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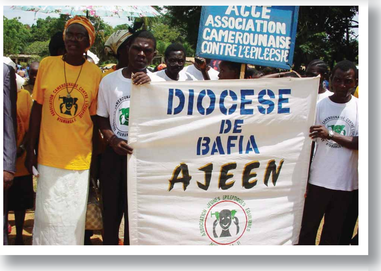
ACCE CAMEROON

In October 2009, the twelve managers of the catholic health centres of the diocese of Bafia took note of the recognition of the Cameroon government to recognise epilepsy as a public health problem and the restructuring of ACCE was thus decided.

Since its foundation on 19th January 2006, the activities of ACCE were restricted to within the territories of the parishes of Nyamanga and Mbangassina. The perimeter of activities is now enlarged to encompass the diocesan boundary, a sign of the maturity and coming of age of the association. The members of the association and the population at large were confused by this change. They feared that they would lose their status as the mother organisation. Monsignor Jean Marie Benoît Bala, our Bishop, gave us his support by visiting the parish of Nyamanga to meet the people. Through his authority, he was able to pacify their worries and fears by clarifying their doubt and misunderstandings.

Each group from each village is now an 'antenna' of the one diocesan association ACCE, with an office formed by the adults (and not by the patients as was previously the case) with financial autonomy.



To create a diocesan association requires informing and encouraging new members to join the association. In November 2009 and June 2010 we had two meetings to alert people to the importance of the association, its advantages, disadvantages and the procedures for creating it.

A General Assembly of ACCE was held in November 2010 to elect a committee and to ratify the creation of nine 'antennae' in Nyamanga and Mbangassina. Unfortunately bad weather conditions, and thc closure and bad state of roads, meant that only 24 people managed to attend.

By 2010, nine antennae had been created, each one meeting once a month to exchange news on the problems of its members, the work in the community field (which is a source of revenue), health education, dispensing of the monthly allowance to resolve problems (such as assistance to members in the case of illness, death of an infant with epilepsy, childbirth, costs of special treatments or examinations, etc.). Those who are ill then have a consultation and receive a month's supply of medication. The bureau meets each quarter to coordinate work, and to share experiences.

On the 20th May, the national feast day, members of the antennae proudly marched wearing tee-shirts carrying the word 'epilepsy'. It was a unique occasion to tell people that a person with epilepsy is just like anyone else, due respect and capable of living self-sufficient lives.

CONTACT DETAILS

Sr M.Christine LONG
Association Camerounese
contre l'Epilepsie, Mission
Catholique Nyamanga II, BP 47
Ombessa, Cameroon.
T: +237 77 105 862
marie_christinelong@yahoo.fr

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EPILEPSY SUPPORT ASSOCIATION OF ETHIOPIA (ESAE)

Epilepsy Support Association of Ethiopia (ESAE) was formed in 1998 in accordance with the legal code of The Federal Democratic Republic of Ethiopia. It became a member of IBE in 1999.

The objectives of ESAE are to promote better understanding of the nature of epilepsy and the needs of people with epilepsy (PWE) by conducting community educational campaigns and to advocate for non-discriminatory practices regarding persons with epilepsy in school, work place and recreation centers among others.

Currently, ESAE has 637 members. Out of these, 245 reside outside the capital city, Addis Ababa. The Association is working hard in partnership with concerned government authorities towards a structured and holistic epilepsy care in the country.

The association has an extensive record of outstanding activities promoting, helping and improving the medical and social circumstances of people with epilepsy in Ethiopia by securing AED's to the most needy patients free of charge, tireless contribution to the process of integration of epilepsy to the primary health care level and developing management guidelines on epilepsy to uplift the spirits of many PWE helping their integration into society.

ESAE organised the first ever campaign under the theme "Epilepsy out of the Shadows" in 2001. The campaign provided training to health professionals on epilepsy management at primary health care level, a mass rally and demonstration by people with epilepsy and their relatives, health care providers and other relevant people, a press conference to express commitments and building working partnership on future projects, and an Ethiopian declaration against epilepsy as a national plan of action to address the needs of people with epilepsy and establish a working document with WHO for future collaboration.

In Ethiopia there are about 400,000 people with epilepsy (in a country of 80 million people). Around 85% are children. Sadly, only 3% of them are getting modern medical treatment because of stigma attached to this disorder. It was therefore imperative and timely to undergo an educational campaign in school through combined efforts of people with epilepsy and their relatives, committed professionals, concerned authorities and institutions, in order to create awareness and promote the care and medical treatment of children and adolescents with epilepsy.

Making use of the funds obtained locally and through Promising strategies, ESAE has made possible the publication and distribution of 5000 leaflets, 2500 posters, 500 copies of CDs/DVDs and 1000 booklets which raise awareness in the various segments of the society and the community at large. Publications are being translated to different local languages and dialects.

CONTACT DETAILS
Dr. Zenebe Gedlie Damtie
Executive Director,
Epilepsy Support Association of Ethiopia (ESAE)
P.O. box 25516 Code 1000 Addis Ababa,
ETHIOPIA.
Tel. +251 116 633 164
E-mail: dr.zenebe.gedlie@ethionet.et

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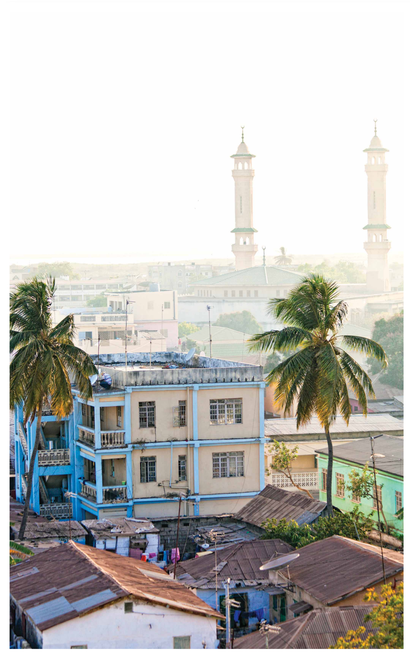
GAMBIA EPILEPSY ASSOCIATION

MANDATE
To improve on the quality of life of all people with Epilepsy in The Gambia and those who care for them.

MISSION
Our mission is to enhance a better social condition and quality of life of people with epilepsy and those who care for them.

VISION
Our vision is to ensure that fear and ignorance about epilepsy are replaced with understanding and care.



TARGET BENEFICIARIES: PEOPLE WITH EPILEPSY AND THE COMMUNITY

In 2007, The Gambia Epilepsy Association was one of 13 associations selected to receive funding under the IBE Promising Strategies Programme. The project involved the provision of training in tailoring, food and nutrition and vegetable-growing for 30 people with epilepsy. At the end of the programme, which involved student placements in various vocational institutions, the participants were expected to have the necessary skills to attain a meaningful living.

The objectives of the programme included advocacy for employment, education and civil rights of persons with epilepsy. To achieve this, the association liaised with the Ombudsman's office and hosted an awareness seminar for employers. The challenges included irregularity in attendance due of seizures by the students, usually caused by non-compliance. However the team of experienced personnel monitoring the programme, helped in preventing undue levels of absence.

CONTACT DETAILS
Gambia Epilepsy Association,
#5 Dippa Durkureh Road, London Corner, PO Box 2230, Serrekunda, Gambia.
T: +220 9955 414
gambiaepilepsy@yahoo.co.uk
Contact: Mr Philip Chiga.

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GHANA EPILEPSY ASSOCIATION

The Ghana Epilepsy Association was formed in 1995 and became IBE member in 1997.

In 1995 through the support of the Danish Community Rehabilitation Program, the Ghana Epilepsy Association held a seminar at the British Council Hall under the theme: Epilepsy is not Infectious, But Treatable.

Between 1995 and 2002 the Association engaged in series of social and publication initiatives in Ghana to bring issues of epilepsy to the social domain as an effort to demystify the stigma associated with the condition.

In 2001, the Ghana Epilepsy Association organised Seminar dubbed "Ghana Campaign Against Epilepsy: Bringing Epilepsy Out of the Shadows".

The Association held talks with educational institutions and church groups with the video "It is not my Choice." Most of these programs were carried on national and radio stations and TV channels.

Due to the interests generated in the Ghanaian community, some students from one of the universities undertook some research studies in social implications involved with persons with epilepsy in Ghana.

CONTACT DETAILS
Ghana Epilepsy Association
c/o Box M230, Accra, Ghana.
T: +233 2166 5421 ext 4420
ayisu@hotmail.com
Contact: Mr Paul Ayisu

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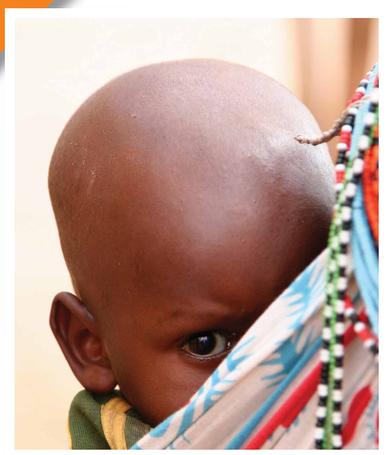
KENYA ASSOCIATION FOR THE WELFARE OF PEOPLE WITH EPILEPSY (KAWE)



CREATED
Created in 1982, affiliation to IBE circa 1985.

GOAL
KAWE's goal is to develop and sustain a comprehensive and integrated epilepsy program that is affordable and accessible to all people suffering from epilepsy countrywide.

ESTIMATED NUMBER OF PEOPLE WITH EPILEPSY IN KENYA
2% of the population i.e. over 800,000. 11,651 people with epilepsy registered at our clinics.

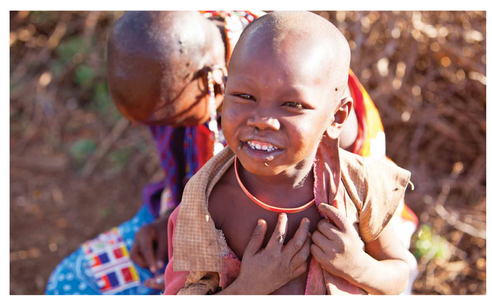
OTHER SUPPORTERS
25 Volunteers and over 200 Friends of KAWE.

KAWE PROGRAMS: INTEGRATED EPILEPSY MANAGEMENT IN KENYA STRATEGY
KAWE's activities centre around three broad programs:

1. Education Awareness and Training
   Epilepsy is not well understood by most communities in Kenya leading to stigmatisation of the sufferers and their families. The focus of the Education, Awareness and Training component of the project is to increase awareness that epilepsy is a treatable medical condition and dispel myths and traditional beliefs on causes of epilepsy such as witchcraft, curses, devil possession, failure to pay dowry and inheritance. This is done through:
   - Oral Presentations in institutions such as schools and churches.
   - Training of over 3,000 local leaders, public health officers and community health workers who then create awareness in their communities.
   - Development and distribution of materials. This includes print as well as radio and TV broadcasts.
   - Training of Medical personnel through collaboration with the Division of Non Communicable Diseases in the Ministry of Public Health and Sanitation. Over 1000 medical personnel serving in public health facilities have been trained to correctly screen, diagnose and treat epilepsy.

2. Medical Provision and Clinic Support
   While working towards having epilepsy treatment services offered in all public health facilities, due to chronic staff shortages and transfers within the public health services, these facilities have not been able to take up provision of the services themselves. KAWE therefore has continued to provide the services directly. These services include direct medical consultations, drug supply and patient follow-up. Most of our patients are well controlled on one drug and are seizure free for periods ranging from 6 months to 3 years. 65% of patients are children. 40% of patients are not able to contribute to the cost of the cost of their treatment.

3. Lobbying and Advocacy
   This programme deals with policies and legislation that affect people with epilepsy. Lobbying activities seek the enactment and implementation of policies and legislation that support epilepsy care and reduce discrimination. These activities enhance political support at the national level for programmes that address issues relating to epilepsy and will help to ensure that epilepsy is treated as a priority.



CONTACT PERSONS
1. Dr. Osman Miyanji, Child Neurologist and Consultant Paediatrician, Chairman KAWE Board of Directors, P.O. Box 60790 00200 Nairobi, omiyanji@yahoo.com
2. Rosemary Gathara, KAWE Program Coordinator P.O. Box 60790 00200 Nairobi, rosemary@kawe-kenya.org

CONTACT DETAILS
Kenya Association for the Welfare of People with Epilepsy (KAWE), PO Box 60790,
00200, Nairobi, Kenya.
T: +254 020 387 0885
nfo@kawe-kenya.org
KAWE Website: http://www.kawe-kenya.org

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EDYCS EPILEPSY GROUP, ISLAND OF MAURITIUS

CATEGORY MEMBER IBE
Full Member

CREATION DATE
24th December 1997

DATE AFFILIATED TO IBE
2001

MEMBERSHIP TO EDYCS
Membership to Edycs Epilepsy Group is categorized into the following:

- Individual Members: 60
- Freelancers or Supporters: 100
- People with Epilepsy and Families known as Beneficiaries: 1150
- Affiliated Organisations (Ngos/Cbos) refer to the Epilepsy Affiliates Support Network: 30
- Corporate Network known as 'Reseau des Entreprises': 40
- IBE Epilepsy Advocacy Schools Network: 25

ORGANISATION'S RANGE OF OPERATION
National

MISSION OF EDYCS EPILEPSY GROUP
Edycs Epilepsy Group aims to promote positive epilepsy care attitudes and behaviors in the community and to actively support the individuals with epilepsy and their families by identifying their needs, advocating their rights and providing them with medical and social assistance.

KEY OBJECTIVES OF EDYCS EPILEPSY GROUP

- To promote epilepsy awareness in Mauritius and Rodrigues Islands through public talks, seminars and conferences.
- To provide people with epilepsy, children and adults with free counseling, medical support, education and training.
- To establish an Epilepsy Health Service Center with provision for care, diagnosis, medication and research.
- To work in close collaboration with NGOs, government institutions, the corporate sector, and international epilepsy bodies.
- To advocate in favor of the people with epilepsy in the education and employment sectors
- To raise fund for the attainment of the objectives set above.

KEY SERVICE PROGRAMS
Edycs Epilepsy Group is committed to bring about changes in the lives of the people with epilepsy via the operating units working to improve their lives and social integration into the mainstream.

EDYCS EPILEPSY HEALTH SERVICE CENTER (MAURITIUS)
Unit providing free full time epilepsy treatment services including therapeutic program, counseling and training to people diagnosed with epilepsy from all over the island.

RODRIGUES EPILEPSY HEALTH SERVICE CENTER (RODRIGUES)
Unit providing same similar services as in Mauritius to people diagnosed with epilepsy.

EDYCS HELP TO GROW EDUCATIONAL AND REHABILITATION CENTER
Unit providing educational support to children and adolescents with epilepsy. The Center, recognized by the Ministry of Education, operates on a non fee paying basis through the provision of donations from the corporate sector.

EDYCS EPILEPSY AMBASSADORS TEENS CLUB
Unit operating to organised recreational activities and leisure programs to 275 children and adolescents with epilepsy. The Club was supported with funding from the European Union Decentralised Cooperation Programme.

EDYCS EPILEPSY ADVOCACY UNIT
Unit grouping all Specialized Schools with children with epilepsy working to advocate issues surrounding education in children with epilepsy and the development of training program for both teachers and head of schools.

CONTACT DETAILS
Youssouf Noormamode, President
Edycs Epilepsy Group
442 Stateland Boulevard Rivaltz Port Louis
Port Louis Republic of Mauritius
Tel and Fax: (230) 2131733 – (230) 2081904
E-mail: Edycs.org@intnet.mu
Website address: http//edycsepilepsy.intnet.mu

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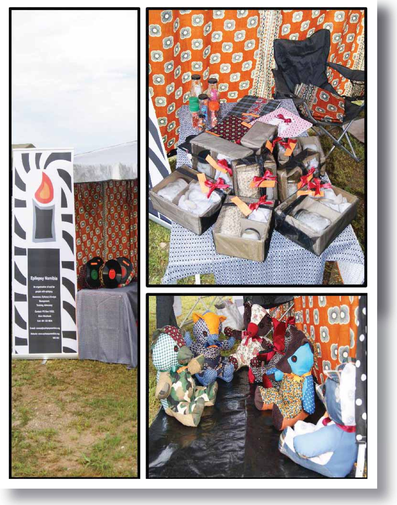
EPILEPSY NAMIBIA, NAMIBIA



WHAT TYPE OF IBE MEMBER
Full Member

CREATION DATE
Registration Namibia: June 2007

IBE REGISTRATION
(Singapore) July 2007

WHAT TYPE OF ORGANISATION
Individual Membership

RANGE OF OPERATION
National

THE GOAL OF THE ORGANISATION
Empower people with epilepsy to take their place in their communities.

DETAILS OF A CONTACT PERSON FOR INTERNATIONAL LIAISON
Harmiena Riphagen. PO Box 11822, Klein Windhoek, Namibia
E-mail: namep@epilepsynamibia.org.
Tel: +264813226834

WEBSITE
www.epilepsynamibia.org

HIGHLIGHTS

(DVD)
"Understand me": An audio-visual production on the condition of epilepsy, lifestyle management and first aid for seizures targeting schools, clinics and communities in the geographical vast areas of Namibia. The soundtrack is in English, the official business language, as well as Afrikaans which is widely spoken. It is accompanied by printed translations in Damara, Herero and Oshiwambo. Detailed information booklets and info sheets about epilepsy are included in the packages that are posted to the different regions.

(BUSINESS INCENTIVE)
Eben Riets from Windhoek is the first recipient of the Epilepsy Namibia "Starter Fund". This business incentive capital is allocated to a person with epilepsy to start or improve a business or income generating project. Eben bought a video camera to film weddings, christenings, funerals, choirs and church celebrations in his community which he sells to the participants. His activities brought him in contact with the national "One Africa Television" station and he now works as a freelance cameraman in their news department as well.

(RE-)
Re- is a principle driven project fashioned on the philosophy of a greener planet by re-making and re-using products that have outlived their personal utility value and at the same time creating opportunities to empower people with epilepsy.

Hats and teddy bears are made from scrap fabrics, handbags from used denim jeans and vinyl records and photo frames from ties and belts. Egg cartons, magazines and scrap paper are used for firelighters and packaging.

People with epilepsy are being trained to manufacture the products which are sold at flea markets and stalls at festivals.

All above programs have been supported by the IBE Promising Strategies Program.

CONTACT DETAILS
Epilepsy Namibia,
PO Box 11822,
Klein Windhoek, Namibia.
T: +264 813 226834
namep@epilepsynamibia.org
Contact: Ms H. Riphagen

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NIGER

POPULATION (2010)
15,204,000.

ETHNIC GROUPS
Hausa 53%, Djerma (Zarma) 21%, Tuareg 11%, Fulani 7%, Beri Beri (Kanuri) 6%; Arab, Toubou, and Gourmantche 2%.

RELIGIONS
Islam (97%); remainder traditional and Christian.

LANGUAGES
French (official), Hausa, Djerma, Fulfulde, Kanuri, Tamachek, Toubou, Gourmantche, Arabic.

EDUCATION
Years compulsory – 6. Attendance – 49% (male), 31% (female).

LITERACY (2008)
29% (17% for women).

HEALTH
Infant mortality rate – 81/1,000.
Life expectancy--58 yrs.

Niger's high infant mortality rate is comparable to levels recorded in neighbouring countries. However, the child mortality rate (deaths among children under age of 5) is particularly high (198 per 1,000 in 2010) due to generally poor health conditions and inadequate nutrition for most of the country's children. Niger's fertility rate (7.8 births per woman), is among the highest in the world, and is far higher than the sub-Saharan African average of 5.4. Two-thirds (66.7%) of the Nigerien population is under age 25.

CONTACT DETAILS
LNCEMNMC,
Service de Psychiatrie, Hôpital National de Naimey,
BP238 Niamey,
Niger
T: +227 723 392
djibo.doumamaiga@gmail.com
Contact: Dr D Douma

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NIGERIA

POPULATION (2010)
152 million.

POPULATION GROWTH RATE (2010)
2.0%.

TOTAL FERTILITY RATE
Avg. number of children per woman in 2010 – 4.82.

ETHNIC GROUPS (250)
Hausa-Fulani, Igbo, Yoruba, and Kanuri are the largest.

RELIGIONS
Muslim, Christian, Indigenous African.

LANGUAGES
English (official), Hausa, Igbo, Yoruba, Fulani, Kanuri, others.

EDUCATION
Attendance (secondary) – male 32%, female 27%. Literacy – 39%-51%.

HEALTH
Life Expectancy (2010) – 47 years.

The most populous country in Africa, Nigeria accounts for over half of West Africa's population. Although less than 25% of Nigerians are urban dwellers, at least 24 cities have populations of more than 100,000. The variety of customs, languages, and traditions among Nigeria's 250 ethnic groups gives the country a rich diversity. The dominant ethnic group in the northern two-thirds of the country is the Hausa-Fulani, most of whom are Muslim. Other major ethnic groups of the north are the Nupe, Tiv, and Kanuri. The Yoruba people are predominant in the southwest.

About half of the Yorubas are Christian and half Muslim. The predominantly Catholic Igbo are the largest ethnic group in the southeast, with the Efik, Ibibio, and Ijaw comprising a substantial segment of the population in that area. Persons of different language backgrounds most commonly communicate in English, although knowledge of two or more Nigerian languages is widespread. Hausa, Yoruba, Igbo, Fulani, and Kanuri are the most widely used Nigerian languages.

EPILEPSY ASSOCIATION OF NIGERIA

1. The Association has expanded and many local branches have been established.
2. Many Treatment Centres have been opened in existing Hospitals and in different localities.
3. In view of this, awareness has been widely created leading to easy accessibility to treatment.
4. The Association has established cassava and poultry farms not only to increase food production but to get the people suffering from epilepsy and their carers employed. This leads to occupational therapy.
5. Town cryers, Radio and Television announcements are employed to reach people at the grassroot.

PROBLEMS

The Association is facing one major problem- that is funding. Lack of adequate funds is dragging the Association back.

- Rate of further expansion has been low.
- Establishment of commercial farming is difficult.
- Radio and Television jingles require huge sums of money which the Association lacks.

CONTACT DETAILS

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

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IBE

International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.
t +353 1 210 8850 **f** +353 1 210 8450 **e** ibedublin@eircom.net **www.ibe-epilepsy.org**

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SENEGALESE LEAGUE AGAINST EPILEPSY

The Senegalese League Against Epilepsy is a non governmental organisation founded in 1995 which is constituted by professionals of health, members of the civil society and tradipracticians. Principal activities are care, formation and information to the patients, doctors, paramedics and population.

The LSCE was selected in 2001 by WHO, International League Against Epilepsy and International Bureau for Epilepsy as pilot of the worldwide campaign against epilepsy "Epilepsy out of the shadows". It consisted of a multiannual strategic action plan which covers all Senegalese areas. Since then, 11 caravans have been done in 9 areas of Senegal; the most recent were in Fatick and Ziguinchor.

In Fatick during two days:

- 56 persons (5 doctors, 47 nurses, 4 public health and community actors have been trained.
- 178 patients with 97 people with epilepsy (55,6%), the other patients (81) suffering from other neurological pathologies (mainly AVC and HTA) have been consulted.

Ziguinchor initiated a new profile of caravan with inclusion of the AVC in the fight's platform: concept of "neurocaravanes". Thus, over 2 days:

- 50 people were trained on the AVC and the Epilepsy including 30 doctors, the remainder concerning the male nurses and voluntary medical.
- 311 patients were consulted including 94 neurovascular cases and 66 people with epilepsy.

In October 2009, the LSCE promoted the research and reinforcement of the capacities in epileptology in Senegal and Africa by creation of a University degree in Epileptology at Medical college of UCAD. The courses began on March 17, 2010 with 11 students this year (neurologists, psychiatrists, neurosurgeons) and a prospect for more inscriptions for the next year.

CONTACT DETAILS

Ligue Senegalaise contre l'Epilepsie,
Service de Neurologie CHU Fann
BP: 5035 Dakar Fann,
Senegal
T: +221338 253678
agallodiop@gmail.com
Contact: Prof. Amadou Gallo Diop

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EPILEPSY ASSOCIATION OF SIERRA LEONE

COUNTRY OF OPERATION
Sierra Leone

TYPE OF IBE MEMBERSHIP
Associate Member

DATE ORGANISATION WAS CREATED
3rd December 1999

DATE ASSOCIATION FIRST AFFILIATED TO IBE
31st August 2005

TYPE OF ORGANISATION
Individual and Organisational Membership

RANGE OF OPERATION
National

MISSION
To improve the standard of life of persons with epilepsy through programmed activities.

GOALS
- To mount a national awareness campaign about the causes and treatment of epilepsy.
- To provide quality means of diagnosing and treating epilepsy.
- To re-integrate excluded school children with epilepsy back into schools.
- To rehabilitate persons with controlled seizures into vocational skills training and livelihood support activities.
- To establish an information centre, to provide materials and disseminate messages about epilepsy and the Association.
- To build the capacity of EASL Staff through continuous development.

STATISTICS
Sierra Leone has an estimated fifty thousand persons with epilepsy. Among this number EASL identified and registered over 3000. EASL is also working with 72 school children with epilepsy to re-integrate them back to school, and with twenty (20) youths training them in vocational skills training and adult literacy.

REGULAR ANNUAL ACTIVITIES
- An ongoing registration of patients and membership drive.
- Counseling of patients and community education done every month for parents and care givers.
- Monthly outreach Epilepsy clinics in 14 towns and cities throughout the country.
- Skills training activities such as tailoring for people with epilepsy.
- Annual seaside picnic for patients and family members.

SPECIAL ACTIVITIES DURING 2009 AND 2010
EASL trained and re-united forty (40) youths, previously rejected, back into their communities after completing three years of vocational skills training in cloth dyeing, tailoring, soap making and adult literacy.

Through the support of Handicap International (HI) EASL jointly celebrated the International Day of the Disabled on the 3rd of December to raise awareness about the misunderstandings surrounding disabilities such as epilepsy which usually lead to discrimination, injuries and prejudice.

CONTACT DETAILS
Names: Mr Max Bangura and Dr D R Lisk
Address: 8 Mansaray Street, Rokupa, POB 381, Freetown, Sierra Leone.
E-mail: epilepsy200074@yahoo.com, durodamil@yahoo.co.uk
Website: www.epilepsyassoc.org

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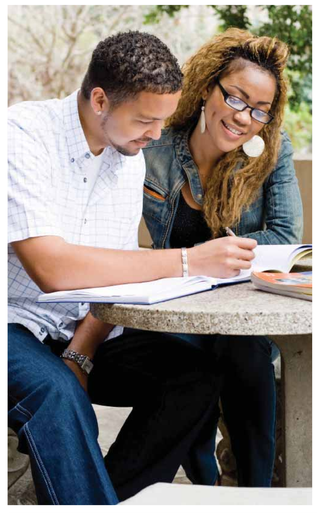
EPILEPSY SOUTH AFRICA



TYPE OF IBE MEMBERSHIP
Full Member

TYPE OF ORGANISATION
Not-for-Profit Organisation, with individual and organisational membership

RANGE OF OPERATION
Epilepsy South Africa is a National organisation with 6 Branches. It was established in September 1967 and provides services to approximately 450,000 South Africans with epilepsy and also those affected by the condition.

MISSION
We are a dynamic organisation providing developmental services nationally to promote equal opportunities for people with epilepsy and other disabilities.

VISION
To provide integrated services that are equitable, accessible, sustainable and people-centered with and for people with epilepsy and other disabilities and all affected by epilepsy, to promote social justice.

FOCUS AREAS
National Media Awareness and Marketing:
We redress the lack of knowledge about epilepsy as a condition and the organisation through appropriate media to increase organisational programme sustainability.

National Sustainability:
We achieve financial sustainability through the identification of partners, donors and funders, as well as the development and maintenance of long-term relationships.

National Social Development:
We aim to combat discrimination towards persons with epilepsy and other disabilities and enhance their inclusion in mainstream society.

Residential Care:
We have 6 residential care facilities for people with multiple disabilities including epilepsy. The focus remains on the integration of people into mainstream society.

National Economic Development:
We economically empower people with epilepsy and other disabilities and assist in their inclusion in the mainstream economy by providing a variety of economic empowerment services. Epilepsy South Africa believes in a holistic and integrated approach which requires input in terms of social, economic and skills development.

SPECIAL ACTIVITIES DURING 2010/2011
We hosted our first National Epilepsy Advocacy and Human Rights conference were 38 people with epilepsy were empowered to become self-advocates and to address the frequent discrimination experienced by people with epilepsy in South Africa. Self-advocacy training will continue for people with epilepsy which will also increase general awareness about the condition.

We launched our Epilepsy South Africa Training Division and provide quality training to other Non-Profit Organisation, Corporates, clients and civil society. Not only does this increase skills and knowledge within the disability and Non-Profit sector, but it also serve as an additional income stream for Epilepsy South Africa.

Our economic development program has achieved great successes in respect of entrepreneurial development. Training of trainers was conducted across South Africa, empowering other trainers to cascade this information to clients with epilepsy and other disabilities, especially rural communities. Many of these clients have now successfully started their own businesses.

We are proud of our first direct service point that was established in Eastern Cape Province where no specialized services for epilepsy was previously available. This is a hugely underserviced, rural and poverty stricken province and thus we have combined social and economic development approaches to achieve maximum benefit for clients with epilepsy.

CONTACT DETAILS
Epilepsy South Africa
PO Box 12100 N1 City, 7463, Cape Town,
South Africa
E-mail: info@epilepsy.org.za
Telephone: +27 21 595 4900
www.epilepsy.org.za

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SWAZILAND EPILEPSY ASSOCIATION

Swaziland Epilepsy Organisation is situated in the Kingdom of Swaziland in Southern Africa. The main focus of our organisation is to offer and support people living with epilepsy in Swaziland. SEO was established in 2003. It became a full member of IBE in 11 July 2007.

Our membership includes individuals and support groups.

We represent over 1000 swazis with Epilepsy. In campaigning we bring Epilepsy out of the shadow with its myth and traditional attachments. Unity and togetherness is the policy to achieve best practice for people with epilepsy. We fight discrimination and stigma by ensuring the right information reaches the people. We also promote the availability of medication. Support groups have also been established to help in the communities.

INFORMATION SERVICES

If you are living around Swaziland and surrounding areas you can access the events and information on Epilepsy through our newly launched website www.epilepsy.org.sz; Nation/Public awareness Campaigns; Offering support on Epilepsy support groups in the rural areas.

Epilepsy Awareness Campaign (Epilepsy Street Jamboree) was held in the capital city in Mbabanelast year in September.

HIS ROYAL HIGHNESS PRINCE BANDZILE INTRODUCED EPILEPSY YELLOW GOLF DAY ON 18 JUNE, 2011

The patron of the Swaziland Epilepsy Organisation takes great pleasure to introduce you to our great concept for a celebrity golf fundraising event for the purposes of raising much-needed funds to support the complex needs of young and old people living with epilepsy.

The Swaziland Epilepsy Golf Fundraising day's goal is to provide a unique opportunity for regular golfers from business, political, sports and communities to socialize and play golf the way it is meant to be played. In doing so they would be supporting a good cause by making a substantial contribution to charity. The organisation aims to raise at least E500 000.00 (Five Hundred Thousand Emalangeni Only), which is hoped to be received from sponsorships, pledges, Donations and participation entry fees.

The young and old living with epilepsy and disabilities form integral component of the Epilepsy Yellow Golf Fundraiser. Funds raised from the event will provide for the proper healthcare, clothing, food and education needs of the people living with epilepsy country-wide. Their needs are immense and we would like to urge you to partner with us and make a difference to the lives of many young and old living with epilepsy disorders and seizures.

CONTACT DETAILS

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

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PARENTS ORGANISATION FOR CHILDREN WITH EPILEPSY (POCET)

The parents organisation of children with epilepsy – Tanzania (POCET), was formed on 12th June 1992. It is a registered as a non governmental organisation with Tanzanian government registrar of societies and given registration no. SO.7674. It has a membership of 900 on record and only 50 of these are paid up members.

THE AIMS AND OBJECTIVES OF THE ORGANISATION ARE

1. To work together using the resources of parents, guardians, caretakers and other interested persons in order to obtain the best possible care for children with epilepsy;
2. To help solve problems concerning the acquisition and/or procurement of anti-epileptic medicines;
3. To follow-up all feasible ways to purchase medicines at the best possible prices;
4. To cooperate with other Organisations which are engaged in the education of the public concerning epilepsy;
5. To work together in understanding childhood epilepsy by doing research;

The organisation after its formation managed to set up a drug bank for anti-epileptics drugs which were sold at a low cost to the patients parents and carers. Those who could not afford to buy were given free. The proceeds from the sale of drugs were used for running POCET office and purchase of a 54 acre piece of land which is used for farming activities.

PROMISING STRATEGY PROJECT

In 2007 the organisation applied and was granted $5000 from IBE under promising strategy project to embark on cashew nuts and vegetable growing project. From the funds received, 15 acres of land was used to plant 500 cashew nuts trees and 4 acres was used to plant a variety of vegetables.

For a few years the farming activities did very well but later faced a problem of animals attacking crops as the organisation could not afford to build a structure and employ some one to take care of the place. Currently the farm is being looked after by three village volunteers who live in the near by village. As a way to encourage these volunteers, they have been allowed to harvest cashew nuts whenever they are in season. This arrangement of barter trade, though it cannot be avoided, has left the organisation without any income.

OTHER ACTIVITIES

The past few years the Association held the following activities:

1. In 2003 the WHO donated $1000 which was used to print brochures, T. Shirts, paying the drama group, school competition , Radio and TV epilepsy program and held epilepsy workshop for health workers and primary school children.
2. Distributed a questionnaire in schools and among health workers on the knowledge and attitude about epilepsy.
3. The organisation in collaboration with Tanzania Epilepsy Association conducted a knowledge and attitude (KAP) survey in Schools, Health centres and Traditional Healers with the support of $2000 from Novartis.
4. A joint one day symposium was held for health workers on the care of people with epilepsy. Dr Joseph Mbatia from the Ministry of Health was the guest of honour.

CONTACT DETAILS

Parents Organisation for Children with Epilepsy (POCET)
PO Box 65293,
Dar Es Salaam,
Tanzania.
Telephone: +255 744 822 517
E-mail: bsmwene@yahoo.com
Contact: Mrs Aisia Mrema

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ASSOCIATION CLINIQUE DE L'EPILEPSIE TOGO

TYPE OF IBE MEMBERSHIP
Associate Member

DATE THE ORGANISATION WAS CREATED:
4.4.2006

DATE AFFILIATED TO IBE
2007

TYPE OF MEMBERSHIP
Organisational Membership

RANGE OF OPERATION
National (Togo)

WEBSITE
www.docteur-sodjehoun.ch

GOAL OF THE ORGANISATION
Association Clinique des Epileptiques, based in Lome, Togo, seeks to offer epilepsy treatment to all members of the population on the basis of evidence based, standard medical procedures. Public and patient education about epilepsy is central to the goals of the Association. The Association Clinique des Epileptiques is a non-profit organisation and relies on third party financing for a large part of its operating budget.

PROMISING STRATEGIES 2009
The goals we had set were achieved. At the meetings, the following topics were addressed and discussed at depth:

- What is epilepsy
- How can epilepsy be treated
- Which types of seizures are there
- Which types of seizures do individuals in the group have
- How do I keep a seizure log
- How are antiepileptic drugs (AED) taken
- When can I discontinue drug treatment
- When do I have to schedule doctor's appointments when taking AED
- Which nutritional guidelines should be followed
- Which foods should be avoided in order not to risk further seizures
- Which guidelines should be followed in pregnancy
- Guidelines for general hygiene
- Guidelines pertaining to sleep-wake rhythms
- Guidelines pertaining to traditional medicine

The teaching was done using PowerPoint presentations, explanations using brain models and by telling stories, all of which was translated into the Ewe language. Before addressing a new topic, a review of what had been taught in the last session was reviewed. The participants from the village Afania came by bus-taxi and the costs for this transportation were covered by the Promising Strategies funding. Participants also came from the capital Lomé, usually a group of 16 to 20 people consisting of patients and their family members who were an attentive audience. Since there are always patients for whom the trip to the outpatient clinic in Sanguera is not possible, we took trips to the village. The village-chief had kindly invited us and allowed us the use of his porch for the promising strategies sessions.The importance of correct hygiene in the preparation of local foods was stressed.

There seemed to be a great thirst for information and the patients demonstrated that they wanted to understand the presented material fully. Only very slowly certain openness seemed to develop in the way epilepsy was talked about in the group. The traditional beliefs that epilepsy could be a contagious disease, that one should not touch people with epilepsy, that one should not wear his clothes, drink from his glass were questioned and discarded.

There is need for further education and we will stay active in this regard. Thanks to the support from the IBE Promising Strategies we had the opportunity to convey important information using modern approaches. This was the first step. We hope to continue the work and are hopeful for continued support.

CONTACT DETAILS
Association Clinique de l'Epilepsie
155, Carrefour de
Rio, 11 B.P. 75,
Lomé, Togo.
T: +228 271 0449
kokousodj@yahoo.com
Contact: Dr Kokou Sodjéhoun.

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EPILEPSY SUPPORT ASSOCIATION UGANDA (ESAU)

ESAU is a membership organisation of people with epilepsy. The association was formed in 1997 at Mbarara University Teaching hospital out of epilepsy clinics that were being run by the psychiatric department.

Our Vision is "A Ugandan society in which epilepsy is understood and people with epilepsy are treated with dignity so that they can exercise their full potential and participate in all development".

With the support of Danida, the association is now operational in 20 districts; Adjumani, Moyo, Arua, Apac, Oyam, Kaberamaido, Katakwi, Amuria, Soroti, Kumi, Jinja, Luweero, Nakaseke, Masaka, Mbarara, Bushenyi, Ntungamo, Kabale, Hoima and Mpigi. We have a membership of around 3000 members.

The Association is a registered NGO with permission to operate nationally. ESAU networks with all the organisations in the disability movement in Uganda. ESAU appreciates the working partnership, support, courage and guidance received from these organisations and government departments.

MISSION

To become the leading organisation that empowers people with epilepsy to participate in developmental processes through advocacy, networking, research and documentation.

ESAU'S WORKING PRINCIPLES ARE

Participation, Empowerment, Networking, Non-discrimination and Gender equity.

ESAU'S GENERAL OBJECTIVES

- To create a platform for persons with epilepsy to meet regularly and share their needs as a united force with a common goal.
- To educate the public, especially parents and the community at large about epilepsy so as to reduce the social stigma.
- To encourage the formation of support groups through which persons with epilepsy and their relatives can get psycho social support and counseling.
- To encourage persons with epilepsy to engage in income generating activities so as enable them live economically independent lives and access regular medication.
- To work together with other partners and NGOs to influence policy makers, so as to achieve a better understanding of epilepsy.
- To empower persons with epilepsy to fully participate in all community aspects.

ESAU SPECIFIC OBJECTIVES

- To create awareness among people with epilepsy, their relatives, health workers, opinion leaders and the community.
- To build networks and alliances through which it can advocate for the rights of PWE.
- To empower ESAU structures and engage decision makers at the district and sub-county levels for effective service delivery.
- To build an association in which people with epilepsy, their relatives and guardians are empowered and participate in advocacy, networking research and lobbying for their rights to dignity and equal service delivery.

CONTACT DETAILS

Epilepsy Support Association,
Plot 3 Ntinda II Road,
PO Box 16260, Wandegeya,
Kampala, Uganda.
T/F: +256 414 287 700
esauganda@yahoo.com

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EPILEPSY ASSOCIATION OF ZAMBIA

TYPE OF IBE MEMBERSHIP
Full IBE Member

DATE THE ORGANISATION WAS CREATED
22nd September, 2001

DATE AFFILIATED TO IBE
2003

TYPE OF MEMBERSHIP
Individual and organisational Membership with 560 members

MISSION
The mission of the Association is to improve the quality of life for people living with epilepsy.

AREAS OF OPERATION
- Conducting Epilepsy Clinics: The Association in collaboration with the Ministry of Health conducts weekly epilepsy clinics in health institutions and the community.
- Promising Strategy Project: The Association was given a piece of land to carry out gardening, chicken rearing, jam making and other rehabilitation activities under IBE PSP support. Through this Initiative the Association is able to support school going epilepsy children and give grants to Epilepsy care teams. Some of the children who have been supported through this initiative are Niggan Chibwe who completed Secondary High School, Cancius Daka who due to seizures dropped out of school, but was enrolled back to school and David Mwila who is currently studying IT in Russia.
- Conducting workshops for teachers health workers and the general public.
- Conducting commemorations i.e. National Epilepsy Day 29th August, Seizure free day 19th December and Purple day March 26th.
- Participating in the National and International commemoration days i.e. World Health Day, World Mental Health Day, World Disability Day, Zambia Trade Fair, National Agricultural Day, Public Service Day etc.
- Participating in Stigma Research project spearheaded by the Neurological and Psychiatric Society of Zambia.
- Production of Epilepsy materials such as brochures, calendars, T. shirts, caps, flyers, nurses aprons etc.

BACKGROUND
The Epilepsy Association of Zambia was formed in 2001 and has more than 500 members country wide. The Association is a full member of the International Bureau for Epilepsy.
The Association collaborates with the Ministry of Health and WHO Country office through the GCAE program which was launched on 29th August 2003.
The Association also works in close collaboration with other local and International Organisations such as Cheshire homes, Action on disability, Africa Decade on disabilities, Mental Health Association of Zambia, Neurological and Psychiatry Society of Zambia, Government Line Ministries, Kauffman Foundation of USA, Middle Tennessee Society of Neuroscience, Media houses and IBE/ILAE chapters around the world.

CHALLENGES
- Lack of adequate funds to achieve objectives
- Stigma
- Lack of sustainable support from the government
- Lack of volunteers to carry tasks on full time basis
- Lack of trained health workers to adequately diagnose and manage epilepsy cases.

CONTACT DETAILS
Mr. Anthony Mulenga Zimba (Chairman)
Epilepsy Association of Zambia
1st Floor, Amandla Ethu Building
Kalundwe Rd
P.O. Box 32443
Lusaka, Zambia
E-mail: eazepilepsy@hotmail.com

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EPILEPSY SUPPORT FOUNDATION OF ZIMBABWE

1990-2010: Join us celebrate 20 years of charitable work towards people with epilepsy in Zimbabwe.

20th Anniversary Theme: Developing into an epilepsy management centre of excellence in Africa.

The Epilepsy Support Foundation was founded on 17 April 1990 in Harare, Zimbabwe by Nicholas Arthur George, friends and professionals. It celebrated its 20th anniversary on 17 April 2010. As part of its 20th anniversary, the Foundation officially initiated moves to build an epilepsy clinic at its George Epilepsy Centre in Harare. The clinic has initial support from the estate of the late Professor of Neurology Lawrence Levy, founder member. On the day of its 20th anniversary, the British Embassy in Harare handed over an EEG machine for use by the Clinic which shall be named after Professor Levy. The vision of this centre is to develop into a multidisciplined unit for epilepsy management in Africa. This is a bright vision whose realization depends on support from organisations and individuals interested in epilepsy world wide. The Foundation appeals for support in any way to realize this vision.

CONTACT DETAILS

Epilepsy Support Foundation of Zimbabwe
43 St David Road Hatfield, Harare, Zimbabwe
Telephone: 263-4-571225
Fax: 263-4-571233
Mobile Phone: 263-773-595241
E-mail:epilepsyzimbabwe@gmail.com
www.facebook.com/epilepsy.zimbabwe

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International Headquarters, 11 Priory Hall, Stillorgan, Blackrock, Co. Dublin, Ireland. Contact: Ann Little, Executive Director.
t +353 1 210 8850 **f** +353 1 210 8450 **e** ibedublin@eircom.net **www.ibe-epilepsy.org**

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MEMBERS IN THE AFRICA REGION

CAMEROON	Association Camerounese contre l'Epilepsie
ETHIOPIA	Epilepsy Support Association of Ethiopia
GAMBIA	Gambia Epilepsy Association
GHANA	Ghana Epilepsy Association
KENYA	Kenya Association for the Welfare of People with Epilepsy (KAWE)
MAURITIUS	EDYCS Epilepsy Group
NAMIBIA	Epilepsy Namibia
NIGER	LNCEMNMC
NIGERIA	Epilepsy Association of Nigeria
SENEGAL	Ligue Senegalaise contre l'Epilepsie
SIERRA LEONE	Epilepsy Association of Sierra Leone (Associate Member)
SOUTH AFRICA	Epilepsy South Africa
SWAZILAND	Swaziland Epilepsy Association
TANZANIA	Parents Organisation for Children with Epilepsy in Tanzania (POCET)
TOGO	Association Clinique de l'Epilepsie (Associate Member)
UGANDA	Epilepsy Support Association
ZAMBIA	Epilepsy Association of Zambia
ZIMBABWE	Epilepsy Support Foundation

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