

INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 51 years

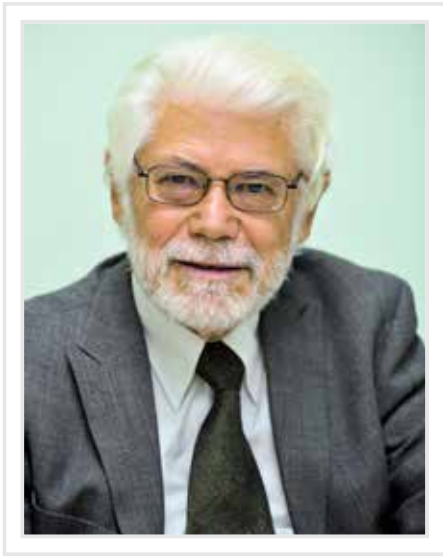
1963-2014

***Focus
on IBE
AFRICA***



**2nd African Epilepsy Congress
SPECIAL CONGRESS ISSUE**

PRESIDENT'S LETTER



Dear friends - especially our friends in Africa

It gives me great pleasure to prepare this letter of greeting for this special issue of the IBE magazine to celebrate the 2nd African Epilepsy Congress.

As I write, I am making final preparations for my travel to Cape Town to participate at the congress and I feel privileged to be doing so as IBE President. I forward to meeting representatives from many of IBE's member associations in the African region during the congress. Through their budgets, both IBE and the IBE African Regional Executive Committee have provided a number of bursaries to support people to attend the congress who would not otherwise have had the funds to do so.

While I am in Cape Town, I also hope to make many new contacts to encourage further membership development in the region. After Europe, Africa is IBE's second largest region in terms of membership numbers. At present there are 21 Full and Associate Members in 20 countries on the African continent, so there is a long way to go yet before we cover the entire region.

Africa is a very special place, bringing with it many challenges and difficulties that are not faced by people with epilepsy, or by those working in the field, in other regions. I am incredibly impressed at the terrific work that IBE members undertake to improve the quality of life and social conditions of people with epilepsy in Africa, working under these difficult conditions where extra efforts are required to overcome the stigma that can destroy the lives of people with epilepsy. Some of our members in Africa have provided reports

Welcome to Cape Town

on their recent initiatives to address some of these issues and you can read about them - and perhaps find inspiration for future projects in your own association - within the pages of this magazine.

The IBE Promising Strategies Program, now in its 8th year, has been supporting epilepsy associations in Africa since 2007. It is one of our most successful initiatives and the one about which we are most proud. It is incredibly fulfilling to know that the Bureau has been able to play a role in capacity building and skills training that have impacted positively on people with epilepsy and their families. Although IBE is facing challenging times with regard to future income, we will do our utmost to continue to support and develop this very successful program.

The African Regional Committee will meet during the congress. This is the chance to meet the elected members of the African Regional Executive Committee - Youssouf Noormamode (Chair), Marina Clarke (Vice Chair) and Miena Riphagen (Secretary), as well as Anthony Zimba, Vice President Africa - to discuss the committee's plans for this term and to have your input into its strategic plan. I also encourage you to attend the special Epilepsy & Society programme on Saturday, developed for people with epilepsy, their families, and those who care for them.

We must join efforts to promote understanding, reduce the treatment gap, alleviate stigma, and promote and protect human rights of people with epilepsy. Meeting together gives us the opportunity to do so. See you in Cape Town and my best wishes to all!

A handwritten signature in black ink, appearing to read 'Athanasios Covanis'.

Athanasios Covanis
President



International Epilepsy News Cape Town Congress Issue

IBE EDITORIAL TEAM

Editor and Coordinator: Ann Little
Email: ibedublin@eircom.net

Regional Sub Editors:

- ⊙ Youssouf Noormamode (Africa)
- ⊙ Chahnez Triki (East Mediterranean)
- ⊙ Anastasia Vassou (Europe)
- ⊙ Tomás Mesa (Latin America)
- ⊙ Mary Secco (North America)
- ⊙ P Satishchandra (South East Asia)
- ⊙ Denise Chapman (Western Pacific)

Advisors:

- ⊙ Athanasios Covanis
- ⊙ Sari Tervonen
- ⊙ Mike Glynn
- ⊙ Ding Ding
- ⊙ Philip Gattone
- ⊙ Najib Kissani
- ⊙ MM Mehndiratta
- ⊙ Janet Mifsud
- ⊙ Lilia Núñez-Orozco
- ⊙ Anthony Zimba
- ⊙ Emilio Perucca
- ⊙ Helen Cross
- ⊙ Sam Wiebe

INTERNATIONAL RELATIONS AND PARTNERSHIPS

WHO

IBE is in official relations with the World Health Organisation (WHO).

ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO

IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA

IBE is a member of the European Federation of Neurological Associations (EFNA).

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In this special congress issue

Dear Readers



This is a unique issue of IE News, especially created to celebrate the 2nd African Epilepsy Congress, which takes place in the charming beautiful city of Cape Town, overlooked by the wonderful Table Mountain.

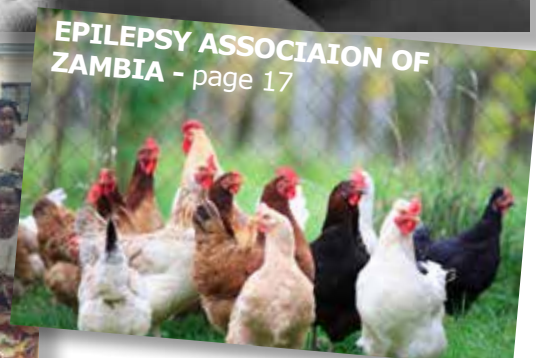
With the focus on Africa, I invited IBE members in the region to share with us the challenges they face and the successes they achieve in their efforts to support people with epilepsy and their families, often in very challenging conditions. You can read their stories and, perhaps be tempted to borrow from their ideas, in this special edition. I would like to thank those who took the time to submit their stories and to search out images to help make this a great magazine.

There is also the opportunity here to showcase the more than 30 projects that have been made possible in the region thanks to the support of IBE's Promising Strategies Program. Many of these initiatives have made it possible for people with epilepsy to learn a skill and become self sufficient. Others have helped increase awareness about epilepsy and thereby dispel the discrimination that can ruin lives.

Finally, I would draw your attention to page 4 where you will find details of the IBE African Regional Committee meeting, which will take place on the Friday morning of the congress. All IBE members, as well as potential new members, are being encouraged to attend.

I wish you all a great meeting and, as always, happy reading.

Ann Little
Editor





Message from Anthony M Zimba IBE Vice President Africa

Dear Delegates

We warmly welcome you to our 2nd African Epilepsy Congress in Cape Town. As you are aware, this is our second congress to be held in Africa so we are very grateful to the IBE and ILAE

Joint Executive Committee for their continued support to our continent.

I was glad that the commencement of regional IBE/ILAE congresses, with the first in Nairobi in 2012, begun during my tenure in office. To me, this is one of the greatest achievements we have as a region. The other notable achievement is in terms of the increase in membership. IBE membership in the region has increased tremendously with the latest new member being Malawi. Our region is second to Europe in terms of membership. Although membership is growing we have a lot of challenges, of which most notable are:

1. Poor communication: This is still a problem especially in terms of responding to IBE and regional office announcements.
2. Lack of Governments support to epilepsy organizations or support groups, and this has really deterred most of our

members' progress. Very few individuals are focused on going ahead and most of those leading the organizations are health workers.

3. Lack of well trained and informed personnel to run associations in many of our countries
4. I have also noticed that very little research is done in Africa Region though this must be encouraged.

IBE has impartially supported our members in the region through its Promising Strategy Program. To date, since the beginning of this project in 2007, Africa has benefited more than other region. We are very grateful about this.

In conclusion I would like to appeal to all our members to put greater effort into building capacity for our organizations. I have noted with sadness that, due to lack of resources, many of our organizations are quite static in terms of growth in membership.

I hope and trust that, as we continue getting support from our mother organization (IBE), we shall reciprocate by working harder and improve in our activities.

Thank you for coming to this congress and enjoy the meeting.

Anthony M. Zimba
IBE Vice President Africa



Message from Youssef Noormamode, C.S.K. Chair IBE African Regional Executive Committee

Dear Colleagues

The International Bureau for Epilepsy African Regional Executive Committee is committed to heightening close collaboration with major stakeholders in epilepsy promotion while

strengthening the works of its bonafide member organisations in the African region.

Epilepsy knows no boundaries and the prevalence of the disorder is consistent across African countries. It is a chronic condition that requires longterm treatment and, if left untreated, can severely impact the life of millions of individuals as well as their families, friends and society.

I am pleased to write down these few lines as new Chair of the IBE African Regional Executive Committee and since we've been elected to office in August 2013, my colleagues, Marina Clarke, Vice Chair; Harmentia Riphagen, Secretary; supported by Anthony Zimba and Ann Little, joined efforts relentlessly and voluntarily in carrying out a survey among the Africa member organisations, the development of our Action Plan 2014 and a helping hand in the organisation of the 2nd African Epilepsy Congress.

Our Action Plan this year focuses on the promotion of region-wide activities, production of online newsletters, sharing and exchange visits with member organisations, support to two epilepsy associations for capacity building workshops, support to young epilepsy patients with innovative projects, Facebook interface and more. The availability of resources, financial and personnel is crucial to the delivery of this Plan.

I urge all my African colleagues attending the 2nd Epilepsy Congress in Cape Town, under the aegis of the ILAE/IBE, to take stock of all the available resources and ensure positive and effective communication with major stakeholders in the promotion of their works.

The IBE African Regional Executive Committee recognises the need to advance the priority of epilepsy and accepts fully its core responsibility of being an advocate for all our members within the African region.

Over the next three years, we'll work strenuously to achieve our planned objectives and programs together with the commitment and support of all African member organisations.

May I wish you all the very best for a fruitful congress through your attendance and active participation in Cape Town.

Youssef Noormamode, C.S.K.
Chair IBE Africa Regional Executive Committee



CAPE TOWN 2014



JOIN US!

Meeting of the IBE African Regional Committee

Chaired by Youssouf Noormamode, the IBE African Regional Committee will meet during the congress. This is a great opportunity to hear about the work of other lay associations across Africa and to exchange experiences and develop contacts.

The meeting is open to representatives of IBE member associations and also welcomes anyone interested in learning more about IBE.



- Date:** Friday 23rd May
Time: 08:00 - 09:00
Venue: Robbin Island Room at the Westin Hotel

EPILEPSY & SOCIETY - Special Programme

A new addition to the African Epilepsy Congress programme is the exciting Epilepsy & Society Seminar, which will take place on Saturday 24th May.

This event is designed specifically with people with epilepsy, their families and caregivers in mind, and focuses in large on social topics related to epilepsy. It will also be of great interest to educators, nurses and other healthcare providers. Among the thought-provoking topics included in the seminar programme are:

- Improved care for people with epilepsy
- Epilepsy and the family and personal experiences
- Women's issues, including contraception, pregnancy and motherhood
- Men's issues
- Epilepsy and schooling
- Epilepsy in old age
- Traditional healers
- Anti-epileptic drugs in Africa.

PROMISING STRATEGIES 2007-2014

The IBE Promising Strategies Program has been running for 7 years and is one of the most successful of all IBE's initiatives. It was set up following an idea presented by Eric Hargis, former IBE Secretary General, and with early support from Epilepsy Foundation in the US, of which Eric was CEO. The aim of the program is to assist Members - particularly those in developing nations - through the provision of financial support for projects whose objective is to improve the quality of life of people with epilepsy. To date, 81 projects in 38 countries have received a total of US\$330,000 in funding. Almost half of this amount has been allocated to projects in the IBE African Region. Showcased here are the projects supported to date in Africa.



2007

UGANDA

Community Drugs Bank Project

The Ugandan Community Drugs Bank was developed to supply low cost drugs to people with epilepsy on a non-profit basis. Regular provision of medication provides stability and reduces stigma. It also increases the number of people with epilepsy attending clinics and helps to capture data and statistics to plan for future service delivery.



CAMEROON

Tomato Growing Project

In Cameroon 5.8% of the population has epilepsy, often due to cysticercus. Stigma and discrimination are major problems. Promising Strategies funded the creation of a tomato-growing project to aid self sufficiency of people with epilepsy.

Poultry Enterprise in Zambia

Epilepsy Association of Zambia trained people with epilepsy in poultry husbandry to help them become self-sufficient and also to help the association to raise funds to run further epilepsy information and training programmes. Revenue from sales of the chickens reared helps fund future work.



The project involved training in tailoring, food and nutrition, and vegetable growing for 30 people with epilepsy, with student placements in vocational institutions. The objectives of the programme included advocacy for employment, education and civil rights of persons with epilepsy.

ZIMBABWE

Demystifying Epilepsy

Epilepsy Support Foundation Zimbabwe created this programme, targeting rural districts, in order to destroy the myths surrounding epilepsy that can discourage people from seeking diagnosis and treatment. An important element are workshops for traditional healers and herbalists.





MAURITIUS

Training in Massage Therapy

Edcys Epilepsy Group Mauritius created a Massage Therapy training program for people with epilepsy. The objectives were to promote massage therapy as an alternative treatment for people with uncontrolled seizures. The results showed a lowering in the frequency of seizures and reduced levels of stress and depression.



SOUTH AFRICA

Entrepreneurship Development Program

Integral to Epilepsy South Africa's National Economic Development Programme is capacity building. The aim is to assist potential entrepreneurs with epilepsy and related disabilities with the establishment of sustainable self-owned small business enterprises.

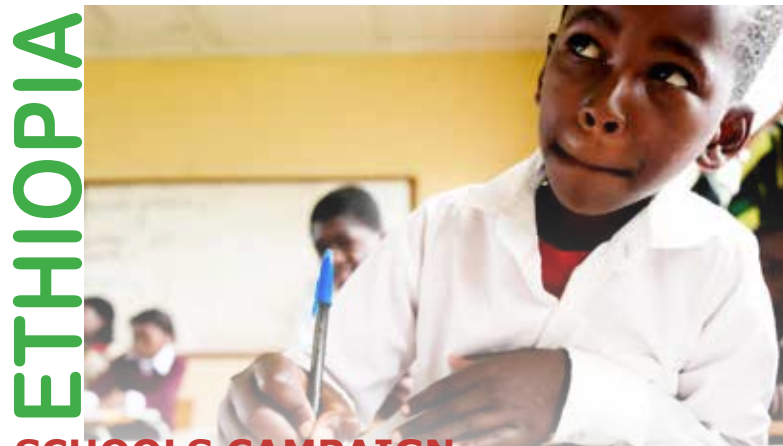
2008



THE GAMBIA

Tailoring Training

This tailoring program targeted 12 persons with epilepsy. At the end of the program the participants were expected to have acquired skills in tailoring that could be put to practical use for the propose of earning a living. An awareness seminar was also arranged for employers to improve knowledge on epilepsy.



ETHIOPIA

SCHOOLS CAMPAIGN

The Ethiopian association created a schools education campaign, aimed at raising awareness in almost 14,000 students. Activities included the publication of information leaflets and posters, and the training of 10 persons with epilepsy in marketable skills such as tailoring crafts, hairdressing and catering.



TANZANIA

Training in Vegetable Growing

To address the alleviation of poverty in young people aged between 13 and 20 years with learning disability, 10 children were trained in vegetable growing for a period of one year before being allowed work on their own. The sale of the vegetables provided funds to continue the project.



Namibia

Onyose Project

Prompted by a mother of a young child with epilepsy, Epilepsy Namibia held a 4-day workshop to train 30 teachers, caregivers and people with epilepsy, to help them better manage the condition. The program included awareness and epilepsy training, lifestyle management and a stimulation program.



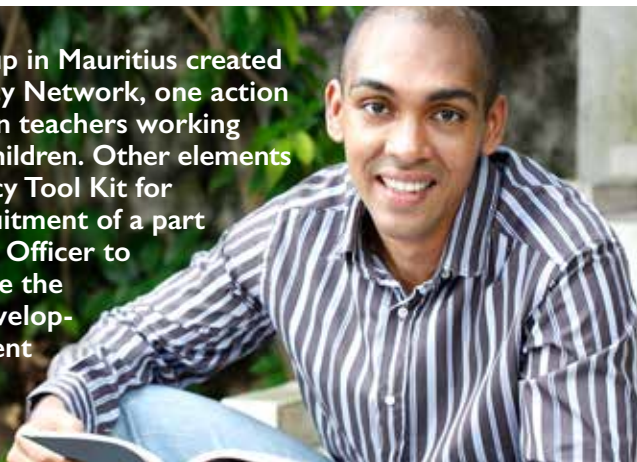
Training in Epilepsy Management

The objectives of the program were to improve knowledge about epilepsy in health personnel in Kenya and to improve the capacity of the ministry of health to train and support epilepsy care in the health sector. Training was given in the form of TOT (training the trainers) from national level cascading down to community level.

2009

MAURITIUS Teacher Training

Edycs Epilepsy Group in Mauritius created an Epilepsy Advocacy Network, one action of which was to train teachers working with special needs children. Other elements included an Advocacy Tool Kit for school boards; recruitment of a part time Visiting Liaison Officer to support and facilitate the programme; and development of an assessment tool to evaluate the programme.



NAMIBIA - DVD Awareness Pack



Epilepsy Namibia produced a DVD pack, together with printed information on lifestyle management and seizure assistance. The multimedia kit explained all about the condition of epilepsy, lifestyle management and seizure assistance for people with epilepsy and their caregivers who do not have access to resource centres in the rural areas of Namibia.



Learning a skill increases self-confidence and self worth and when that skill leads to self-sufficiency the value is multiplied. The Market Gardening Skills project of the Epilepsy Association of Zambia trained people with epilepsy in basic gardening and vegetable production skills. This project followed on the earlier poultry rearing project, which the association established in 2007.

ZIMBABWE Peanut Butter Project



Epilepsy Support Foundation of Zimbabwe received funding to support the establishment of a peanut butter processing project.

The main objective of the initiative was to improve income generating skills of 100 people selected for training, all of whom were unemployed.

The association renovated a building at the Epilepsy Centre to provide a training area and an employment workshop, where the peanut butter is produced.

In Togo, poverty, illiteracy, language barriers and gender discrimination are obstacles to obtaining proper epilepsy treatment. The project targeted women and children with epilepsy as well as their family members. The project included education on epilepsy recognition, prevention and treatment; a seizure calendar using symbols and pictures; and information on distinguishing between helpful tradition medicines and those which are harmful.



2010



NAMIBIA

RE-tailing

The concept of the second hand shop is not new: it's a way of generating funds for charities around the world. However, the plans Epilepsy Namibia for RE– broadened the scope of this enterprise. RE– followed the structure of a commercial retail outlet and people with epilepsy were given preference in the selection of staff. The shop also acted as an awareness and information centre. .

UGANDA

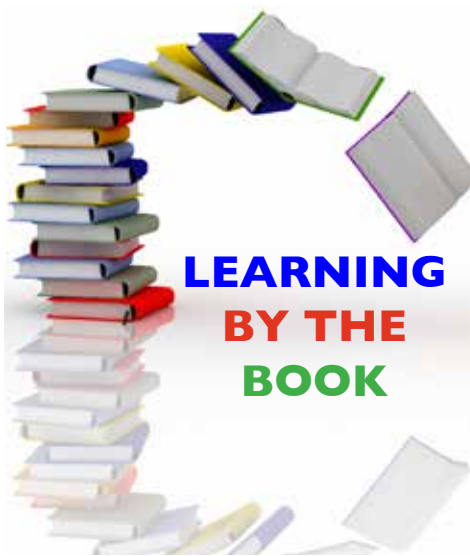
Goat Rearing Enterprise

In rural Uganda goat rearing ranks high in animal husbandry. In addition to generating income through milk and goat meat, goats are considered as a symbol of wealth and are used as dowry payments in marriages.

This project provided participants with a pregnant goat and instructions on its care. In return each person was asked to donate two young goats to the project within a period of 2 years, as a means of extending the programme.



SOUTH AFRICA



LEARNING BY THE BOOK

Epilepsy South Africa developed a self-advocacy, human rights and rights-to health training manual for use by its National Social Development Manager in self-advocacy training workshops for members of the community and staff members from the association's branches.

A secondary objective was to train 30 trainers, from seven Epilepsy South Africa branches during 2010-2011, on a train the trainer basis.

2011



ZIMBABWE Speaking Out

This project created a lobbying and advocacy programme whereby people with epilepsy were encouraged to speak out and write about their condition, their successes and the challenges faced. These testimonies were collated into books, DVDs and promotional materials in both print and electronic media.

Jamming it in ZAMBIA

Epilepsy Association of Zambia added value to the tomato-growing enterprise already in place in the association's garden by embarking on a jam-making enterprise. The finished product is sold in a new association shop that located in the garden.

The shop also stocks garden and poultry products produced by people with epilepsy working in the garden.



With 69% of Swazis living below the poverty line, the situation for people with epilepsy is even more difficult. The Swaziland Epilepsy Association launched a poultry rearing project to improve the socio-economic status of people living with epilepsy and other disabilities, by providing them with a job.

The project also helps to promote independent living and better self-esteem amongst members of the association's support group.

SWAZILAND Poultry Enterprise





MAURITIUS

Family Training

Edycs Epilepsy Group ran a large scale training workshop for 100 newly registered families. Its objectives were to help in recognizing seizures and post seizure activity; to provide appropriate support to people with epilepsy; to promote understanding on the use of anti-epileptic drugs in controlling seizures, while recognising potential side effects; and to build confidence in parents responsible for administering emergency epilepsy medication.



Going bananas!

ZAMBIA

As an income generating project, Epilepsy Association of Zambia developed a banana plantation. One thousand banana trees were planted. 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.

Kick-starting Careers

Suitable employment is a very important step towards the independence of people with epilepsy and is also one of their biggest challenges. Epilepsy Namibia developed a supportive program for school leavers and the unemployed with epilepsy. The program consists of Career Development Seminars and Small Business and Information Technology Training.



NAMIBIA

School Epilepsy Clubs

The Epilepsy Support Association of Uganda set up School Epilepsy Clubs in 20 secondary schools in Kampala. The aim is to sensitise teachers and school managers on the needs of students who have epilepsy and to create a conducive and favourable environment for them, so as to encourage better performance in their studies. The clubs teach students about epilepsy and the young students are brought together for an annual day of special activities.



UGANDA

CAMEROON - teaching a trade

CODEF introduced income generating activities, including pig rearing, hairdressing, and tailoring, to support 45 people with epilepsy who live in the north west of Cameroon. 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 achieve this goal.



ZIMBABWE - training in best practice

The prevalence of uncontrolled epilepsy is high in rural Zimbabwe and this is underpinned by cultural beliefs that reinforce resistance to the medical control of epilepsy. The health gap presents extra tragedies to the already depressed conditions of people with epilepsy, reducing their self-images, self-esteem and self-opinion. To address the problem, the Epilepsy Support Foundation of Zimbabwe provided training in best practice in the management of epilepsy to health professionals and community-based psycho-social practitioners.



Schools Programme

The National Learner Awareness Programme of Epilepsy South Africa was piloted during 2012. This initiative aims to derive its purpose directly from the UN Convention on the Rights of Persons with Disabilities; to link to the Life-Skills programme of the South African curriculum; take on the form of an inter-active awareness kit that involves the class in simulative activities while learning about epilepsy and inclusive education.



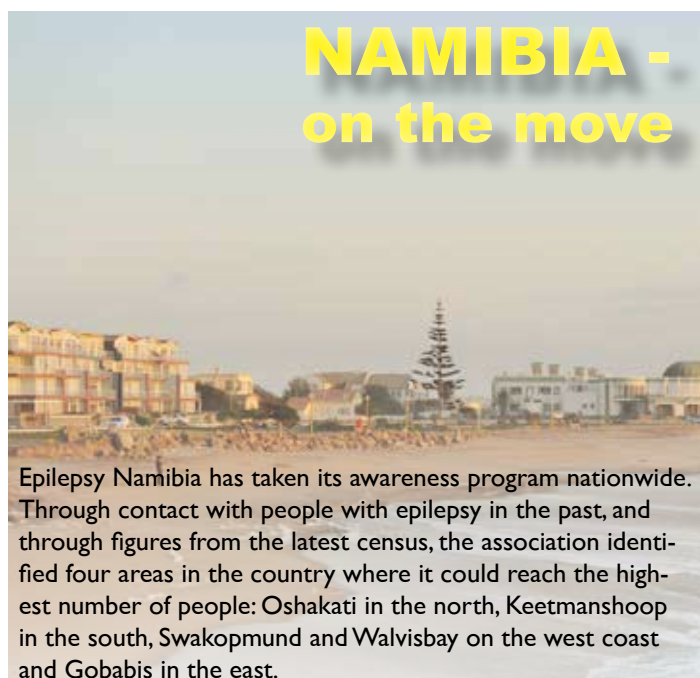
2013

ZAMBIA - educational materials production

The project developed an educational materials production unit to produce brochures and flyers, both in local and English languages, for free distribution. The unit also produces calendars and seizure diaries, which are sold at low cost. The diaries are used by members and clients at other health centres to keep a record of seizures, appointments and medication. Other printing such as T-shirts, banners, and epilepsy education books, will also be considered.



NAMIBIA - on the move



Epilepsy Namibia has taken its awareness program nationwide. Through contact with people with epilepsy in the past, and through figures from the latest census, the association identified four areas in the country where it could reach the highest number of people: Oshakati in the north, Keetmanshoop in the south, Swakopmund and Walvisbay on the west coast and Gobabis in the east.

At each point Epilepsy Namibia will establish contact with the clinic that forms the backbone of care for patients in the region. Public awareness is planned for town centers, with information distribution as well as a DVD presentation.

Community Drama for Epilepsy Awareness

With 42 ethnic communities in Kenya, each with its own mother tongue, norms and beliefs that can affect attitudes and reactions to epilepsy, KAWE realised that it is very difficult to address the specific myths prevalent in each community through generic messaging. To develop information materials in local languages is also very expensive.

The project will increase epilepsy awareness by recording community dramas for broadcast on local TV and radio stations.



SWAZILAND - Dairy farm project

The organisation is training people with epilepsy in dairy farm husbandry, for which the association has already acquired land. The association began the project by buying eight Friesian cows. Each cow can produce milk for ten months annually, and has the potential to produce between twenty to thirty-five litres of milk per day.

Through training, those involved in the project will acquire the means and skills to become self-reliant.





Edyecs Epilepsy Group MAURITIUS

Report by Youssouf Noormamode, President of Edyecs Group



Young Rodrigues Choir in action



Salon de Santé event



Meeting with CEO of Mauritius Telecom

Edyecs Epilepsy Group is pleased to be associated with the publication of this special edition of the IBE newsletter for the 2nd African Regional Epilepsy Congress.

Reaching its 17 years existence is a great landmark in the history of our organisation. Our Executive Board is presently rethinking its strategies and striving to adapt to changing circumstances and conditions, especially as the environment becomes more uncertain and challenging.

Over the years, epilepsy has been emerging as an important public health issue, recognised as a treatable brain disorder in the Republic of Mauritius, including in

Rodrigues island. Edyecs Epilepsy Group, as a leading non-governmental organisation, believes it is vitally important to inform and educate all relevant stakeholders about epilepsy, and to promote best practices in its management by both healthcare professionals and non-medical professionals.

17 years existence is a great landmark

Strong collaborations were established with major stakeholders in the implementation of a number of projects undertaken with the CSR funders, among others, the Mauritius Telecom Founda-

tion, Partners in Progress Foundation, Currimjee Foundation and the European Union Decentralised Cooperation Programme.

Today, Edyecs Epilepsy Group is operating four full time Epilepsy and Educational Centers in both Mauritius and Rodrigues islands, fully equipped with personnel trained in epilepsy.

Our team is ready to take up new challenges and to give a new dimension and orientation to the work of Edyecs Epilepsy Group through seeking greater participation of new stakeholders and giving more visibility to the work of our association.



NIGERIA

Great start for NVOSI NGWA Women's Group

By Dr Solomon E. Nwakwue, President of Epilepsy Association of Nigeria

Epilepsy Association of Nigeria launched a new group in NVOSI NGWA, Abia State of Nigeria in February of this year.

The aim and objective of the group, among other things, includes the creation of awareness, fundraising to support those living with epilepsy, and encouraging company bosses to employ people with epilepsy. Many people attended the ceremony and made donations to help the group.

STREET CELEBRATIONS

Epilepsy Association of Sierra Leone celebrates National Epilepsy Day

Report by Radcliffe Durodami Lisk

On the 26th March, a meeting took place at the Council of Churches Hall in Freetown as one of the activities organized by Epilepsy Association of Sierra Leone (EASL) for National Epilepsy Day. This brought together members of the public from all walks of life, as well as health professionals, to discuss epilepsy issues and the work of the EASL.

The meeting was attended by the Deputy Chief Medical Officer, a representative of the WHO country director and a representative of the Mental Health Coalition.

In her keynote address, Dr Sarian Kamara, Deputy Chief Medical Officer, stated that the Government of Sierra Leone is committed to improving the quality of life of persons with epilepsy. To demonstrate this commitment, she told the meeting that the government had appointed a focal person for epilepsy in the primary healthcare unit at the ministry to coordinate epilepsy-related activities.

Dr Virginia George, Developing Country Partner of the UK Basildon Hospital/ Lumley Hospital Link Epilepsy Project, told the meeting that the project and EASL had trained 859 primary health care workers in the Peripheral Health Units (PHUs) in the 12 districts in Sierra Leone. This covered all 149 chiefdoms of the country. The aim is to disseminate epilepsy services at village level.

In addition, 13 Social workers, known as Epilepsy Support Workers (ESWs), were trained and positioned in the 12 districts to support persons with epilepsy and their families and to promote awareness of the condition.

The main public attraction for National Epilepsy Day was a float parade that travelled from the extreme east of the city to the National Stadium, a distance

of 11 miles. Together with music, songs and sketches performed by comedians on the float, a lively sensitization tour across the city was well received by hundreds of passers-by who joined in the event.

Frequent stops were made at strategic points where short talks on epilepsy were given by members of EASL. Demonstrations on what to do in the event of an epilepsy attack were acted out by the professional group on the float. There were banner displays of the EASL slogan 'Epilepsy no Problem' in many locations on the route and information leaflets were distributed to bystanders. The parade lasted five hours and ended in the National Stadium where Max Bangura, Coordinator of EASL, gave an address. The event was hugely successful and drew the attention of the general public to the plight of people with epilepsy and the stigma associated with the condition.

Activities to mark the day were also organized in the other 12 districts of Sierra Leone, including awareness raising activities conducted by 80 teachers who had received training for this purpose in their respective schools.



The government of Sierra Leone is committed to improving the quality of life of people with epilepsy

Two schools in Koinadugu and Kambia districts conducted a march past of school children with addresses made by the Chief Administrators of the district councils at the close of the event.

Radio discussions and a radio jingle were aired on local community radio stations. In Freetown, Sierra Leone Broadcasting Corporation broadcast live radio and TV discussion programmes on epilepsy, and a locally produced sensitization video was widely shown on national television and on street video billboards.



IBE SOLIDARITY FUND

The creation of the Solidarity Fund in 2005 was consistent with IBE's strategic goals of supporting its members and their involvement in IBE activities. One of the purposes of the fund is to provide financial support to those IBE members in less well-off countries who would otherwise struggle to meet their dues commitments. This is on the premise that no association should be denied IBE membership solely on the basis of inability to pay annual dues. Thanks to the generosity of IBE members, who donate to the fund on a regular basis, 17 IBE member associations in Africa have their dues supported through the fund.

THE MIGHTY TREE OF EPILEPSY

Text & photos provided by Nsom Kenneth Ninying, CODEF Cameroon



Fire burns, wounds and other epilepsy related issues and challenges faced by CODEF in Cameroon can only be likened to a mighty tree. This needs a lot of galvanized forces to cut it down. Recently, Nibah was a victim of epilepsy burns. He was instructed by a traditional healer to cover himself at 12 midnight under a blanket to inhale the smoke of some traditional concoctions to “cure” his epilepsy. Seizures occurred, he fell down and scattered the burning concoctions which spark off a fire that caught the

blanket. Due to the presence of kerosene, which he sells, his whole house burnt down with him inside it and he sustained 3rd degree burns. This was in a remote area in north west Cameroon. CODEF, with limited resources, came to give him assistance with his wounds.

In Cameroon, epilepsy is viewed as a non-fatal and non-disabling condition. Society at large main-

tains a high level of mysticism, isolation and discrimination about epilepsy. These impose self stigmatization in persons with epilepsy, which can be aggressive at times. Neurologists are few in number and are even more difficult to contact. There is very limited information on epilepsy on the curricula of training schools of health personnel both in public and private institutions. No health activities on epilepsy exist either at regional, district or health area levels of the health delivery system of Cameroon. There is limited activity at central level. The few existing anti epileptic drugs are not readily available. CODEF has been raising awareness, lobbying and advocating through contacts and advocacy marches and meetings.

CODEF has also crafted employment opportunities for some persons with epilepsy, though both funds and other support are very hard to come by. Thanks to the IBE Promising Strategies Program support in 2012, which we remain indebtedly grateful for, we were able to help people to be self employed, independent and to purchase their anti-epileptic drugs.



Clockwise from below:

- Sewing project supported by IBE Promising Strategies
- Pig farming initiative funding by IBE Promising Strategies
- Demonstrating for improved epilepsy services
- Nibah has his burns dressed by a CODEF worker



CALLING ON MEMBERS IN THE AFRICAN REGION

If your IBE dues are supported by the IBE Solidarity Fund, please remember that you are still obliged to complete and return the annual Dues Form to confirm that your association continues to meet the criteria for membership and to ensure that our contact details for your organisation remain accurate.

EPILEPSY NAMIBIA

Harmiena Riphagen, Chairperson of Epilepsy Namibia reports on a special concert in Windhoek and brings news on its mobile initiative, part funded by IBE Promising Strategies Program, to raise awareness in all parts of the country.



Musical Interlude

This year's benefit lunch time concert, played on a home visit to Namibia by classical pianist Menanto Chamberlain, who studies at Deree College in Athens, Greece had a romantic mood.

The setting, in the garden of "Take Note Music", a music instruments supplier in Windhoek, enhanced the feeling of well-being and optimism.

As the sounds of Debussy and Liszt lingered, interesting conversations took place around the contact some of our guests had with people with epilepsy and the issues surrounding them.

While distributing information about epilepsy, serious concerns were raised about stigmatization around the condition as well as curiosity about the devel-

opment of new treatments and research. Menanto played another full recital at the College of the Arts for Epilepsy Namibia on her visit and "Take Note Music" has made an offer to host regular benefit concerts in the future. Sponsors and supporters are invited to the benefit concerts as a gesture of thanks for their support to our organization.

Epilepsy Namibia visits Oshakati

An epilepsy awareness event, specially planned to reach people with epilepsy in the northern part of Namibia, was conducted in perfect weather conditions on Friday 25 and Saturday 26 April 2014.

On Friday afternoon we met with neurologist Dr Hilma Shipanga, Acting Director Mr Albert Ndahalele and Ms Hannah Kambowe representing the CBR (Community Based Rehabilitation) program from the Oshakati State

Hospital, to co-ordinate the distribution of care packages in the most effective way. Due to the specific way in which the community is organized, the information packages were left in their capable hands to identify the areas where these would be most beneficial. Arrangements were made for the supply of more information digitally as well as for translations into local languages.

Saturday morning took us to meet the

general public at the Game shopping centre in Oshakati, where we set up an information station where shoppers and passers-by could ask questions, obtain information about epilepsy or tell us about people with epilepsy that they knew.

The project is sponsored by the IBE Promising Strategies Program and ITCS (Information Technology Consulting Services) Windhoek.



A wealth of services at EPILEPSY SOUTH AFRICA

REPORT BY MARINA CLARKE,
NATIONAL DIRECTOR, EPILEPSY
SOUTH AFRICA

Founded in 1967 as the South African National Epilepsy League (SANEL), Epilepsy South Africa is the only South African non-profit organisation offering specialised and comprehensive services to people with and affected by epilepsy on a national basis.

The organisation consists of a National Office (Cape Town) as well as six regional Branches. Services provided include:

SOCIAL DEVELOPMENT

- **Health and wellness programme:** recognising the need for a pro-active approach to community wellness.
- **Counselling services:** Individual, group and family counselling to persons with epilepsy and their families and caregivers.
- **Daycare facilities:** Offers family respite and allows family members to continue working.
- **Child and youth development programme:** Advocacy and self-advocacy training at schools.
- **Lifeskills training:** Empowering adults, youth and children with epilepsy with skills associated with managing and living a better quality of life and living to their full potential.

- **Food security projects:** Epilepsy SA's vegetable garden projects also provide potential for economic development initiatives.
- Residential care for persons with epilepsy and other disabilities.

COMMUNITY DEVELOPMENT

- Support groups provide educational and emotional support to people with epilepsy and those affected by the condition.
- **Home-based care:** provided by volunteers for those who, in addition to having epilepsy, are living with HIV, TB and other health challenges.
- **Mobile neurology clinics:** providing comprehensive epilepsy support in inaccessible rural areas.

ECONOMIC AND SKILLS DEVELOPMENT

- Protective workshops that offer clients opportunities to develop employment skills in a protected employment environment.
- Income generation activities assist individuals/groups to identify niche markets to develop sustainable income generation projects.
- **Technical skills training:** a valuable tool to access the open labour market or to start a self-owned entrepreneurial venture.

- **Epilepsy & Disability Employment Support Services (eDESS):** empowering people with epilepsy and other disabilities to become independent and self-sustainable.
- **Entrepreneurship training:** Training courses ranging from business idea development to advanced skills in the business growth.
- Epilepsy South Africa Educational Trust offers financial support exclusively to students with epilepsy towards their tertiary studies. Approximately 10 to 12 students receive bursaries annually.

ADVOCACY AND HUMAN RIGHTS

- **Advocacy and self-advocacy training:** to empower people with epilepsy to stand up and speak out about their rights to inclusion, acceptance and full participation within society.
- **Human rights support:** Epilepsy SA is a vigorous advocate for the human rights of persons with epilepsy.
- **Information services:** a Helpline offering online counselling, as well as a much-needed referral service.

Captions:

Main image: Residential care home.

Below left: Advocating for human rights.

Below right: Advocacy training.



Epilepsy Association of Zambia

Report by
Betty Barbara Nsachilwa,
Secretary

Epilepsy Association of Zambia was formed on 22nd September 2001 and became a Full Member of IBE in 2003. In August of that year, the association became a partner in the ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows' demonstration project in Zambia, in which the Ministry of Health of Zambia was also involved. Epilepsy Association of Zambia has 840 paid up members, but provides services to more than 2,000 people with epilepsy. We conduct four projects supported by the IBE Promising Strategies Program: market gardening, chicken-rearing, jam making, and the printing of epilepsy information materials.

AREAS OF ACTIVITY:

Epilepsy Case Management

Introduction of Special Epilepsy Clinics at various centres in Lusaka:

- Chainama Hills College Hospital Filter Clinic
- Levy Mwanawansa General Hospital,
- Epilepsy Association Office
- Kanyama Health Centre
- Cheshire Home CBR.



Public & Professional Awareness about epilepsy

This has been achieved through the celebration of special epilepsy awareness days. We commemorate our National Epilepsy Day on 29th August, Seizure Free Day on the 3rd Friday of December as well as Purple Day.

We have introduced capacity building to strengthen partnerships in epilepsy care – organizing of training workshops, skills training at a centre established for Promising Strategy Program projects and School Support.

Fundraising Ventures

The production of an annual calendar, which attracts advertisement income from some pharmaceutical companies and pharmacies, has been the most outstanding fundraising venture. The calendars are sold at a token price just to raise more money for School Support.

CHALLENGES:

The Epilepsy Association of Zambia has taken up the task of bringing attention to epilepsy, as most people do not consider



it as a topical issue.

Some companies even refuse to sponsor epilepsy activities saying that they cannot be associated with sadness.

The health authorities have their own priorities and mainly concentrate on communicable diseases. It has always been the vision of the association to educate all stakeholders to take responsibility in the care of epilepsy. However, lack of resources hinders most of our plans from coming to fruition.



SWAZILAND



Swaziland Epilepsy Association has been using the colour yellow to great effect over the past few years, in a range of novel fundraising and awareness campaigns.

The first initiatives to use yellow was the now established annual golf tournament with competition players wearing yellow golf shirts.

More recently the association used yellow roses to raise funds for its activities in its 'Buy Me a Yellow Rose' campaign.

CAMEROON - Full Member

Association Camerouaise contre
l'Epilepsie - Full Member
Coordination Diocésaine de la Santé
Bafia
T: +237 743 333 75
E: santbafia@yahoo.fr
Contact: Sr Marie Christine Long

CAMEROON - Associate Member

Community Development & Epilepsy
Foundation (CODEF) - Associate Member
Box 22, Bali Nyonga, c/o Mr. Godwin Che
Box 2082, Bamenda, North West Region
T: +237 750 744 42
E: codefcameroon2002@gmail.com
Contact: Mr Nsom Kenneth Ninying

DR CONGO - Associate Member

MHCD Centre for the Prevention and
Treatment of Epilepsy - Associate Member
Luvungi Naturopathic Hospital
Luvungi/Uvira
T: +243 994 931 840
E: moulymasu@gmail.com
www.mhcdafrika.org
Contact: Dr Luc Mulimbalimba-Masururu

ETHIOPIA - Full Member

Epilepsy Support Association of Ethiopia
PO Box 25516
Code 1000 Addis Ababa
T: +251 155 3617
E: dr.zenebe.gedlie@ethionet.et
Contact: Dr Zenebe Damtie

THE GAMBIA - Full Member

Gambia Epilepsy Association
P.O.Box 2230, Serrekunda
T: +220 995 5414
E: epilepygambia@yahoo.com
Contact: Paul Colley

GHANA - Full Member

Ghana Epilepsy Association
c/o Box M230, Accra
T: +233 2166 5421 ext 4420
E: ayisu@hotmail.com
Contact: Mr Paul Ayisu
Alternate: Mr Leonard Agbley
PO Box SD 233, Stadium, Accra
E: agbleleo@yahoo.com

KENYA - Full Member

Kenya Association for the Welfare of
People with Epilepsy (KAWE)
PO Box 60790 00200
Mbaazi Avenue – Lavington, Nairobi
T: +254 072 2594 268
E: info@kawe-kenya.org
E: omiyanji@yahoo.com
E: Rosemary@kawe-kenya.org
Contact: Ms Rosemary Gathara



CONTACT DETAILS FOR MEMBERS IN THE IBE AFRICAN REGION

MALAWI - Full Member

Malawi Epilepsy Association
P.O.Box E681, Postdotnet, Blantyre
T: +265 999 020 469
E: amos_action@yahoo.co.uk
Contact: Mr Action Amos

MAURITIUS - Full Member

Edycs Epilepsy Group
442 Boulevard Rivaltz
Port Louis
T: +230 213 1733
E: edycs.org@intnet.mu
www.edycsepilepsy.intnet.mu
Contact: Mr Y Noormamode

NAMIBIA - Full Member

Epilepsy Namibia
PO Box, 11822 Klein Windhoek
T: +264 813 226 834
E: namep@epilepsynamibia.org
www.epilepsynamibia.org
Contact: Ms Harmiena Riphagen

NIGER - Full Member

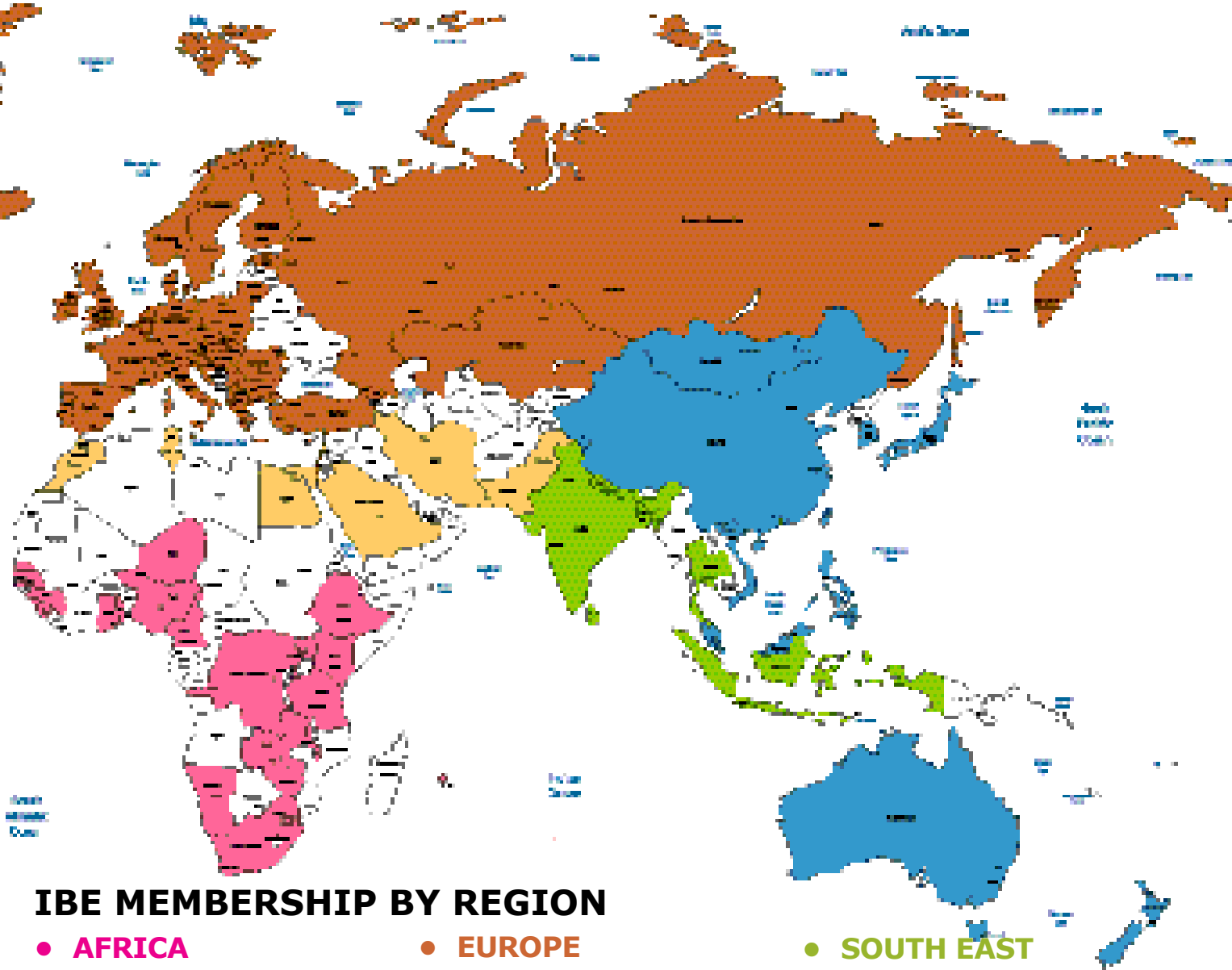
LNCEMNMC
Service de Psychiatrie
Hôpital National de Niamey,
BP238 Niamey
T: +227 722 442
E: djibo.doumamaiga@gmail.com
Contact: Dr Djibo Douma

NIGERIA - Full Member

Epilepsy Association of Nigeria
No 2 Weeks Road by 84 Asa Road Aba
Abia State
T: +234 708 183 2837
E: drmohaniclinic@yahoo.com
Contact: Dr SE Nwawkwe

SENEGAL - Full Member

Ligue Senegalaise contre l'Epilepsie
Clinique Neurologique
Centre Hospitalo-Universitaire de Fann
BP 5035 Dakar-Fann
T: + 221 338 253 678
E: agallodiop@gmail.com
Contact: Prof. Amadou Gallo Diop



IBE MEMBERSHIP BY REGION

- **AFRICA**
- **EUROPE**
- **SOUTH EAST ASIA**
- **EASTERN MEDITERRANEAN**
- **LATIN AMERICA**
- **WESTERN PACIFIC**
- **NORTH AMERICA**

SIERRA LEONE - Full Member
 8 Mansaray Street, PO Box 381
 Freetown
 E: epilepsy200074@aol.com
 www.epilepsyassocsl.org
 Contact: Mr Max Bangura

SOUTH AFRICA - Full Member
 Epilepsy South Africa
 PO Box 12100, NI City 7463
 Cape Town
 T: + 272 159 54900
 E: nationaldirector.no@epilepsy.org.za
 Contact: Ms Marina Clarke
 www.epilepsy.org.za

SWAZILAND - Full Member
 Swaziland Epilepsy Association
 P.O. Box 7220, Mbabane H100
 T: +268 404 7028
 E: admin@epilepsy.org.sz
 www.epilepsy.org.sz
 Contact: Mr Mbuso Mahlalela

TANZANIA - Full Member
 Parents Organisation for Children with
 Epilepsy (POCET)
 PO Box 65293, Dar Es Salaam
 T: +255 754 822 517
 E: basamwene1@yahoo.com
 Contact: Mrs Aisia Matowo Mrema

TOGO - Associate Member
 Association Clinique de l'Epilepsie
 155 Carrefour de Rio 11, B.P. 75 Lomé
 T: +228 224 03018
 E: kosodjehoun@yahoo.fr
 Contact: Dr Kokou Sodjéhoun

UGANDA - Full Member
 Epilepsy Support Association Uganda (ESAU)
 Plot 695 Gombe B
 Off Kayunga-Kinoni-Wakiso Rd
 Wakiso Town Council
 P.O BOX 16260, Wandegaya, Kampala
 T: +256 772 450 383
 E: mugarura2012@gmail.com
 www.epilepsy.org.ug
 Contact: Mr Augustine Mugarura

ZAMBIA - Full Member
 Epilepsy Association of Zambia
 Amanda Ethu Building
 Kalundwe Road, PO Box 32443
 Lusaka
 T: +260 977 789 042
 E: eazepilepsy@hotmail.com
 Contact: Ms Betty B. Nsachilwa

ZIMBABWE - Full Member
 Epilepsy Support Foundation (ESF)
 43 St. David Road
 Hatfield, Harare
 T: +263 457 1225
 E: epilepsyzimbabwe@gmail.com
 www.epilepsyzimbabwe.co.zw
 Contact: Mr Taurai Kadzviti

FUTURE CONGRESSES



11th European Congress on Epileptology
STOCKHOLM
29th June - 3rd July 2014
ILAE-CEA



10TH ASIAN & OCEANIAN
Epilepsy
CONGRESS

SINGAPORE 2014
7 - 10 AUGUST




17-20 *Setiembre* 2014
BUENOS-AIRES
VIII CONGRESO LATINOAMERICANO DE EPILEPSIA




31st International
Epilepsy Congress
06-10 September 2015
ILAE
Istanbul 2015

