INTERNATIONAL

Epilepsy News





ast year marked my first visit to Africa, when I was the guest of the Zambian Epilepsy Association and was amazingly well looked after by IBE's Vice President for Africa, Anthony Zimba and all his colleagues. Due to this, I am looking forward enormously to the very first African Epilepsy Congress to be held in Nairobi, Kenya in June 2012. The additional challenges people with epilepsy in Africa face, such as lack of access to diagnosis and treatment, Neurocysticercosis and the still widespread fear of infection, mean there is huge work to be done there by IBE. This 1st AEC and proposed new Global Campaign initiatives in Africa will be major steps in this work.

Africa and Asia two exciting meetings!

In March, the IBE Management Committee held a meeting in Tokyo, en route to the 9th Asian and Oceanian Congress in Manila. This meant that we were able to attend a symposium marking the first anniversary of the dreadful tsunami and earthquake in northern Japan. It was really heartening to hear about all the great work that the Japanese Epilepsy Association and their ILAE colleagues were able to do for the people with epilepsy affected by the disaster.

The 9th AOEC in Manila proved a great success; it was very well attended with excellent sessions, including a great IBE Epilepsy and Society day. One of the highlights was the great social evening which was widely acknowledged as one of the best anywhere, ever!

Following on from the success of the PAHO initiative in Latin America and the Caribbean, and the European Declaration,

the recent publication in North America of the Institute of Medicine's report on epilepsy means that epilepsy is now on the map more than at any time before. To ensure that IBE remains at the forefront of this work, the IBE International Executive Committee will have its 2012 meeting in August this year.

With best wishes to all

Mike Glynn President



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Cyberonics



am sure that the moment you picked up this issue, you realised that something was different! To celebrate the 1st African Epilepsy Congress, we decided to include a special report on IBE in the African region. So you will be able to enjoy reading about the work that many of our 20 members in Africa are undertaking.

The magazine is also full of other news and articles. The IBE Management Committee spent a few days in Tokyo, attending a special Memorial Symposium on the anniversary of the earthquake and tsunami. We also met with the local association and left the city with some wonderful memories of the kindness and dedication of everyone we met in Japan.

A bumper issue full of interesting news!

You can also enjoy a report from the 9th Asian & Oceanian Epilepsy Congress in Manila, which was attended by over 1,400 delegates, who enjoyed an excellent meeting and a wonderful welcome from the local people.

Recently, the latest projects for funding under the Promising Strategies Program were selected. In this issue we introduce you to half of the new projects. We have so many reports to share with you that we have had to hold the second half until the next issue!

Harry Meinardi presents us with the next instalment of IBE's history. I would like to thank Harry, again, for the wonderful and interesting articles he has written for us.

From Canada, Mary Secco sent us a report on a summer camp that welcomes children with epilepsy; we hear about a Fun Run in Taiwan, as well a special postage stamp that has been designed by the Taiwan

Epilepsy Association to raise awareness, the results of the Excellence in Journalism Award 2011, and a special anniversary is celebrated in Ecuador.

Finally, we bring you the news that the Institute of Medicine report on epilepsy has now been published and with important recommendations. We look forward to reporting more extensively on this in the next issue.

Kind regards

Dr Carlos Acevedo Editor

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PROMISING 2012 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

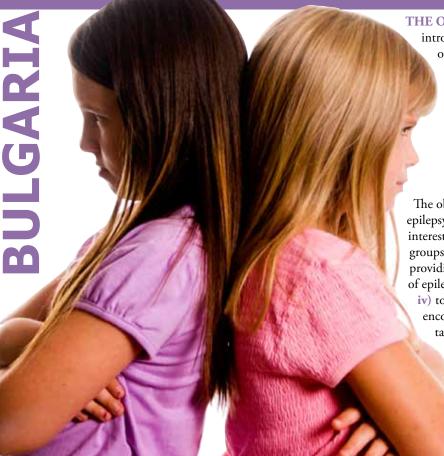
- Is a strategy that can be used to generate policies and initiatives to address systems issues and common problems impacting people with epilepsy and their families
- Is likely to be implemented in collaboration with other strategic partners and has a mechanism to evaluate results and get feedback to 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 this issue you can read about 11 of the latest projects. The next issue will include information on the remaining nine projects.

Information on all 70 projects, funded to date, can be found on the IBE website, where you can also find further information on funding criteria. The next call, for projects to be considered for funding in 2013, will be circulated to IBE member association in September 2012.

The Other Side of Epilepsy



THE OTHER SIDE OF EPILEPSY campaign of APДE will introduce an innovative way to focus on target groups in order to break stereotypes and epilepsy stigma. Lavender (the plant and its colour) are symbols of the campaign. The initiative will involve representatives from various community groups who are affected by epilepsy:

TARGET GROUPS:

- Parents of children with epilepsy and parents of healthy children;
- Teachers and students;
- Journalists from national and regional media.

The objectives of the campaign are: i) to raise awareness about epilepsy by generating positive media reports - provided in an interesting and engaging way; ii) to inform the various target groups on how to recognize and how to cope with epilepsy - providing information about treatment, symptoms and control of epilepsy; iii) to train health journalists from national media;

iv) to stimulate dialogue with state institutions, in order to encourage an active state policy for epilepsy; v) to maintain constant media interest in the campaign; and vi) to improve public awareness of epilepsy, eliminate stigma

and generate positive attitudes in society towards those suffering from epilepsy.

CAMPAIGN ACTIVITIES:

Among the planned activities are distribution of printed information on epilepsy to target groups; creation of a filmed ad campaign; organisation of an art exhibition, press conferences; and the symbolic planting of lavender shrubs.

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



The Georgian Society of Young Epileptologists (GSYE) is in permanent search of more efficient ways to improve public understanding of epilepsy and tolerance. The present idea is three-fold:

- To organise a full-day event at the city's largest shopping mall, preferably on a public holiday weekend to attract as much attention as possible. The event will include distribution of epilepsy-related information booklets and souvenirs. Snacks will also be served and a puppet-show staged for children. A large monitor will show a short documentary on social stigma of epilepsy. Journalists from national television and radio broadcasters will be invited to report on the event.
- To make use of a top-rated talk show on the popular television channel, which will focus on epilepsy-related problems, as well as on our past and future projects. The programme will feature, among others, experts invited to the studio, who will take live phone calls from viewers and conduct a live opinion survey - the first ever live epilepsy-related opinion survey on Georgian television.
- To keep the public constantly informed and interested in epilepsy-related issues and to organize opinion polls through the Internet, especially via social networks.

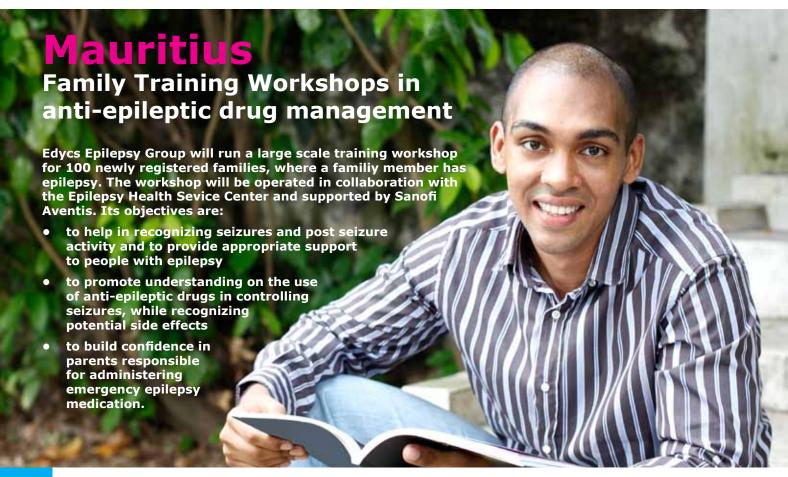


The aim of this project of LESIA is to develop a network structure of integrated services, aimed at the provision of decentralized services, increased access to service provision, engagement of non-governmental organizations as well as provision of integrated services tailored to the individual needs of people with epilepsy.

The expected outcome is a sustainable provision of services on a regional level and maximum on-site provision of services for people with epilepsy. As Lithuania does not have the financial capability to establish a National Centre for Epilepsy, this would be an economical model, not only for the target group of people with epilepsy, but also, for the state. The network would facilitate access of the target group to comprehensive service provision such as treatment, counselling on various epilepsy related issues, social rehabilitation and professional rehabilitation. The model of integrated services network would cover all levels of treatment and health care.

The project outcomes would serve as the basis for the development of a National Epilepsy Programme.

ArgentinaBangladeshBrazilBulgariaCameroonChileChina ColombiaCzechRepublicEcuadorTheGambiaGeorgia GuatemalaHaitiIndiaIndonesiaKenyaLaosLebanon



Kick Start

Career Development Training for People with Epilepsy

Suitable employment is a very important step towards the independence of people with epilepsy and is also one of their biggest challenges. Given Namibia's unemployment figure of 51%, and the current difficult worldwide economic situation, finding employment has become even more difficult.

After conducting an Epilepsy Schools Awareness program during 2011, it has become clear that the average school leaving student is not fully able to make a career choice; does not have a sufficient grasp of the career possibilities available; lacks basic skills required; and does not know how to present themselves to potential employers.

Epilepsy Namibia has, therefore, developed a supportive program for school leavers and the unemployed with epilepsy. This program consists of Career Development Seminars, and Small Business and Information Technology Training.

We believe that people with epilepsy stand a better chance to find suitable jobs if they can make informed decisions, present themselves properly and have the skills required.



MAMIBIA

LithuaniaMauritiusMongoliaNamibiaNepalThePhilippines Romania Sierra Leone South Africa Swaziland Tanzania Tibet Togo Uganda Western Pacific Islands Zambia Zimbabwe

GOING BANANAS!

As an income generating project, the Epilepsy Association of Zambia plans to develop a banana plantation. One thousand banana trees will be planted and are expected to start producing fruit within six months of planting.

The association expects that the plantation will produce sufficient quantities of fruit to meet local supply needs. The funds raised, through the sale of the banana crop to the local public, will be used to support members of the association.

The trees will be grown at the Promising Strategy site where other activities, supported by previous rounds of Promising Strategies funding, such as vegetable growing, jam making and poultry rearing, are already taking place.



School Epilepsy Clubs - informing Uganda's young people

The Epilepsy Support Association of Uganda (USAU) is setting up School Epilepsy Clubs in 20 secondary schools around Kampala. It is estimated that a target group of 10,000 young people will be reached. The aim is to sensitize teachers and school managers on the needs of students who have epilepsy and to create a conducive and favourable environment for students with epilepsy, so as to encourage them to perform better in their studies.

The clubs will teach students about epilepsy, using a range of materials and ESAU will follow the HIV/AIDS model and structure already being used in the schools, so that teachers managing the HIV/AIDS clubs in the schools will already be used to mobilizing students.

The young students with epilepsy, or their siblings, will be brought together for an annual day of special activities. The holiday camp activities will include counselling, information on epilepsy and reproductive health, relationships and sexuality, and careers. Young professionals with epilepsy will be invited to deliver motivational talks to the students at the camp.



ArgentinaBangladeshBrazilBulgariaCameroonChileChina ColombiaCzechRepublicEcuadorTheGambiaGeorgia GuatemalaHaitiIndiaIndonesiaKenyaLaosLebanon



CODEF is introducing income generating activities - including pig rearing, hairdressing, and tailoring - to support 45 people with epilepsy who live in the north west of Cameroon.

Living on less than a dollar a day, 20 of those to be trainined reported being subject to discrimination and

25 also said that they had not attained any level of primary education.

CODEF believes that every person living with epilepsy has the right to be an active citizen in their community and to achieve both social and economic sufficiency. Developing a trade will help them to achieve this goal.



ZIMBABWE - Training in Best Practice

The prevalence of uncontrolled epilepsy is very high in rural areas of Zimbabwe, where 80% of native Zimbabweans reside. This is underpinned by cultural beliefs that reinforce resistance to the medical control of epilepsy. It prevails in backgrounds where knowledge about the management of epilepsy remains scant among health professionals. Unregistered clinicians continue to earn a living from unsuspecting individuals, families and communities that care for persons with epilepsy. The majority of the practitioners is unlicensed and lacks the requisite technical expertise to reduce the strain caused by epilepsy. The health gap presents extra tragedies to the already depressed conditions of people with epilepsy, reducing their self-images, self-esteems and self-opinion.

Against this backdrop, the Epilepsy Support Foundation of Zimbabwe intends to facilitate in regulating and strengthening community-based rehabilitation by providing training in best practices in the management of epilepsy to health professionals and community-based psycho-social practitioners.

This will result in improved access to health care to the affected individuals, families and care givers. Advertently, this will enhance the overall well-being in society of people with epilepsy, facilitating the significant advances required in integrating their quest for belonging and beneficial participation in national development on equal basis with others.

LithuaniaMauritiusMongoliaNamibiaNepalThePhilippines Romania Sierra Leone South Africa Swaziland Tanzania Tibet Togo Uganda Western Pacific Islands Zambia Zimbabwe

National Learner Awareness Programme for Primary Schools

The National Learner Awareness Programme of Epilepsy South Africa will be piloted by its National Office during 2012. This preliminary countrywide initiative aims to:

- Derive its purpose directly from the UN Convention on the Rights of Persons with Disabilities;
- Link to the Life-Skills programme of the South African curriculum and therefore be endorsed by the South African Department of Education;
- Be adaptive to the needs and capacities of different age groups;
- Take on the form of an inter-active awareness kit that involves the class in simulative activities while learning about epilepsy and inclusive education.

The vision of the organisation is to develop a culture of inclusion of persons with epilepsy at the psycho-social life stage model: age six to eleven, in South Africa, Africa and globally. We believe this intervention will help to develop a generation of epilepsy- and disabilitysensitive people who will be able to convey this culture to future generations.



LEBANON: Sweet Success **Training in Chocolate Sales** and Marketing

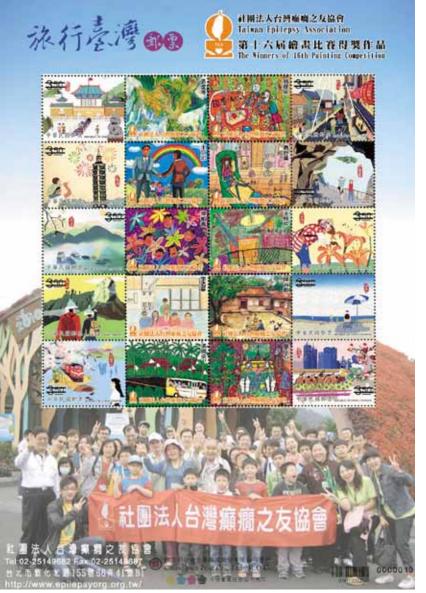
> In 2010, the Association for the Care of People with Epilepsy in the Lebanon received support from the Promising Strategies Programme to develop a Chocolate Making initiative for young people with epi-

lepsy, called the ECAL project. Now that it is running successfully, the association believes it is time to encourage the people with epilepsy working in the project to become more involved in all aspects of the endeavour from manufacture, through marketing, to the point of sale.

To achieve this, the association is planning to offer an ESP course (Arabic and English for Specific Purposes) to teach those involved all about the work they do, from the terminology that relates to their work, to all the procedures that pertain to pro-

duction, and the social skills they need in order to sell the produce. Included in the training will be a simulation of face-to-face communication situations with customers.

In the absence of schools for Special Education Needs and the Ministry's support, due to the current economic crisis in Lebanon, and as long as people with epilepsy are forced to leave school once they have seizures, the support of the Promising Strategies Program plays an important role in helping people with epilepsy become more communicative and independent social citizens.



STAMPING ITS MARK!

Taiwan Epilepsy Association finds a new way to raise awareness about epilepsy

Members of Taiwan Epilepsy Association (TEA) have very good reason to celebrate. They have just launched an exciting new public awareness campaign, which will take quite a bit

These colourful images (left) are the artwork of talented TEA members, eight of which have been transformed into official Taiwan postage stamps.

The stamps have a two-fold purpose: they demonstrate the creative talent of members of TEA and they also expose the public to the condition.

And just think of the domino effect that can result! Everytime someone uses one of these stamps, and the colourful stickers that accompany them, an untold number of people will see them - including post office workers in the sorting office, the postman delivering the mail and the recipient of the letter or parcel.

What an excellent idea!



The Association of Parents of Children with Epilepsy (APNE), and initiator of the founding of the National Epilepsy Center, which have worked together since 1991, forming the Ecuadorian Full Member of IBE, has just celebrated it's 25th anniversary.

The association promotes activities related to the educational, social and occupational fields, for people with epilepsy and their families.

An immediate goal for this year has been the submission to the National Assembly of Ecuador of a legislation proposal to ensure legal protection for people with epilepsy. Later in the year, Quito will host the 7th Latin American Epilepsy Congress, at which the work of the association will be showcased.

IBE sends its warm congratulations to Dr Galo Pesantez and the members of APNE.

ERRATUM



Issue 4, 2011 of IE News reported the death of Pakistani prodigy, Arfa Karim, as being due to epilepsy. We are grateful to Prof Hasan Aziz who has alerted us to the fact that media reports suggesting that Ms Karm suffered from Idiopathic Epileptic Seizures were incorrect. It seems that the cause of death was probably an acute encephalopathy of uncertain cause.

IE News, which reported the news in good faith, wishes to issue its apology.

Winning Stories









Excellence in Epilepsy Journalism Awards 2011 Winners Announced

IBE and UCB recently announced the winners of the 2011 Excellence in Epilepsy Journalism Awards. Aimed at raising awareness about epilepsy globally, the awards recognise journalists who have excelled in reporting informed stories that engage the audience on the often misunderstood condition of epilepsy. Impressed by the standard of the articles submitted, Mike Glynn, IBE President commented: "We were pleased to receive almost 50 entries from 24 countries across the world. The importance of accurate, insightful journalism across the globe is important for the epilepsy community, who often face deep-seated stigma and misconceptions about the reality of the condition." "Our hope is that, over time, we can help to encourage more reporting that begins to

break down these barriers to understanding and acceptance for many people living with epilepsy across the world."

Print Category

The winner of the print category was Maj My Midtgaard Humaidan from Denmark for her article Living Amidst Seizures and Lack of Empowerment that appeared in the Danish newspaper Fyns Amts Avis.

"We felt that this was a powerful and compelling piece of writing, something which really set this article apart," commented David Josephs, a UK Epilepsy Advocate. "The entry brilliantly depicts the portrait

of someone living with severe epilepsy and just how challenging this can be."

Broadcast Category

Birthe Tønseth from Ireland was the winner in the broadcast category for her programme Life with Epilepsy broadcast on Radio Telefís Éireann's RTÉ One.

"This programme looked at the lives of three people with different types of epilepsy, in an accessible and uplifting way," said Robert Cole, CEO of Epilepsy Association of South Australia and the Northern Territory. "The stories reference various challenges such as the symptoms, common problems, stigma and discrimination, but also the hopes, dreams and achievements of people living with epilepsy. The entry was well researched and a worthy winner."

Victoria Macdonald from the UK was highly commended for her piece Patients Not told of Epilepsy Sleep Death Risk which was broadcast on Channel 4 News.

"There was a high standard of entries in the broadcast category this year," said Robert Cole. "Victoria Macdonald's news piece highlighted the case of two families who lost daughters to Sudden Unexpected Death in Epilepsy (SUDEP), who had not been warned of the risk. SUDEP remains an important topic, and this entry was highly commended by the judges."

Online Category

The winner of the online category was

Comfort Mussa from Cameroon for her article Epilepsy Myths Promote Stigma, Prevent Care in Cameroon that appeared on the Global Press Institute website.

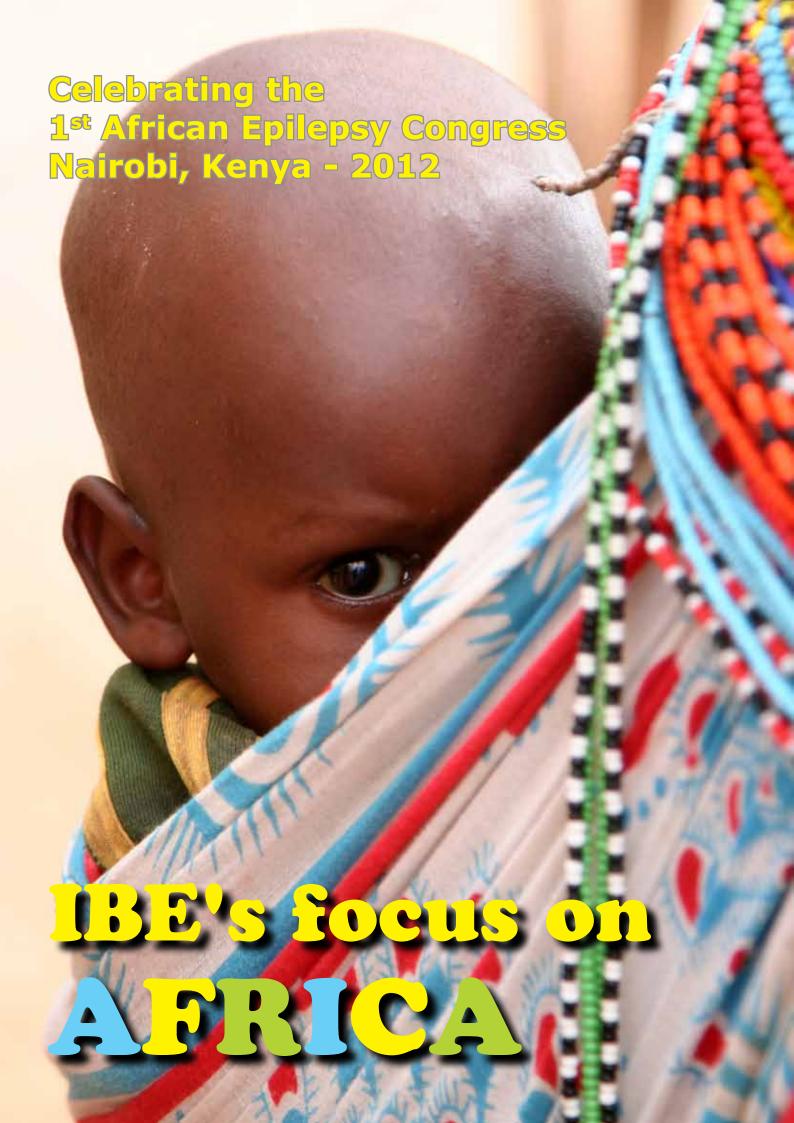
"Comfort Mussa tackled an important issue in Africa, the demonising of epilepsy, and did so in a very compelling way," commented Joachim Mueller-Jung, writer and journalist of Frankfurter Allgemeine Zeitung, Germany.

"The story explores how myths promote stigma and sheds light on the importance of sensitising the community to accept people with epilepsy to ensure optimal care."

The awards are a joint initiative of the IBE and UCB and are open to consumer, health and medical journalists writing for print, broadcast or online outlets.

International Judging Panel:

- Mr Robert Cole, Australia
- Dr Carlos Acevedo, IBE Secretary General and Editor, IE News, Chile
- Mr Joachim Mueller-Jung, Germany
- Mr David Josephs, UK
- Dr Mark Porter, GP & Medical Correspondent for The Times, UK
- Mr Randolph Siegel, President, Local Digital Strategy, Advance Publications, USA
- Mr Mike Glynn, IBE President, Ireland.



Is final touches are put in place for the first African regional epilepsy congress, it was decided to expand this issue of the newsletter in order to celebrate the inaugural African Epilepsy Congress and IBE's involvement in Africa, which can be traced back almost to the founding of the Bureau itself. In the intervening half century, since IBE's foundation in Rome in 1961, the connection between the Bureau and the African continent has been well documented in IBE's newsletters.

Elsewhere in this issue you can read Harry Meinardi's latest instalment of the Bureau's history but, thanks to an earlier chapter, I have been made aware of the very long history of IBE support to Africa. One of the earliest reports dates back to 1969, when the Secretary General paid two visits to Africa, meeting doctors and social workers in Nigeria, Ghana, Uganda, Kenya, Zambia and Malawi, and from which the idea of a workshop evolved 41 years ago!

A report in the July 1971 issue tells of the frustrations in bringing to fruition plans for the workshop, and a new plan to introduce the concept of a Travelling Workshop instead. As delegates gather in Nairobi, it seems fitting to reproduce the July 1971 article in this issue of IE News. It is also pleasing to be

able to report that the September 1973 issue of Newsletter (as the magazine was then called) told how the Travelling Workshop had visited Ghana, Sierra Leone, Nigeria, Uganda, Kenya, Tanzania and Malawi over a period of six weeks. Taking part were Dr Maurice Parsonage, Dr Peter Jeavons, George and Sylvia Burden, as well as well more than 1,000 African participants!

Africa is now IBE's second largest region, after Europe, with 20h members and with indications of membership interest in at least four further African nations. It will be interesting to see what the next 50 years bring!

Text: Ann Little, IE News Coordinator







AFRICA WORKSHOP - IBE Newsletter: July 1971

Report by George Burden, IBE Secretary General

Members of the Bureau will remember that during the past three years we have given much thought and expended no little energy in preparing for the first Epilepsy Workshop in Africa. In our July *Newletter* we confidently stated that this workshop would take place in Kampala in June. Alas, we have to admit that this has not been possible. Professor Alan German, who had done a great deal of prepartory work on our behalf, advised us in May that our plans for an international workshop were not working out. Twelve doctors and health workers would be coming from Uganda but only five, maybe less, would be coming from outside Uganda.

The programme was to have included Professor Benjamin Boshes talking about 'The Convulsive States', Professor JK Merlis talking about 'Late Onset Epilepsy', Dr Christopher Ounsted talking about 'Epilepsy in Children', case demonstrations by local and visiting doctors, discussions on the social aspects and films about epilepsy diagnosis and treatment. The workshop was to receive support from the Commonweather Foundation and Geigy-CIBA, Roche, Katwijk and Rhien-Pharma.

We had about twenty-four hours of depression and gloom, and then began to plan again. We asked ourselves, if doctors in the different countries have so much difficulty in travelling to an international meeting, and if twelve Ugandan doctors would come to a meeting in Uganda, why do we not take the workshop to each country in turn? What is more, why did we not think of this before?

So we set to work. We contacted the Director of the Commonweath Foundation and he thought it was a good idea. We consulted Professor German and Professor Merlis and they were in favour.

Somewhere in the middle of March 1972, we plan to assemble an epilepsy team on the West Coast of Africa, probably in Sierra Leone. We will then spend three or four days in the following

Commonwealth countries: Ghana, Nigeria, Uganda, Kenya, Tanzania, Zambia and Malawi. We hope to find time for a two-day meeting in each country recruiting, we hope, 10, 15 or 20 people to come and meet the team and to discuss their problems concerning epilepsy. The whole programme will take five or six weeks.

Professor Boshes from Chicago and Dr Ounsted from Oxford have said, regretfully, that they cannot spare so long a period of time away from their own hospitals. We hope, however, that Dr Peter Jeavons, Birmingham, will be able to join Professor Merlis, Baltimore, and of course we shall have local specialists suppporting the team in each centre.

At the time of writing, our plan for the travelling workshop is as follows:

Sierra Leone: suggested dates March 19-22. We have written to Dr Stuart. No answer.

Ghana: suggested dates March 22-25. Written to Dr Edoo and Prof D Haddock. Replied in favour of project. Awating firm date.

Nigeria: suggested dates March 25-29. We offered two meetings. Reply (Prof Osuntokun): one meeting better at either centre, possibly Lagos. Reply (Dr Dada): agrees. Suggests to include an African doctor in the team.

Uganda: suggested dates April 5-8. Prof German in favour and will invite representative from Mauritius.

Kenya: suggested dates April 9-12. No answer.

Tanzania: suggested dates April 12-15. Dr Swift in favour and would make local arrangements. Have written to Chief Medical Officer, Ministry of Health at his suggestion.

Zambia: possibly visit mid-April - no reply to letters.

Malawi: possibly visit mid-April. Dr Mair has offered to make arrangements.



Dear colleagues and friends

I am delighted to welcome you warmly to the 1st African Regional Epilepsy Congress in the wonderful city of Nairobi, Kenya from 21st to 23rd June 2012. Although there have been smaller national epilepsy conferences and meetings in many parts of Africa, this is the first time ever that the International League Against Epilepsy

IBE's Presence in Africa

IBE is represented in 19 African nations, with two members (Full and Associate) in Cameroon. These 20 associations comprise IBE's African Regional Committee. The region is supported by the African Regional Executive Committee (AREC), which comprises an elected Chair, Vice Chair and Secretary. Other non-elected members may be introduced by the IBE President, subject to the approval of the IBE International Executive Committee.

IBE is currently represented in the following countries:

- Cameroon
- DR Congo
- 💲 Ethiopia
- 💲 Gambia
- 💲 Ghana
- Kenya
- Mauritius
- 💲 Namibia
- Niger
- 💲 Nigeria
- 💲 Senegal
- Sierra Leone
- South Africa
- Swaziland
- 💲 Tanzania, United Rep of
- 💲 Togo (associate member)
- 💲 Uganda
- Zambia
- Zimbabwe

EPILEPSY IN AFRICA:THE CURRENT STATUS

Report by Anthony M Zimba
IBE Vice President Africa and Chair, African Regional Executive Committee

(ILAE) and the International Bureau for Epilepsy (IBE) have organised a Regional Epilepsy Congress in the region. We would like to sincerely thank the two organizations for this great development.

As you may be aware, the ILAE and the IBE work together to advance research and improve the quality of life of those afflicted with epilepsy. The two organizations work in collaboration to raise awareness around the world and to help to provide a broader understanding of the nature of epilepsy and the needs of persons with epilepsy.

The League was founded in 1909 as the world's preeminent association of physicians and other health professionals, whilst the Bureau was founded in 1961 as an organization of laypersons and professionals interested in the medical and non-medical aspects of epilepsy.

One of the mandates of the two organizations is to organize regional congresses in all the regions of the world. However, while the IBE African Regional Committee was established in 2001, the organizations felt that Africa was not ready to host a regional congress in the absence of an ILAE African Commission. Several meetings were held in order to enhance the formation of ILAE and IBE member asso-

ciations in the region. In May 2000, under the aegis of the ILAE/IBE/WHO Global Campaign Against Epilepsy, a meeting was held in Dakar, Senegal, at which the participants agreed to the declaration that 'Epilepsy should be a health priority in Africa".

In 2003, IBE and ILAE demonstrated their commitment to Africa with substantial financial sponsorship of delegates from Africa to attend the 25th International Epilepsy Congress in Lisbon, Portugal. At the congress a Constituent Assembly on African Affairs was held, attended by African delegates with the aim to discuss the formation of commissions in Africa.

In November 2010 the dream came true in Dakar when an ILAE African Commission was formed and immediately it was announced that Africa would hold an African Regional Epilepsy Congress in the near future.

EPILEPSY IN AFRICA

It has been estimated that, of the 50 million people suffering from epilepsy worldwide, 10 million live in Africa. Progress in the management of epilepsy in Africa has been slow, with the treatment gap estimated at 80 to 85%. This is due to lack of specialised personnel, insufficiency



of materials, lack (or high cost) of drugs, and incorrect cultural interpretation of the condition.

Although the declaration "Epilepsy a

health priority in Africa" was made in May 2000, very little has been achieved in the interim. People with epilepsy in Africa are still living in the shadows of stigma. Many countries in Africa include epilepsy under their mental health programs and many people with epilepsy are cared for in mental health institutions, a situation which creates stigma and mismanagement. Lack of political will by many governments, especially in sub-Saharan Africa, compounded with high disease burden, makes the situation worse. As a result of this, 90% of people who live with epilepsy in Africa do not receive any form of treatment whatsoever. One of the reasons for this is that there is serious social stigma attached to the condition. Many people believe that epilepsy is contagious, demon possession, bewitchment or that it is "an African disease" which needs to be treated

In recent years, the WHO launched a non-communicable diseases (NCD) program in the WHO AFRO region, as it became obvious that NCDs had become a major burden in Africa. Epilepsy has been mentioned in this program but still it receives very little attention. More emphasis has been placed on other diseases such as cancer, asthma, trauma, diabetes, etc. For example, in the "Diseases Control Priorities Project Bulletin 2007" all non communicable diseases have been mentioned, with the exception of epilepsy. It is hoped that with the formation of the IBE Regional

by tradition methods only.



Committee and the ILAE African Commission, together with the introduction of the IBE/ILAE African Regional Epilepsy Congress will see the situation change for the better.

ACTIVITIES TO DATE:

Since 2005, the IBE Regional Committee has undertaken the following activities:

- Regional committee meetings in South Africa, Uganda and Rwanda
- Support to African conference held in Uganda
- Visits to members in The Gambia, Senegal, Ethiopia, South Africa, Kenya, Tanzania and Zimbabwe

- Visited prospective new members in Malawi and Rwanda
- Contacts were made in Botswana, Mozambique, Sudan, Eritrea, Angola, and Lesotho
- Attended international and regional congresses
- Two AREC members attended an African Decade on Disabilities workshop in Ethiopia
- An AREC member attended the Africa Decade on Disabilities board meetings and its General Assembly meetings



PROMISING STRATEGIES IN AFRICA

The IBE Promising Strategies Program 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. The African Region has been the biggest beneficiary of support from the IBE Promising Strategies Program, with the following 27 projects, undertaken by members in the African region, having received financial support from the program to date:

2007

Cameroon: Tomato growing
The Gambia: Vegetable growing
Mauritius: Massage therapy
South Africa: Entrepreneur Program
Uganda: Anti-Epileptic Drugs Bank
Zambia: Poultry rearing

Zimbabwe: Epilepsy Awareness program **2008**

Kenya: Epilepsy Care
Ethiopia: Awareness raising

Namibia: Epilepsy care giver training Tanzania: Poverty alleviation program

2009

Namibia: DVD Awareness Pack Togo: Epilepsy health education Zambia: Market gardening skills Zimbabwe: Peanut butter project

2010

Uganda: Goat rearing **Namibia:** Second hand shop

South Africa: Train the trainers course

2011

Swaziland: Poultry rearing **Zimbabwe:** Advocacy Training

2012

Cameroon: Employment training
Mauritius: Family Training Workshop
Namibia: Career Development
Uganda: School Epilepsy Clubs
South Africa: Schools Programme
Zambia: Banana Plantation

Zimbabwe: Health Professionals Training



Report by Marina Clarke National Director, Epilepsy South Africa

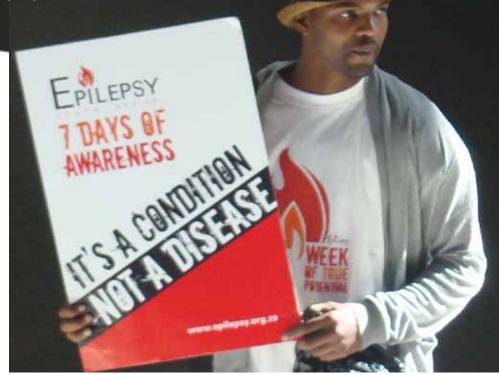
African views have traditionally stemmed from the days when Europeans looked at our continent as the "dark continent" in need of the "light of civilisation". With good intentions, Europeans set out to save Africa and through colonisation planted a Euro-centric vision of our home. European traditions and lifestyles were established in Africa, forever changing our view of ourselves and our continent.

It was only in 1994 when the first democratic elections in South Africa marked the end of apartheid that the phrase African renaissance was first used. In his I am an African speech in May 1996 then-Deputy President Thabo Mbeki celebrated adoption of the new South Africa constitution:

"I am born of a people who are heroes and heroines ... Patient because history is on their side, these masses do not despair because today the weather is bad. Nor do they turn triumphalist when, tomorrow, the sun shines. ... Whatever the circumstances they have lived through and because of that experience, they are determined to define for themselves who they are and who they should be."

While post-colonial Africa is characterised by decolonisation and the outbreak of democracy across the continent in the early 1990s, we are now seeing the African renaissance driving towards social cohesion, democracy, economic rebuilding and growth, with Africa being established as a significant player on the world stage. Sadly, people with epilepsy have largely remained chained in the "dark continent" stage of African development. Discrimination, stigmatisation and violation of the human rights of people with epilepsy remain a daily reality in Africa. While this might seem a desperate situation, we should remember the words of Anne Sullivan Macy (the well-known instructor/ companion of Helen Keller): "Every renaissance comes to the world with a cry, the cry of the human spirit to be free." It is this very cry for freedom of Africans with epilepsy that led to the 1st African Epilepsy Congress in Nairobi in June 2012.

For Epilepsy South Africa this event came at an opportune time. In the words of Barack Obama: "Change will not come if we wait for some other person or some other



time. We are the ones we've been waiting for. We are the change that we seek."

Our recent achievements

During recent years, Epilepsy South Africa has been redefining our focus and thus our work. Since its establishment in the 1960s the organisational focus has been largely on social development with economic development incorporated as a major programme at the start of the 21st century. During the last decade organisational marketing and branding was added. As such, in recent years our work was focused around a number of themes:

- Media awareness and marketing aimed at increasing knowledge about epilepsy and Epilepsy South Africa through the utilisation of various marketing and communication media, resulting in decreased discrimination against people with epilepsy and increased organisational sustainability. In addition to the usual media (print, radio, television), the explosion of social media worldwide (but in South Africa in particular) created a new medium to interact with our audience. Another focal area has been organisational branding, including the establishment of a monthly newsletter available in both electronic and print format.
- Sustainability aimed at providing efficient, cost-effective fundraising to maintain organisational goals. In addition to traditional funding via donors,

Epilepsy South Africa also hosted special events such as a National Wine Auction and participates annually in Casual Day (a cross-disability national fundraising event).

- O Social development aimed at redressing discrimination and exclusion experienced by people with epilepsy on a daily basis with advocacy as a key focal area in addition to social work services. Our online counselling service consistently gained popularity as it provided access to counselling to people in often remote rural areas. It is in these very remote areas that Epilepsy South Africa endeavoured to establish services. This is evident from the location of Branches in small towns and even villages around South Africa. National Epilepsy Week is celebrated in June annually with specific attention to celebrations on 21 June as National Epilepsy Day.
- O Economic development aimed at creating opportunities for gainful employment and the economic empowerment of people with epilepsy, including employment in the open labour market, protective employment and self-employment (entrepreneurship).
- O Skills development aimed at ensuring compliance with relevant South African legislation for the development, empowerment and up-skilling of personnel, volunteers and clients.

The Epilepsy South Africa Educational

Trust was established in January 1999 and provides tertiary education bursaries to students with epilepsy. Studies have been very diverse, ranging from medical and dentistry to human resource management, political science, information technology and beauty therapy.

Future plans

It was Victor Hugo that said: "An invasion of armies can be resisted, but not an idea whose time has come." This is particularly true about the human rights of South Africans with epilepsy. During the 2012/2013 financial year, Epilepsy South Africa will be focusing on epilepsy as a human rights issue. As such, our programmes and projects reflect this focus - building on the traditional programmes described above.

The Eastern Cape is one of the poorest rural provinces in South Africa where people with epilepsy are exposed to extreme discrimination - often due to traditional views about the condition linked

to witchcraft and demonic possession. Some three years ago, Epilepsy South Africa established a service point in East London (one of the largest cities in the Eastern Cape). In the current year we will be developing this service point into a fully-fledged Branch of the organisation and expanding access to services.

We will continue working to reduce discrimination and stigmatisation faced by people with epilepsy through:

- The development of a human rights charter for people with epilepsy based on the United Nations Convention on the Rights of People with Disabilities (UNCRPD);
- Quantitative and qualitative research on the violation of human rights of people with epilepsy;
- The provision of advocacy training and development services to people with epilepsy; and

• The provision of public education and awareness. One of the focal areas of this project will be quarterly media campaigns built around specific themes. The first campaign (April – June 2012) targets schools (educators and learners) and parents, while other themes include celebrating the achievements of people with epilepsy, establishing epilepsyfriendly medical services and holistic wellness for caregivers of people with epilepsy.

Many people with epilepsy are not able to access adequate healthcare. The fact that South Africa currently has the highest epilepsy-related mortality rate in the world underlines the need to ensure the availability of effective drug therapy. This initiative will be supported by a nutritional educational project to ensure food security. Tapeworm infection is one of the major causes of epilepsy in South Africa and will be counteracted through an educational



project on sanitation which will be piloted in the Eastern Cape. A major shortage of neurological services means that many people with epilepsy are not able to access such services. Building on an existing service, Epilepsy South Africa will provide mobile neurological services to rural areas.

Despite excellent employment equity legislation in South Africa, people with epilepsy remain marginalised. We are developing an employment manual and guidelines on reasonable accommodation

in the workplace. Our entrepreneurship programme will be expanded through the addition of new training programmes enabling growth of protective workshops and income generation projects, as well as advocacy skills for entrepreneurs with epilepsy and the organisations representing their interests.

We will also develop and implement a training programme for the establishment and effective functioning of support groups, as well as a guide for the caregivers and family of people with epilepsy.

The Northern Cape is the largest province in South Africa, but sparsely populated. This presents many challenges in terms of service delivery. We will be focusing on self-advocacy, education and awareness.

When Thabo Mbeki said "we will continue to count on your unwavering support and commitment to working with leaders of our continent in bringing about the desired renaissance of Africa" he was not speak-

ing about people with epilepsy. However, these are the words that bind us together as Africans joined in the struggle for equal rights of people with epilepsy.

Structure

The National Office of Epilepsy South Africa is based in Cape Town with five Branches throughout the country:

- 1. Western Cape Branch, Cape Town; 2. South Cape/Karoo Branch, Knysna; 3. Free State & North West Branch, Parys (with a satellite office in Vryburg);
- 4. Mpumalanga & Limpopo Branch, Dullstroom (with a

satellite office in Elandsdoorn);

5. Gauteng Branch, Springs.

Main photo: In June 2011 Epilepsy South Africa drew attention to epilepsy through a flash mob at the main Cape Town railway station.

This page: Ryk Neethling (South African Olympic gold medallist - swimming) photographed with Gary Gabier (a young man with epilepsy) as part of the ILAE Stand Up For Epilepsy Campaign.



The Community Development and Epilepsy Foundation (CODEF) has been working in the North West of Cameroon for 10 years to improve the lives of people with epilepsy.

Under the law in Cameroon epilepsy is considered as a disability.

There are still many myths and misconceptions, particularly in the villages of Cameroon, that create stigma and isolation for people with epilepsy and that can have a dangerous impact on their lives and prevent treatment. For instance, there are such practices as putting the feet of

CAMEROON:

COMMUNITY INCLUSION OF PEOPLE WITH EPILEPSY TUBAH, NORTH WEST CAMEROON

Report from Nsom Kenneth, Coordinator of CODEF Cameroon

persons living with epilepsy in fire to prevent seizures, or inverting children's heads over the pit latrines during a seizure. Others tag them with names like "wo ngeh" meaning a cursed person and some traditional healers are known to

beat them seriously in an attempt to cure their epilepsy.

CODEF recently worked with Tubah Council, VSO (Volunteer Services Oversees), the Coordinating Unit for the Association of Persons with Disabilities (CUAPWD), and experts on leprosy to carry out sensitization sessions in the four villages of Tubah Municipality.

The purpose of these forums was to bridge the gap between people with disabilities, traditional leaders and other community members. The presentations aimed to educate people on the meaning, causes, first aid measures and treatment of epilepsy.

The response from participants was very favourable. People asked many questions such as; "Is epilepsy contagious?", "Can you put a spoon in the person's mouth to prevent biting their tongue when having a 'fall' (seizure)?" At the end of the forums people commented that they no longer feared those with epilepsy and would stand by someone and help when they were having a seizure. It was very inspiring to experience these changes in attitudes. CODEF is currently working with Tubah Council, VSO and the CUAPWD to continue this work. The next steps will include forming support groups, further sensitization and education and advocacy on the laws and human rights of people with epilepsy.

SIERRA LEONE

The Epilepsy Association of Sierra Leone, which was founded in 1999 to advocate for people with epilepsy and to provide treatment and care, organized several events in March throughout Sierra Leone. Six schools in the eastern part of Freetown were visited. These were Peninsular Secondary School and LoreWnz Gorvie Memorial Secondary school in Waterloo on the 21st of March; Ahmadiyya Secondary School and Richard Allen High School, were visited on the 22nd of March; while John F Kennedy Primary School and St Theresa Primary School were visited on the 23rd March. More than 3,000 school children were contacted and informed about epilepsy. The key messages were that:

- Epilepsy is not demonic nor caused by witchcraft;
- Epilepsy is not contagious and can be controlled with medication;
- Of major importance is that people should stop discriminating against

- persons with epilepsy and that they deserve their human rights and dignity;
- Persons with epilepsy need support and care, particularly when they have seizures.

During the school awareness campaign, some children came out bravely to inform the EASL team that, indeed, they had epilepsy and that, as of that day, they would no longer be ashamed of the condition and would always inform others about the knowledge they have acquired on epilepsy. The school sensitization campaign was reported on by the Sierra Leone Broadcasting Corporation (SLBC).

To capture a wider audience, radio discussions on the key messages about epilepsy were held on the following stations: Radio Viasity FM 106.6, Radio Lion Mountain at Waterloo, TUMAC Radio at Portee, Citizen Radio FM 107, and Sierra Leone Broadcasting Cooperation. The events

were also covered on SLBC's Tea Break, Good Morning Sierra Leone and the National News. A documentary 'Living with Epilepsy in Sierra Leone' was aired on the SLBC programme Healthways.

School children, including persons with epilepsy, were taken to Bureh Beach for recreation. Fifty children participated in the beach outreach. This activity was organised in an effort to debunk the notion that persons with epilepsy should not mix with others and should not go to the beach to avoid contact with demons.

The exercise encountered numerous challenges, ranging from insufficient resources, particularly financial. The other constraint was that of mobility. The organization had no vehicle to convey the campaign team and, as such, taxis were used to access the schools selected. This limited the activities undertaken to mark the event.

EDYCS - MAURITIUS

In recent years, Edycs Epilepsy Group has been building a strong working collaboration with Corporate Social Responsibility (CSR) institutions and foreign donor agencies to support empowerment of people with epilepsy and to de-stigmatise epilepsy in the community. In parallel, Edycs Epilepsy Group succeeded in putting epilepsy high on the agenda at government agency level. Some projects include:

Epilepsy Management Training

Teachers from pre-primary and primary Schools in the Republic of Mauritius and Rodrigues Islands were trained in epilepsy management in class. The project was funded by the Women and Children Solidarity Programme, Ministry of Gender Equality, and Child Development and Family Welfare. The training focused on epilepsy in children and young adolescents, school related problems, seizure management and psychiatric disorders. The Ministry of Education and Human Resources, the Early Childhood Care and Education Authority, the Port Louis Gymkhana, the MES Society and the Commission for Education and Health in Rodrigues Island collaborated with us.

The sessions were conducted by medical professionals, educators and therapists from Edycs Epilepsy Group, in particular, Dr Dominique Lam Thuon Mine, R

Sheedeshwar, M Parsad Taukoorah, Iqbal Gooljar, Joyvani Rose, Keerti Purmessur, Hashim Malleck and Youssouf Noormamode.

During the sessions emphasis was also put on the development and application of a Seizure Action Plan and Seizures Record Management in the school setting.

Practical aids for Epilepsy Management

The Commonwealth of Australia Direct Aid Program, through the Australian High Commission, supported practical aids for epilepsy management through care, community awareness, education and empowerment. The project focused on the purchase of medical equipment, furniture, and

publications to strengthen existing services at Edycs Epilepsy Health Service Center, followed by two seminars held in Mauritius and Rodrigues Islands. The Australian High Commissioner, HE Mrs Sandra





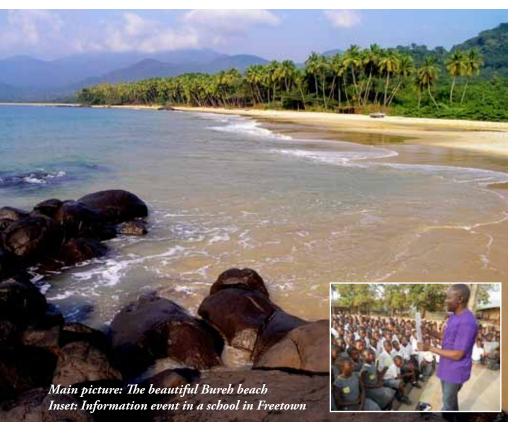
Top photo: Hon Dr A Rashid Beebeejaun, GCSK, Deputy Prime Minister opening the Edycs Educational Center. Photo bottom: Her Excellency Mrs Sandra Vegting, High Commissioner for Australia, signs the Visitors Book

Vegting, visited the Edycs Epilepsy Center and graced the opening of the seminar in September 2011.

Educational & Rehabilitation Center

The Currimjee Foundation and Sun Resorts CSR Fund Ltd helped in the opening of the rehabilitation center for children and adolescents with epilepsy in Port Louis. The official opening was hosted by Dr The Hon AR Beebeejaun, GCSK, Deputy Prime Minister and Minister of Gender Equality, Child Development and Family Welfare, the Hon Mrs Indranee Seebun. The center is presently accommodating 20 children and adolescents with learning disabilities.

The center offers a complementary inclusive program based on personality development, creative skills, computer learning, languages, keep fit and regular outdoor social activities and is recognised by the Ministry of Education and Human Resources and receives a partial aid grant to meet its running costs.





Epilepsy Learner Awareness

Funding for this program was awarded by the Department of Health and Social Services in February 2011. There was a bureaucratic delay in obtaining permission from the department with the result that the program could only be implemented in schools in the second academic term.

Schools preferred to receive the Ten-Minute-Teacher's Tea time Training first as a kick-off for the program. This enabled them to decide on the next phase of awareness/training that was required.

Assembly awareness was presented at primary schools, while secondary schools mostly preferred to tailor training to their specific needs: individual information and guidance sessions, training for hostel staff, long term assistance plans and educational environment problem solving.

Assembly Awareness at Emma Hoogenhout School

Life Skills lessons on epilepsy for Grade 1-12 were developed and presented to the Life Skills Teachers participating in the program to be tested before presenting it to the Department of Education.

Epilepsy Day 2011

21 June was celebrated with an Awareness Day at Maerua Mall where the public could come in contact with the organization and receive information. Products from the RE-project were displayed. Neil Horn and Albertus Garoeb assisted with public inquiries.

- Radio interviews were made with Namibian Broadcast Corporation (Afrikaans and German Services), Kosmos Radio and Kanaal 7.
- The newspapers: Die Republikein, The Namibian and Southern Times reported on the event.
- Ilse Eiseb presented an information program at Otjemuise School.

RE- Project.

Having changed the project's format we attended a total of 12 market stalls in 3 locations. Funding from the IBE Promising Strategies Program was used to develop and stabilize the project. In the future the RE-Project will be able to run in this format as an independent business unit.

We were offered a regular slot once a

month for 2011 by Louisa van Zyl of NBC Afrikaans Radio to talk about epilepsy. Ten interview/discussions were broadcast live on subjects covering all the information pages, epilepsy and art, as well as news and projects of the organization.

Career Development Training

During the Epilepsy Learner's Awareness Training it became obvious that students were ill prepared to choose and develop a career. A program was developed by Epilepsy Namibia to assist students with epilepsy in this process. It consists of three short courses:

- (a) choosing a suitable career, preparing a CV, interview etiquette and presentation, as well as work ethics.
- **(b)** Small business development, organization and administration.
- (c) Basic Information Technology (IT) literacy including documents, spreadsheets, email and internet.

Epilepsy Namibia was selected to receive a Promising Strategies Program 2012 grant for "Career Development Training". A full proposal was handed in to Namibia Department of Health and Social Services.





Under Construction

The Epilepsy Support Foundation of Uganda ESAU has, for over a year, been struggling to build office premises and a national epilepsy information centre. As we go to print, the association has completed 90% of the work and will move into the new building very shortly. This activity has taken up a considerable amount of time and energy, as the work was undertaken from the association's own funds raised from its 10,000 members. Augustine Mugarura, who heads up the association, was on site everyday to supervise the work. The photo, left, shows the buildin in the early stages of construction. We look kforward to publishing a photo of the completed centre in a future issue! In the meantime, suggestions for a name for the building, located in Kampala are invited! These should be emailed to Augustine at mugarura2012@gmail.com

ZAMBIA

INTRODUCTION

The Epilepsy Association of Zambia was formed in 2001 and became a member of IBE in 2003. There are currently 600 members of the association, although services are provided to more than twice that number.

At the present time, the association is working on three projects, each of which has been supported by a grant from various rounds of the IBE Promising Strategies Program. These are chicken rearing, market gardening, and jam making. A further initiative, banana growing, has recently been selected in the 2012 round of the Promising Strategies Program.

SUPPORT SERVICES

- Epilepsy Case Management: special epilepsy clinics are held each week at Chainama Filter Clinic.
- Public and Professional Awareness about epilepsy through celebration of the following special epilepsy awareness days:
- National Epilepsy Day: usually organized in partnership with the WHO Country Office and Ministry of Health
- Seizure Free Day: A day dedicated to promoting adherence to prescribed medical treatment.
- ♦ Capacity Building to strengthen partnership in epilepsy care organizing of training workshops, skills training at established centres and school support.
- Jam making workshop through the Promising Strategy Programme

FUNDRAISING

The production of a yearly calendar with advertisements from pharmaceutical companies and pharmacies has been the most outstanding fundraising venture. In 2011, through advertisements and sale of calendars we raised the equivalent of almost US\$5,000. In 2010 we also joined another campaign which provides an opportunity to sell purple items such as wrist bands and t-shirts, thus raising funds for our association.

We provide financial aid to 10 students to support their studies. This includes David Mwila, who is an IT student in Russia; Cephas Rhiri, a Clinical Officer studying medicine; and Rose Mwanza, a Secretarial College student.

VISIT OF IBE PRESIDENT

Most members of the IBE Africa Region Committee experience similar challenges in their epilepsy activities. These usually include insufficient supplies of drugs, lack of skilled health personnel and inadequate resources budgeted for epilepsy activities and treatment. In Zambia, we experience all the above mentioned challenges and a visit by our President was a great milestone in highlighting the many problems faced by African society. The President visited the following:

- ♦ Health Authorities and the WHO Country Office.
- University Teaching Hospital (UTH), Neurological & Psychiatric Society of Zambia
- Private radio stations where interviews were broadcast Radio Christian Voice and Joy FM
- ♦ Official Visit to the Epilepsy Rehabilitation Project Site Chainama Hills College Hospital



The Epilepsy Association of Zambia wishes to do more in alleviating the burden of epilepsy but lack of adequate resources has been a hindrance. We are certainly grateful to IBE for initiation of the Promising Strategy Project, which has helped us to reach people with epilepsy who really need support and skills training. It is our hope that our next project will be as successful as the previous ones. We look forward to developing the banana plantation.

PHOTOS

Above: Zambia First Lady, Dr Christine Kaseba Sata, at the banana plantation on Seizure Free Day, with WHO Country Representative Dr Babaninyi (right) and Anthony Zimba, Epilepsy Associaion of Zambia (left)

Below left: IBE President Mike Glynn is interviewed at Radio Joy FM

Below: Street parade on Seizure Free Day









Meeting of the IBE African Regional Committee in Nairobi

Date: Wednesday 20th June

Time: 14:00-17:00

Venue: Crowne Plaza Hotel

Room: Nzoia (tbc)

All IBE members in the African Region are invited to attend

Potential new members are also welcome to be present

NIGERIA

Recruitment of Rural Service Aids (RSA)

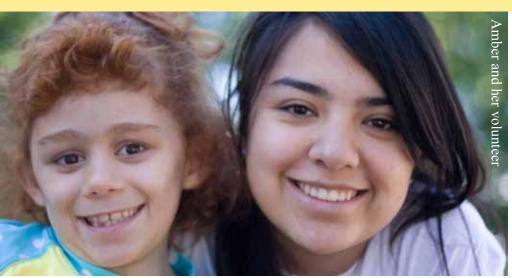
The Epilepsy Association of Nigeria have been busy recruiting RSAs to help the large numbers of people living in rural areas of Nigeria who are suffering due to lack of information, medication and care. The association has trained two levels of RSAs:

- Publicity/Enlightment Aids
- Care/Treatment Aids

Dr Nwakwue, who is President of the Nigerian association reports that the Aids underwent a 7-day training course, at the end of which each participant was presented with a certificate. During the course, serious interactive discussion took place. Participants had the opportunity to ask questions and their questions were answered clearly. Some people with epilepsy were also invited to help with the training, so that they could have an idea of what they would meet in the field once the training was completed.

The association spent a lot of money on the programme and, as soon as its income improves, hopes to extend the service to areas that have not yet benefitted from the programme.

Wacky Wednesday's Summer Camp by Mary Secco, IBE Vice President North America and Director, Canadian Epilepsy Alliance



If you were a child who was told you couldn't go to gym class, on the field trip, ride the regular school bus or go out for recess, would you like going to school? How would you stay fit and active? How would you develop social skills and make new friends? Too often, parents of children with drug refractory seizures say their child is excluded from organized sports, camps, and social and recreation programs at school and in the community. For these children, the Epilepsy Support Centre in London, Ontario, Canada offers the Wacky Wednesday's summer camp.

The summer camp matches youth volunteers (aged 14-25 years) one to one with a child (aged 5-12 years) who has epilepsy. In 2011, 40 children attended the 10 day summer camp. All of the participants had drug refractory seizures and many had cognitive, communication and behavioural challenges. The summer camp is organized to help the child with epilepsy to reduce their isolation, to learn new skills, make friends and have fun. Youth volunteers receive a comprehensive training where they learn about epilepsy, different seizure types and seizure first aid. These youth become role models to the child living with epilepsy. In addition, the youth develop leadership and conflict resolution skills. Many youths use this experience to get paid employment working with children or to apply to professional schools.

Seven-year-old Amber attends summer camp. When Amber's father, Shane, first connected with the Epilepsy Support Centre, he said that her friendships, academics, problem solving, coping skills and physical activities were all affected by her seizures. He was looking for a summer camp where Amber would be safe if she had a seizure

and where she would be included in all the group activities. He also hoped that Amber would make a friend at the summer camp. Amber was matched with a youth volunteer. Together they played games, made crafts, rode yellow school buses and even went horseback riding. They went on field trips to amusement parks and splash pads, dressed up as pirates, super heroes and princesses. Amber learned valuable communication and problem solving skills and had the opportunity to be more physically and socially connected to her community. Most importantly, she had fun and did make friends. "The summer camp has been a blessing in disguise for the whole family. Camp gets Amber out of the house, she really looks forward to camp and she comes home so tired. We've never been able to tire her out that much before," says Shane.

A survey of all forty families whose children attended the program last summer revealed that 95% of the campers had no other organized recreational activities and that summer gap filled a void for these children.

Since children with epilepsy face a disproportionately high risk of underachievement at school, learning disabilities, mental health problems, social isolation and poor self-esteem - the summer camp is being offered as an early intervention program. The camp experience helps children with epilepsy to become more resilient, to learn new skills and to feel successful and valued in their community.





The 140 year-old Black Pine (Kuromatsu) Bonsai tree, above, is symbolic of the resilience of the Japanese people. Since the moment on the 11th March 2011, when the country experienced the terrible earthquake, with its ensuing tsunami, that resilience has been greatly tested.

At a moving symposium, organised by the Japan Epilepsy Association JEA (IBE member) and Japan Epilepsy Society JES (ILAE chapter), the horrors of the disaster following the earthquake, and the actions taken by these associations to provide emergency support to people with epilepsy affected by the tsunami were recounted. It was the first anniversary of the disaster.

It is almost impossible to imagine a wave that is more than 40 metres high or to estimate the damage that will be left in its wake. At 40.5 metres high, the Japanese tsunami caused absolute devastation in the area affected and was responsible for the deaths of more than 20 thousand people.

With infrastructure - roads, communications, electricity, water - put out of service, it is thanks to the dedication of the members of JEA and JES that one day after the



disaster struck, emergency support services were already being put in place.

Four days later, the first teams had been sent to the disaster area. Emergency crews would continue to arrive in Sendai province over the following weeks, each staying about five days before returning home to rest. During their stays in the disaster area, they slept dormitory style on the floor.

More than 40 thousand people would visit the emergency centre in Sendai following the tsunami. The centre was based in a school that was one of the few buildings to have survived without extensive damage. Many of those looking for help had nothing left after the tsunami and were desperate for medical supplies. For people with epilepsy, their was an urgent need to ensure they had their medication. By 19th March, the first AED supplies were being sent to the region, thanks to the support of the pharmaceutical industry and to the transport union which came to the rescue to transport supplies to the affected area.

Dr Hidemoto Kubota, Vice President of JEA, who was one of those who travelled to Sendai, reported these details in his compelling presentation. He also talked about other actions to help those affected by the tsunami: the information magazine and the emergency telephone hotline that was operational 10 days after the tsunami struck. The hotline, in particular, proved a vital line of connection. During the first weeks, most of the calls related to access to AEDs but, as time passed, the calls moved to more general queries on epilepsy. Such was the level of calls received to the hotline

that a decision was taken to maintain the initiative as a permanent support mechanism for people with epilepsy.

The first international speaker was IBE President, Mike Glynn, who presented on activities in Europe. From January to June 2013, Ireland will hold the European Union (EU) Presidency. This is in line with EU procedures, with the Presidency rotating among members on a six-monthly basis. During the Irish Presidency, a Forum on Epilepsy Research will take place in Dublin, organised by the IBE/ILAE Joint Task Force Epilepsy Advocacy Europe, and with the suppport of an EU grant.

A concern is the disparity in prevalence figures for people with epilepsy in Europe; the WHO states a figure of 6 million while the European Brain Council cites a figure of 2.1 million. In some countries no survey has ever been undertaken to determine prevalence. This makes planning for adequate provision of treatment and care very difficult to implement. It is proposed to undertake a definitive survey, using the same methodology in each country, to establish the correct prevalence rates for epilepsy across Europe.

Mike Glynn also spoke about the EU Directive on Driving, which came into force in August 2009 but which has still to be implemented in some countries.

Dr Byung-In Lee, Korea, presented on the introduction of a new name for epilepsy in Korea – Cerebro Electric Disorder. The aim is to try to reduce the very real stigma that is connected to epilepsy in Korea, which is due, in large part, to cultural is-



forbidden disease.

Despite the fact that there has been a lay epilepsy association in Korea since 1964, lack of

information and awareness about epilepsy remains a problem because of Korean culture. For example, just 40% of Korean's believe epilepsy can be treated; 64% would object to their child marrying a person with epilepsy; 57% believe that a person with epilepsy should not have children.

The old Korean name for epilepsy meant 'crazy' or 'mad'. It is now hoped that the new name, proposed in 2009 and approved by the Korean Medical Association in May 2011, will help to change things for the better. The new name will be celebrated at a special ceremony during the Korean association's annual congress.

Providing the Latin American picture, Dr Carlos Acevedo, IBE Secretary General, presented on the PAHO Strategic Plan, informing delegates that the treatment gap in Latin America is 50% and 20 million people have epilepsy in the region. He said PAHO Chair state, on the occasion of the signing of the Strategic Plan on epilepsy, that 'epilepsy will no longer be a hidden disease'. Dr Acevedo explained that North America and Latin America have different mental health advisors and separate strategic plans. Each works independently but with reference to each other.

Prof Emilio Perucca, ILAE Treasurer and President-elect, introduced the EU Written Declaration on Epilepsy which was approved in the European Parliament in September 2011: the efforts required for its approval and how the declaration will help with future activities in Europe.

Prof Perucca explained that epilepsy care is fragmented both across Europe and even within some European countries. While most people see Europe as a well developed and wealthy region, the treatment gap for epilepsy is as high as 90% in some areas and 58% of countries do not have an epilepsy surgery programme.

The afternoon session focussed, in the main, on scientific topics, as follows:

Pictured left, in the grounds of the Imperial Palace: Tatsuya Tanaka, Emilio and Tita Perucca, Ana and Sam Wiebe, Mike Glynn and Ann Little

Pictured below, symposium speakers and chairs: back row from left: Akio Ikeda, Shiqeki Kameyama, Edward Bertram, Masako Watanabe, Carlos Acevedo, Jean Gotman, Gary Mathern. Front row: Tatsuya Tanaka, Emilio Perucca, Sunao Kaneko, Nico Moshé, Mike Glynn, Byung-In Lee and Sam Wiebe

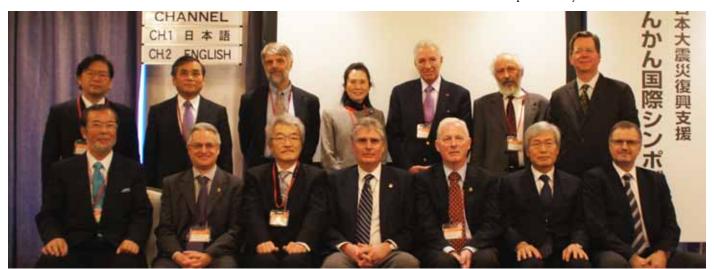
Pictured previous page, from left: Satsuki Watanabe and Ichiro Takumi

Main photo: A 140 year old black pine bonsai tree, in the beautiful grounds of Happo-en Gardens, Tokyo

- Nico Moshe, ILAE President: Infantile Spasms: New frontiers
- Jean Gotman, ILAE Director of Interactive Media: Recent Developments in EEG and Functional Imaging
- Tatsuya Tanaka, ILAE 1st Vice President: Epilepsy Network in Animal Models of Epilepsy
- Edward Bertram, ILAE Information Officer: Medical treatment of Intractable Epilepsy: State of the Art
- Samuel Wiebe, ILAE Secretary General: Timing of Surgery in Patients with Intractable Epilepsy
- Gary Mathern, Chair of ILAE Strategic Planning: Pediatric Epilepsy Surgery: State of the Art.

The IBE Management Committee would like to congratulate JES and JEA for an excellent symposium. Particular thanks go to Dr Tatsuya Tanaka, Dr Sunao Kaneko, and Dr Masako Watanabe for their great kindness to us throughout our stay in Tokyo. Also thanks to Dr Ichiro Takumi and Dr Satsuki Watanabe, two excellent guides.

We departed Tokyo with warm memories!





The conversation suddenly went quiet and our hosts began to steer us hurriedly towards the door. Then, to our surprise and delight, a 2-metre high red doll entered the room. In her bright red dress and flower strewn hat, she looked amazing! This was Akari, the mascot of Japan Epilepsy Association (JEA) - a great big hugable doll that gets fantastic attention everywhere she goes. Whether she is out and about in the busy shopping streets of Ginza (as you can see on the front cover) or in the quieter surroundings of one of Tokyo's manicured gardens (above), Akari is an unstoppable force.

She is used by JEA as a way of attracting attention whenever, and wherever, the association is organising public information events. Akari is also the logo of the association and appears on all its promotional and information items.

portunity to visit the offices of the JEA during our stay in Tokyo, at the invitation of Mr Keiji Tsurui, President of the JEA and Dr Hidemoto Kubota, JEA

Vice President. We also met some younger members of the association, including those who were looking forward to travelling to the congress in Manila a few days later.

Speaking on behalf of the association, Dr Kubota gave us a brief introduction to the history of JEA (which is one of IBE's oldest member associations) and told us about its current activities.

Thanks to its very enthusiastic young workers, the association is currently compiling an epilepsy care network and is also introducing education for people with epilepsy and for non-medical professionals. Another projects in hand is the revision of a successful guidebook on epilepsy.

An ongoing activity is the regular newsletter produced by the association, in which Junichi Kawakami plays a major role. We admired covers of previous issues that adorn the walls of the office's meeting room.

living well with epilepsy.

The association has also begun to use the logo 'Out of the Shadows', considering this to be a very appropriate slogan to adopt after the tsunami and earthquake.

But the association has also had to deal with some difficult issues. In April 2011 six school children were killed in Tochigi Prefecture when a mobile crane ran over them after its driver is believed to have had an epileptic seizure.

The driver had renewed his driver's licence without reporting his condition.

While it was clear that the man should not have been driving, the public blacklash to the accident was very difficult to deal with for the association.

On a more positive note, JEA is very busy working on its new public awareness initiatives. There will be future appearances by Akari, of course, at busy railway stations and stopping malls. It is clear that there is great enthusiasm among its young members, who spoke about their plans as we enjoyed a wonderful evening with them in a typical Tokyo casual restaurtant.

Thank you to everyone we met at JEA and, especially, Mr Tsurui and Dr Kubota, who gave up part of their valuable public holiday to meet with us.

Photo: Hidemoto Kubota and Keiji Tsurui

RUNNING TO STAND UP FOR EPILEPSY

Shunglon Lai, IBE Vice President Western Pacific sent us this news report

While the rest of Taiwan was enjoying the Chinese New Year in 2006, Kevin Lin was flying the Taiwanese colours in the harsh Antarctic environment to win Taiwan the honor of being home to an ultra-marathon champion. This was the fourth leg of the legendary Four Deserts Race.

"Taiwan needs a new spirit. Something fresh and new. Something that can let everyone temporarily put aside concerns of politics, corruption, and social issues. Something that will stir the people to the bottoms of their souls and give them something to remember," stated Lin.

The Four Deserts Race is made up of four legs: China's Gobi Desert, Chile's Atacama Crossing, Egypt's Sahara, and the final leg, Antarctica. Each leg spans seven days and six nights, and covers a distance of 250 kilometers. Each competitor must prepare their own equipment and provisions for the seven days and carry them themselves. In 2003 Lin was placed third in the Gobi

leg; he followed this by taking first place

in Chile in 2004; 2005 saw him secure

second place in the Sahara Desert race; and in the final leg, Antartica, in 2006, he took third place. In aggregate across the four legs, Lin's results placed him ahead of the pack, earning him the title of overall champion.

"Being world champion isn't really that important to me--the biggest benefit of all this has been the experience and the journey, because

through these extreme races, I've really come to realize the power of life," says Lin, in what should be a reminder to all of the value of life.

Running through the Sahara Desert, Kevin Lin experienced and overcame the fierce weather conditions, which is just like the person with epilepsy who experiences storms in their life and difficulties that they must work to overcome. So in a very

educational and symbolic event, organised by Taiwan Epilepsy Association (TEA) on May 12th, Kevin Lin was the main guest in a Stand Up for Epilepsy Fun Run that took place in the Memory Hall of the Nation in the capital city Taipei.

Several other activities took place at the same time to promote epilepsy awareness, including the sale of merchandise made by members of TEA and a special muscial performance by the TEA choir.



Epilepsy Across the Spectrum: Promoting Health and Understanding IOM Report is Published

The Institute of Medicine IOM was asked to examine the public health dimensions of the epilepsies, focusing on public health surveillance and data collection; population and public health research; health policy, health care, and human services; and education for people with the disorder and their families, health care providers, and the public.

The long awaited report Epilepsy Across the Spectrum: Promoting Health and Understanding was published by the US Institute of Medicine on 30th March, following a comprehensive study by the Committee on the Public Health Dimensions of the Epilepsies, with experts from many sectors within the field of epilepsy.

This report focuses on the unmet health care needs faced by people with epilepsy and by those who care for them. The recommendations include the need for

better information about the epidemiology and consequences of epilepsy. There is also a call for the creation of standards for epilepsy care and for better training for health care professionals at all levels. The Committee found that knowledge in the general medical community about epilepsy, and about how it can destroy lives, was very limited.

The IOM strongly recommends the engagement of people with epilepsy and their families in education, dissemination, and advocacy for improved care and services and calls for better integration and coordination of care as well as enhanced advocacy. Increasing public awareness of epilepsy and its consequences was also an important area for attention.

The report will help efforts to improve epilepsy care in the United States and will undoubtedly be referenced by those in



other parts of the world in their advocacy efforts. It follows the approval of the European Declaration on Epilepsy in September 2011 and the adoption of the Strategic Plan on Epilepsy by PAHO earlier this year in a resolution to make epilepsy a healthcare priority.



Harry Meinardi

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

The year 1977 saw an important change. IBE and ILAE start to organise their symposia and congresses together. A merger can not yet be achieved; instead a new organisation is introduced: "Epilepsy International" (EI), an executive body that will act for both groups. Officers of EI will be the presidents and secretaries-general of IBE and ILAE. Actions will need the consent of both organisations. EI will have an office in Switzerland, with a paid director. In line with this development, International Epilepsy News changes its name to Epilepsy

International News.

The 1973-1977 executive steps down. The title of Honorary President is conferred on Ellen Grass and George Burden, recognizing their outstanding achievement in creating IBE and, through it, improving care and rehabilitation of persons with epilepsy world-wide. Special thanks go to Dr Earl Walker for his excellent management of the Bureau's finances.

George Burden

IBE's new executive comprises Harry Meinardi, President; Richard Grant, Secretary General; Michael Jones, Treasurer; Francesco Castellano, Patsy McCall-Owens and Karl-Axel Melin, Vice-presidents, and Joop

Loeber, Editor of EI News. The executive is asked to make "Prevention of the onset of epilepsy one of the prime goals".

March 1978: EI meets in Washington DC. A head of the office in Switzerland is selected, with some misgivings since he is monolingual. James Autry, President of the Epilepsy Foundation of America whose profession is as editor at Meredith Publishing Company - is appointed Chief Honorary Advisor of EI News. Publication is announced of the US National Plan for Epilepsy, fruit of the Health Services Act passed by the US Congress in 1975, which directed that "A commission for the Control of Epilepsy and its Consequences" should be established. The report is presented at the White House in Washington by Dr Richard Masland, the commission's executive director.

Richard Masland served as an IBE Vicepresident for the term 1981-1985 and as IBE Secretary General for the term 1985-1989. He died, at the age of 93 years, in December 2003. Several obituaries highlight his many achievements; however, interestingly, his important contributions to the improvement of conditions for persons with epilepsy are not mentioned. Be this a belated "Chapeau bas!!!" as indeed the field of epilepsy has much to be grateful for to him.

June 1978: increasing awareness and knowledge about epilepsy are seen with contributions from Denmark, Great Britain, Indonesia, Israel, Italy and Norway. Technology is important to progress. Here "The Epistrator" is described: a board of plywood, carrying pieces of piezo electric material connected in parallel lines covered by a formica membrane, which is placed below a mattress. Movements of a sleeper on the mattress are detected and sent to an analyser which, when the movements are consistent with clonic seizures, activates an alarm and a recording camera. This new appliance can be installed at home and abolishes the need for observation, in a clinical setting, to establish whether a person suffers from such nightly seizures or when nightly seizures require assistance.



Look Back with Pride Part 5

To bring the constitutions of IBE and ILAE more in line with each other, IBE announces that, in future, individual membership will be available only in countries where there is not yet a national organisation.

September 1978: the Geneva office of EI is introduced. Richard Gibbs, the new director, immediately establishes an effective relationship with Dr Leone Bolis, Neuroscience Consultant to the Division of Mental Health at the WHO. The sole link that organisations concerned with neurological disorders have with the WHO is through that Division!

The December 1978 topic is the Vancouver symposium. Delegates from 30 countries attended. The editor of EI News critically discusses the pro and cons of such expensive events; he (not surprisingly) reaches the conclusion that they are worthwhile. For two of IBE's vice-presidents this is especially true – during the symposium Francesco Castellano and Patsy McCall-Owens announce their intention to be married!

Francesco Castellano

April 1979: EI announces a new set-up of the newsletter. On the advice of James Autry (for once characterized in the colophon as Chief Editorial Editor), the themes in the future will be EI Speaks (commentary from the Board), Forum (letters to and from people concerned about epilepsy);

Research; From All Nations; News in Technology; Public Education; Special Events; and People. An effective distribution system for EI News will need to be developed; a tentative goal for 1979 is to distribute 10,000 copies.

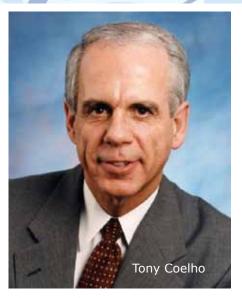
July 1979: The efforts of EI to improve world-wide knowledge about epilepsy and standards of care is achieved, not only through its biennial world congresses, but also, through input into local meetings which may advertise these events as being held under the auspices of EI, provided the board of EI is informed and satisfied about the programme and the involvement of recognised experts on epilepsy.

"From All Nations" announces that, for the first time, a person known to have epilepsy, Tony Coelho, has been elected to the United States Congress! Interestingly, Tony earlier had intended to become a Catholic priest but, because of his epilepsy (although by then completely controlled), was told priesthood was not for him.

Certain problems for people with epilepsy mentioned in reports from member



countries still exist today. The root of all evil is money: if someone in the family cannot work and needs to pay for daily medication such may be unaffordable. In September 1979 a report from Chile describes how they are trying to cope with this problem through the establishment



of a system of drug-banks. In Canada, although a prosperous country that has systems in place to cover the costs of illness, remedies to counter the psychological and social consequences of epilepsy are not included. This was one reason to start an epilepsy association to fill this gap.

December 1979: In the past "lay-associations" where formed by parents of persons with epilepsy with or without the help of doctors. In Berlin, Germany in August 1977 people with epilepsy, themselves, decide to meet and discuss their problems. A year later they hold their first public information meeting about epilepsy. They call themselves a Self-help Group. They found an association, are able to find financial support and, in October 1979, open a centre with rooms for group meetings and hobbies, a club hall, and a room for lodging in case of emergencies. Germany also has a first: with Heinz Penin being appointed Professor of Epileptology in Bonn.

EI sends guidelines to chapters to help structure the organization of symposia, national and regional meetings and workshops. EI is aware that in developing countries local support for epilepsy will be hard to garner because of other, quantitatively more important, scourges. Support from EI, however, will depend on the earmarked funds EI might be able to raise.



MANILA MEMORIES

A glimpse back at the 9th Asian & Oceanian Epilepsy Congress

Who could have expected such a wonderful congress! From the moment the Opening Ceremony Pageant began, it was obvious that the 9th Asian & Oceanian Epilepsy Congress was going to be something rather special.

The hardworking Scientific Advisory Committee, co-chaired by Dr Josephine Gutierrez, Robert Cole and Dr Byung-In Lee ensured that the more than 100 local, regional and international speakers presented on a range of topics that were highly relevant to recent scientific, clinical and social developments in epilepsy.

The main topics of the Congress were:

- Epilepsy and the Developing Brain
- Epilepsy Genes and Beyond
- Impact of Epilepsy and its Treatment
- Epileptic Networks and Seizure Propagation

In addition to the main and the post main sessions were a range of parallel sessions that focused on the pertinent issues of epilepsy practice and research, the Masakazu Seino Memorial Lecture, practical video sessions, lively debates, interactive workshops and topical satellite symposia.

The Asian Epilepsy Academy (ASEPA) organised a series of didactic lectures by world-renowned experts in their respective fields on interesting topics such as Seizure and Epilepsy Classification, Psychosocial Aspects of Epilepsy, Brain Stimulation, EEG Monitoring in the ICU and Autoimmune Seizure Disorders.

Photos top row, left to right: Prof Byungin Lee, Korea, sounds the gong to open the congress officially; Robert Cole and Denise Chapman, both from Australia; Mike Glynn presents Ding Ding (China) with the ILAE funded Promising Strategies Program Award;

Second row: Shunglon Lai and Yuan-fu Tseng, both from Taiwan, attending the Epilepsy & Society Symposium; Dr Shi-

It all kicked off with an Opening Ceremony that was an event to be remembered!

The organisng committees and dignatories formed a formal pageant to enter the hall led by flagbearers. During the ceremony the IBE Outstanding Persons with Epilepsy Awards were presented, as well as the ILAE Asian & Oceanian Outstanding Achievement Epilepsy Award. These awards were in recognition of those with a distinguished contribution in the field of epilepsy in the region.

The Opening Ceremony concluded with the sounding of the congress gong by Dr Byung-In Lee and everyone then filed out to enjoy a most wonderful evening of excellent food and a Cultural Night called a "Pagdiriwang" or Celebration, couresy of the Philippines Department of Tourism.

A highlight of the congress programme for people with epilepsy and those who care for them was the full day Epilepsy & Society Symposium that took place on Saturday 24th March.

This programme was also of great interest to staff from community organisations supporting people living with epilepsy. All of the speakers involved gave excellent presentations and the day was attended by well over 100 delegates. The Epilepsy & Society Symposium continues to grow in strength!

IBE would like to thank all those who were instrumental in ensuring that this would be a terrific day - but, in particular Denise Chapman, Jeannie Khonghun, and

chuo Li, China with Dr Xiangdong Wang, WHO Regional Advisor for Mental Health and Neurological Disorders; participants at the Joint Meeting of the South East Asia and Western Pacific Regional Committees;

Third row: Prof Hasan Aziz and Dr Zarine Mogal, both from Pakistan, at the Global Outreach Stakeholders meeting; participants at the Stakeholders meeting; dancers at the Opening Ceremony Reception;

Robert Cole. Their hard work ensured a very successful event.

Apart from the official congress programme, Manila provided the opportunity for a number of business meetings:

- The IBE Editors Network, Chaired by Robert Cole, met to share ideas on publications, both traditional and electronic. This is always a most interesting meeting and there is never enough time available!
- The IBE South East Asia Regional Committee and the Western Pacific Regional Committees met both separately and as a joint group. Representatives from each of the regions presented reports on recent activities and discussed common problems.
- ♦ A meeting of the Global Outreach stakeholders was very well attended. This incorporates the Global Campaign Against Epilepsy and other initiatives such as the PAHO Strategic Plan, the work of the IBE/ILAE European Joint Task Force, and other regional issues such as the US Institute of Medicine's initiative. A guest at the meeting was Dr Xiangdong Wang, WHO Regional Advisor for Mental Health and Neurological Disorders.

The IBE and ILAE regional structures also met to consider the venue for the $10^{\rm th}$ AOEC and information on the location will be made available as soon as the final decision is taken!

Text: Ann Little

Bottom row: Opening Ceremony Reception; Jeannie Khonghun, Philippines and Dr Sunao Kaneko, Japan, speakers at the Epilepsy & Society Symposium; Yashoda Wakankar (India), Baldwin Chua Kho (Philippines), Yung-Chih Chen (Taiwan) and Raffaele Martin (Australia), Outstanding Persons with Epilepsy Award recipients, pictured with Dr Josephine Gutierrez at the Opening Ceremony.























Future Congresses 2012



1st African Epilepsy Congress

Nairobi, Kenya 21st - 23rd June 2012 www.epilepsycongress.org





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



