by Canadians affected by the disease. Most respondents said that they relied on medication to manage their seizures, and that they have been prescribed an average of four different drugs since being diagnosed.

Standing up for epilepsy

"In light of these survey results, it is time for Canadians to take a stand in support of people living with epilepsy.

"Together, we must strive to eliminate stigma through greater public education, expect and demand the best specialized care and social supports, and ensure better access to all safe and effective treatment options for optimal seizure control," Gail Dempsey concluded.



Minister of Health opens 1st African Epilepsy Congress

Congress speakers report on the plight of women and children with epilepsy in the African region

Photo left: Hon Prof Peter Anyang' Nyong'o

Photo below: Members of KAWE and Youth on the Move

Cover photo: Masai mother and child

All photos by Ann Little

It was an auspicious occasion for all those present and a very proud moment for Kenyan delegates when the 1st African Epilepsy Congress was officially opened by Kenya's Health Minister, Hon Prof Peter Anyang' Nyong'o on the 21st June.

Just under 300 delegates from 58 countries travelled to Nairobi to attend the congress, with significant bursary funding made available to delegates from less well-off nations. A total of US\$20,000 was provided by IBE to ensure that at least one member from each of its member associations in Africa was able to attend. ILAE had a similar bursary fund in place.

While the congress program was both wide and varied, a topic of particular interest was the plight of young people and women with epilepsy. In a region where epilepsy prevalence is estimated to be as high as 15% in some places, this was the opportunity to call the attention of African governments to the urgent need to address the burden of epilepsy in general, and, in particular, in women and children.

Dr Angelina Kakooza, a paediatrician from Uganda spoke about the high prevalence of epilepsy in children in East Africa. Young people and women have borne the brunt of the problems associated with epilepsy in many African countries to the detriment of national economic growth.

"Children with epilepsy have to grapple with poor academic performance, difficult speech, impaired motor and perceptual skills," Dr Kakooza said.

Mr Augustine Mugarura, Director of IBE's Full Member in Uganda, and a member of the IBE African Regional Committee,

told delegates how children with epilepsy are often stigmatised by uncaring teachers, whose attitude can discourage the pursuit of vocational skills that could otherwise provide the basis for employment.

"Stigma, abusive teachers, siblings and parents demoralize children and youth with epilepsy. Career choices for them are limited," said Mr Mugarura.

He urged African governments to invest in epilepsy management programs for children and young people. We can alter the status quo through training specialized teachers to handle children with epilepsy. Continuous health education and awareness on epilepsy are crucial," he added.

Dr Amadou Gallo Diop, Senegal, who is Chair of the ILAE Commission on African Affairs called on governments to introduce epilepsy programs that should target high risk groups. He told how the majority of people with epilepsy in Africa will visit traditional healers instead of modern doctors

due to poverty and ignorance. People with epilepsy in Africa who attend conventional medical care centres are usually living in cities and have higher education and income levels.

The special closing session of the congress provided the opportunity to review the topics discussed over the course of the meeting. It was widely agreed that the congress had been a major success, in terms of delegate attendance, scientific program, and the level of media attention it attracted in Nairobi.

For their sterling work in ensuring the success of the meeting, thanks are due to the co-chairs of the Scientific Committee - Mr Anthony Zimba (Zambia), Dr Gallo Diop (Senegal) and Dr Samuel Wiebe (Canada). A special *Thank You* to Dr Osma Miyangi and Dr Paul Kioy; to the members of KAWE (IBE's Full Member in Kenya); and to Youth on the Move; all of whom worked hard to ensure a terrific meeting.





GLOBAL OUTREACH MEETING

Learning from the past in order to plan for the future

An invitation to IBE and ILAE member associations in the African region to participate in a Global Outreach stakeholders meeting, during the 1st African Epilepsy Congress, received a very positive response with a large attendance.

The congress provided the opportunity for a stakeholders meeting to review past and current activities in the African region being carried out at national level, as well as initiatives in other regions that could be replicated or adapted for the African region.

The meeting, which was co-chaired by Dr Tarun Dua, from the WHO, and Prof Nico Moshé, ILAE President, was very pleased to welcome Dr Shekhar Saxena, Director, Department of Mental Health and Substance Abuse at the WHO and Dr Sebastiana d’Nkomo da Gama, who is WHO Regional Advisor for Mental Health in Africa.

Dr Saxena stated that the WHO decided 15 years ago, when the ILAE/IBE/WHO Global Campaign Against Epilepsy was created that epilepsy would be a priority within neurological disorders and epilepsy was still one of the highest priorities of his department. Dr Saxena also spoke about mhGAP, the WHO treatment gap programme introduced four years ago, of which epilepsy is one of eight priorities.

Dr Helen Cross (UK) made a presentation on recent Global Campaign initiatives as well as on projects of the European Joint Task Force of IBE and ILAE, including the Written Declaration on Epilepsy, which could be the inspiration for similar projects in countries in Africa.

This was probably the first time that representatives from lay and medical organisations in the sub-Saharan region had been able to come together to talk about the problems faced by people with epilepsy in their countries and to tell how these problems are being addressed.

During open discussion it was apparent that many of the same issues arise across the region. A common thread was the misguided belief that epilepsy was a punishment or was connected to evil spirits. Also common was the belief that epilepsy could only be treated by traditional healers. Economic hardship was often a deterrent to seeking appropriate treatment.

There was animated discussion on the terminology used in describing epilepsy and it was agreed that the use of correct terminology in awareness-raising efforts is very important. Consistency of message, across the region, is also significant when working to interest national health ministries in the need for epilepsy programmes to address the disease.



In closing the meeting it was agreed that, while much had been done, there is still much to do and that working together would lead to changes for the better.

Banner photo: Delegates attending the stakeholder meeting

Photo: Priscilla Shisler

Above, l to r: Dr Sebastiana d’Nkomo da Gama and Dr Shekhar Saxena

Below: Dancers entertaining delegates at the Congress Opening Ceremony.

Photos: Ann Little



A VISIT TO LAO

Report by
Dr Shung-Lon Lai,
IBE Vice President
Western Pacific Region



The Western Pacific Region, which is composed of 37 countries and territories, encompasses an extraordinary diversity of cultures, socioeconomic structures, and health service arrangements.

At the present time IBE has 10 members in the region. Some of the poorest countries of this region do not have the resources to establish an association and there are the serious problems of stigma, social disadvantage (both contributing to the burden of epilepsy), and lack of access to appropriate treatment. Lao People's Democratic Republic is one such country. Under IBE's Promising Strategies Program, a project to improve the quality of life of persons with epilepsy is being supported in 2012 and I had the opportunity to visit Lao and to understand the situation there.

Lao is a landlocked country, sharing borders with Vietnam and Cambodia and also with Thailand, China, and Myanmar. Lao remains one of the poorest countries in South East Asia. In 2011 GDP was US\$1,010 per capita, according to World Bank figures, and health indicators were among the lowest in the region. The country ranks 138 out of 187 nations on the Human Development Index (2011).

Health expenditure per capita in Lao was \$46.17 as of 2010 and over the past 15 years this indicator reached a maximum

value of \$46.17 in 2010 and a minimum value of \$9.95 in 1999 (World Bank). The imposition of user fees triggered a big increase in 'out-of-pocket' household expenditure on health care. Of health expenditure per capita, about 10% is from Lao government sources, 30–35% from external sources, and 55 to 60% from household expenditure at the time of illness.

The treatment gap, at about 90%, is daunting.

The predominant mechanism of health care delivery in Lao is through public health facilities, with a network from central level to local level. The quality of these health facilities is quite uneven, especially at grassroots level.

Health facilities are underfunded and central and provincial hospitals that are functioning rely on patient fees, mainly from revolving drug funds, for 50–80% of their total operating budgets. At present, there are more than 254 private clinics, of which 108 are in capital, Vientiane.

The most common source of curative health care for an illness, however, is from one of the over 14,200 registered private pharmacies or from the multitude of informal drug sellers. The care from these private sources is of low cost but also of

low quality, as far as rational drug use and the quality of drugs that are dispensed.

Lao has only two fully trained neurologists (with a further two undergoing training in Thailand) and nearly 6.5 million inhabitants. The country has one electroencephalogram (EEG) machine, located in Vientiane. There are five CT scanners, three of which are in the capital. Patients who need an MRI study are forced to pay out of pocket in neighboring Thailand. Most people with epilepsy are cared for by general practitioners and psychiatrists.

From studies undertaken by Institute Francophone pour la Médecine Tropicale (IFMT), the prevalence of epilepsy was investigated within a population of 4,310 people, resulting in an estimated prevalence of 7.7%. This is the only study on epilepsy prevalence to have been undertaken in Lao.

Only 50% of pharmacies in the capital and none in rural areas (where 70% of people with epilepsy live) have phenobarbital

Based on this information an estimated 50,000 people with epilepsy are currently living in Lao. Observation showed that only a small portion of these are currently



receiving treatment. The treatment gap at about 90% is daunting. The official first line of treatment is phenobarbital and there are six essential anti epileptic drugs (AEDs) right now. Phenobarbital is stocked at provincial and district hospitals and pharmacies. But availability is poor: only 50% of pharmacies in the capital and none in rural areas (where 70% of people with epilepsy live) have the drug.

The development of care for epilepsy is closely related to the IMFT. Since IMFT and partners conducted prevalence research in epilepsy 2003 they began to move from research to a project to implement access to treatment in 2008. In

2009, an initiative for epilepsy treatment in Laos was launched with a fund from "Sanofi Access to Drugs".

During the visit, the IMFT organized a symposium and invited general practitioners, psychiatrists, neurologists and social workers, students and those who are in charge of care for persons with epilepsy in Lao to discuss the current situation of epilepsy care and future direction. Dr Phetvongsinh Chivorakoun from Laos

talked about the initiative for access to treatment in Laos. She introduced previous studies and the current situation on epilepsy care in Lao. Dr Somchit Vorachit shared experiences on the pilot opening of an outpatient division for persons with epilepsy, and graduate student from IMFT shared the 2011 survey study of prevalence in epilepsy from six provinces. The prevalence rate was lower than in 2003, around 2.2% but the treatment gap was still very similar.

Professor CT Tan talked about the issue of stigma and methods to overcome this stigma. I gave a speech regarding epileptic psychosis. Very warmly, the neighboring Thai group not only talked about how to manage epilepsy with limited resources but also they presented a fund for an epilepsy study for Lao.

The meeting then divided into four workshop groups to discuss future direction including the following:

- ◆ What are the short, middle and long term objectives for the Association Against Epilepsy in Lao?
- ◆ How to increase screening, follow up and the control of seizures in people with epilepsy in Lao?
- ◆ How to increase the availability of AED and reduce the treatment gap in Lao?
- ◆ Stigma and Epilepsy: How to evaluate stigmatization? What are the strategies needed to reduce the stigmatization? And how to evaluate results?

From their discussion, I was very happy to learn that they will set up the network and establish the association against epilepsy in Lao in the short term and will have more

training for doctors, nurses, and pharmacies for working together, to establish guidelines for treatment and to expand access to the treatment program in order to reduce the treatment gap.

A 2011 epilepsy prevalence survey from six provinces showed the rate to be lower than in 2003, at around 2.2%, but the treatment gap was still very similar.

From the public sector, they will undertake more public education on epilepsy on TV and radio and in newspaper in order to reduce stigma. It's very nice to learn that there is one NGO organization, BasicNeeds, focusing on mental disorders in Lao. It currently supports nine district areas of the capital city, including persons with epilepsy. Their web address is www.basicneeds.org.

In conclusion, the goal of current research and practice is to improve epilepsy detection; to increase the number of people with epilepsy receiving AED treatment long term, and attending follow-up; to improve networks of health care personnel involved in the treatment of epilepsy, by recruiting more medically qualified physicians and the existing NGO networks; to overcome the problem of poor availability of AEDs; to work towards greater commitment of the Lao health authorities to epilepsy care; to initiate a patient based epilepsy association; and to ensure the long term sustainability for the care of epilepsy in Lao.



Promising Strategies in BULGARIA

From 1st June to 3rd June in the scenic location of Betolovoto Golf Course, located between Razlog and Bansko, the Association of Parents of Children with Epilepsy, Bulgaria held a workshop course on medical and social therapeutic services for children and adults with epilepsy.

The seminar, with was made possible through funding from the Promising Strategies Program, was attended by 32 people from different regions of the country.

A new Name for Epilepsy in Korea

Dr Byung-In Lee, Chair of the ILAE Commission on Asian & Oceanian Affairs, provided an outline of a long road travelled



Street scene, Seoul

Despite the modern thinking of Korean society, public attitude to epilepsy remains quite negative, leading to stigma. As a result, people with epilepsy often choose to hide their condition and regard epilepsy as the worst chronic disease that one can have. As a result, epilepsy is not openly spoken about. Much of the problem is believed to lie in the traditional word for epilepsy '*ganzil*' which translates to English as 'mad disease' and which leads to deeply entrenched perceptions of the disease.

In 2007, Korean epilepsy organizations decided that the most effective way of challenging the social concept of epilepsy would be to 'rename epilepsy' to a more neutral terminology. This would be both a difficult and tedious mission but one, the organizations believed, would be worthwhile for people with epilepsy in Korea.

In August 2008, a Rename Epilepsy Task Force was created, chaired by Dr K Huh and with eight members representing Korea Epilepsy Society (KES), Korea Epilepsy Hospital (KEH) and Korea Epilepsy Association (KEA). The purpose of the task force was to provide guidelines for the new name, with a preference for neutral terminology, that would imply a modern scientific basis, but unconnected to the terms convulsion, fit or spasm. The new term should be easy to use both as a noun

and an adjective and be a term that would be widely accepted.

In September 2008, an invitation for suggestions was circulated through email and on websites and this resulted in the submission of 10 proposals. Following review, this number was reduced down to four by the task force. In May 2009, through a ballot of KES and KEA members, the shortlist of four was further reduced to two. The following month, June 2009, 'Cerebro-Electric Disorder' was selected as the new name for epilepsy during the General Assembly of KES.

But, of course, this was only the start of the process, not the end!

The next step, which began in October 2009, was to request opinions on the new name from the relevant Academic Societies and by March 2010 official approval was received. Two months later, in May 2010, the Korean Medical Association added its approval to have Cerebro-Electric Disorder accepted as the medical term for the disease. A further landmark was approval of the new name by the National Institute for the Korean Language, resulting in Cerebro-Electric Disorders replacing the old term in the Korean Language Dictionary. Once this had been accomplished KES and KEA were able to change their names, to incorporate the new term, in June 2011.

Efforts now begin to replace '*ganzil*' with 'Cerebro-Electric Disorders in all medical and academic publications. In order to have the new name recognized as 'legal terminology', Mr SJ Shin, a congressman from the Hannara Party submitted the reform to the Korean National Assembly for its approval. The Korean National Parliament gave its approval in the parliament on 29th June 2011.

But still, this was not the end of the story. While epilepsy has a new name in Korea, recognized legally, medically and by Korean epilepsy associations, there is still the task of having it accepted as 'public terminology'. This will take some time as 'old habits die hard'. On June 7th this year a celebration took place in Seoul with an official Ceremony of Dedication, with press conferences and interviews and with media coverage. This was a good start.

More events will take place to broadcast the change to the public and educational program are planned, including media campaigns, schools programs and family workshops.

As Dr Byung-In Lee (Korea), Chair of the ILAE Commission on Asian & Oceanian Affairs, explained: 'the process of renaming epilepsy is just the start of a long journey against epilepsy. Many other issues need to be addressed in the long term'.

Spreading the word!

Main photo: Louth Tay, Dublin Mountains
Insert, from left: Alan Gallagher, Jane Whelan, Eoin O'Sheanon (all from IBE/ILAE congress office) and Ichiro Takumi

A visit to the IBE Office

Ichiro Takumi, M.D., Ph.D.

Functional Neurosurgeon & Clinical Epileptologist,
Nippon Medical School Musashi Kosugi Hospital,
Kawasaki, Japan



Stillorgan, Dublin, is located in a nation saturated with green. On my recent visit to the IBE office in June 2012, I was very pleased to discover that the Dublin office was situated in such a friendly community, where people are warm-hearted and possess a spirit of caring for each other.

Although it was a busy week due to the 1st African Epilepsy Congress, Ms Carla Glynn, Mr Eoin O'Sheanon, and other IBE/ILAE congress staff kindly welcomed me on my visit. During our discussion, I realised that misconceptions are rampant, not only in my own country, but also throughout the world. I knew it. I had been aware of this before, to some extent, but the message was brought home to me again during these friendly discussions. I found it fascinating that the IBE/ILAE staff is working very hard to raise funding for epilepsy which will lead to a better quality of life for those people - normal people - who just happen to be living with epilepsy.

Back in Japan, where social and the medical resources for epilepsy are not sufficient, several consecutive traffic accidents have occurred in which people—possibly those with epilepsy—were involved as the driver of the vehicle, catapulting the topic of epilepsy into the news media. Also consider the bright, female college student

in my out-patient clinic who might lose her future job in journalism because of her previous *possible* diagnosis of epilepsy.

It is crucial that we convert these stigmatic tragedies into positive advocating episodes and stories to strengthen the public's understanding of epilepsy. BUT I cannot do it alone. As a clinician as well as an epilepsy surgeon, what I can do, starting today, is to encourage my colleagues and med students to learn more about the recent treatment advances for epilepsy and their availability, in the hope of drawing their interest and attention toward epilepsy medicine as their sub-specialty - to both increase the number of specialists nation-

wide and to help to establish a society where epilepsy imposes no burden. This is my dream.

On my flight back to Japan, I was a little bit excited to share my experiences from this visit. This has been a short visit to Ireland, but a big journey to recognize epilepsy, to meet people who recruit advocates and to raise awareness for epilepsy, and to re-dedicate myself to bettering the lives of people with epilepsy.

Note from Ann Little, IBE Executive Director: *It is with great regret that, due to attendance at the 1st African Epilepsy Congress, I was unable to meet with Ichiro personally during his visit to Dublin.*

IBE International Executive Committee ELECTIONS 2013-2017

Elections for the next term of office get underway at the end of August. The next issue of IE News will contain details on nominated candidates and the election process.

For further information, visit the IBE website or contact the IBE office ibedublin@eircom.net.





Harry Meinardi

presents the sixth instalment of IBE's history as reported in its newsletters

March 1980: EI has to cope with a negative balance sheet. The salaried director, stationed in Geneva, has to step down and close the office. The honorary managing editor of EI News, Joop Loeber, accepts also to act as honorary executive director, working from his office in Heemstede. Despite the fact that funds to maintain an office in Geneva are lacking, other activities that have had funding ear-marked, such as workshops, continue and diversify. Thus the first Workshop on Psychological Assessment of People with

Epilepsy is reported.

June 1980: Masakazu Seino describes the first special centre for epilepsy in Japan built on the slopes of the Holy Mountain Fuji at Shizuoka. This modern complex is equipped with special advanced facilities for the treatment of people with epilepsy. Given the stigma of epilepsy, also deep-rooted in Japan, the centre, besides offering intensive assessment and treatment, will also function as a base for improving "social care" as regards family dynamics, schooling, employment, marriage and childbirth.

In London, commemorating the Gowers lectures in 1880, a symposium was held on the psychiatric aspects of epilepsy, which was organised by Dr Edward Reynolds (King's College) and Dr Michael Trimble (National Hospital).

September 1980: EI announces the appointment of Mrs Patsy McCall Castellano as the new Executive Director; she exits the executive committee of IBE to assume her new role. The office is moved from Heemstede to Milano, Italy, where Patsy and Francesco Castellano live.

The 12th EI Symposium at Copenhagen featured growing interest in: endocrine aspects of epilepsy, methodological and statistical problems in controlled trials of AEDs, neuropsychological testing with electronic data processing to detect

difficult to observe absence seizures, and long-term EEG combined with video monitoring.

A panel discussion was held between people with epilepsy. Furthermore several aspects of public education were discussed.

Many small steps make one great stride. The small steps are published in EI News by its chapters. The December 1980 issue writes about how plastozone, a material similar to foam plastic but insoluble in acetone, which was developed for space travel, has improved the design of wig-covered protective helmets. Czechoslovakia has created a new neurological sub-speciality 'EEG-epileptology' (which requires three years of training).

National organisations for professionals can usually cope with the number of those working in their field. Organisations for lay people interested in a specific disease, in principle, have to deal with a magnitude of such numbers and therefore the tendency is to restrict membership to those living in a smaller region. International organisations like to deal with one member per country and encourage either the formation of a single organisation or at least of a federation which can speak on behalf of its members. On St Valentine's Day 1981 such a Federation was formed in Italy and Gilbert van Wessem was elected as its first president.

June 1981: "EI Speaks" notes that representatives from developing countries often ask whether EI can support its members financially. The answer is obviously No, the cost of the administrative apparatus is hardly met by the membership fees received. However the prestige of EI is such that it can raise funds to be ear-marked for specific projects. As an example it is mentioned that, thanks to EI, the Dutch Government paid, from its bilateral aid programme with Sri Lanka, for a study to assess whether genetic and alimentary differences between people with epilepsy in Asia and their Western counterparts (on whom the pharmacokinetic data regarding dose and effectiveness had been tested)

1980-1981

A time of change and new developments

Look Back with Pride - Part 6



would require different prescription advice for the antiepileptic drugs used.

The WHO has persisted for many years in maintaining epilepsy in the category of psychiatry, since in developing countries more (neuro-)psychiatrists take care of epilepsy patients as compared to neurologists. That such an administrative decision is not completely harmless can be seen from a report from India where (at that time) epilepsy is not mentioned as a cause for divorce under any law in India but mental disorder is, and at a meeting in Bombay (presently Mumbai) several members of the audience reported on court cases where persons were divorced on the grounds that epilepsy was a mental disorder.

December 1981: at the Kyoto Congress the merger between ILAE and IBE into one new organisation, 'Epilepsy International', should have taken place, however, it became clear that a plurality of ILAE members objected. The newly elected president of ILAE Dr Mogens Dam writes in EI News "I felt there was really an inclination among the delegates to vote for a merger, but that some misunderstandings arose about the possible results of such a decision, perhaps because of too short a time being available for discussion of the problems".

The executives of IBE and ILAE decided to maintain the existing collaboration under the name of EI for the next four years and depending on the wish of its members either merge, and, if not, end the EI construction.

Electing Francesco Castellano as its president for the term 1981-1985 IBE, just as it had done at the beginning, put a layperson at its helm.

All roads lead to Paris...

...as the Governance Task Force and the IBE International Executive Committee both travel to the French capital in early August for extensive meetings.

The Governance Task Force, chaired by Johan Falk-Pedersen (Norway), is undertaking the first major review of the Constitution and By-laws since their adoption on the 31st December 2004. The other members of the task force are Susanne Lund (Sweden), Grace Tan (Singapore), Alexandra Finucane (USA)

and Christopher Morris-Cooles (UK). It is expected that any proposals for change to the Constitution will be presented to the IBE General Assembly at the 30th International Epilepsy Congress in Montreal next year.

The Executive Committee will meet over a two-day period to discuss a wide range of issues as the committee enters the final year of its term of office. Reports on both meetings will be carried in the next issue of IE News.



Future Congresses



**7th Latin American
Epilepsy Congress**
Quito, Ecuador
14th - 17th November 2012
www.epilepsyquito2012.org



2013 MONTREAL

23rd - 27th JUNE, 2013

30th INTERNATIONAL EPILEPSY CONGRESS



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