



EPILEPSY AFRICA NEWS

Issue 11

July 2018

A newsletter of the African Regional Committee of the International Bureau for Epilepsy (IBE)



Images: Training of trainers project in Zimbabwe. This project seeks to train doctors so that they train nurses working in rural communities to manage epilepsy. Report by Taurai Kadzviti in the next issue.

Epilepsy Day

11 February 2019

Purple Day

26 March, 2019

**4th African Epilepsy Congress,
Kampala, Uganda**

22-24 August 2019

Contents of this Newsletter

- Youths projects: results and feedback.
- Advocacy project information.
- Epilepsy day.
- Poster for epilepsy day.

About this newsletter: Editorial team: Jacob Mugumbate; Youssef Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** Monthly **Distribution:** Email and other social media. **Email contributions to:** ibeafrica@gmail.com. Enjoy your reading!

How to join us:

WhatsApp group for people with epilepsy and significant others: +260977789042, group for professionals interested in epilepsy: +260977789042. **Epilepsy Africa Facebook** group:

<https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts>

Twitter: [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica). **Email list:** We have three email lists – for social issues, for professionals and for associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrica@gmail.com.

Chairperson & Editor's message

Welcome to the 11th issue of Epilepsy Africa newsletter. In this newsletter you will find information about two funding opportunities: The Advocacy Project funded by BAND Foudnation and the promising Strategies Project funded by the IBE. I urge you to apply before the deadlines and to ask your AREC team if you have any questions. You will also find a report from Sierra Leone. The call for session topics for the 4th African Epilepsy Congress to be held in Kampala, Uganda from 22-24 August 2019 has closed and I am hoping we will get a good number of presentations from our associations. I want to encourage you to contribute to this newsletter by sending an email to ibeafrika@gmail.com. Enjoy your reading. *Jacob*.



Funded projects: Young people with Epilepsy Support (YES) project

These are the projects that have received funding in this round.

Country	Applicant/Project leader	Project type and description
Kenya	Eric Ngware Mburu	Awareness
Malawi	Sammy Chigamba	Awareness
Sierra Leone	Jeneba Kabba & group	Training (African Necklaces & Bracelets)
Zimbabwe	L Dube and group	Awareness
Zambia	Rebecca & group	Training (Poultry rearing)

We wish the project leaders and their associations success. Please work with AREC Secretary Betty to ensure that all information required for payments to be processed is submitted.

AFRICA EPILEPSY ADVOCACY (AEA) PROJECT

CALL FOR EXPRESSIONS OF INTEREST TO IMPLEMENT AN ADVOCACY PROJECT IN YOUR COUNTRY

Introduction

In 2015, the World Health Organization (WHO) General Assembly passed a landmark epilepsy resolution known as WHA68.20: *Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications*. This resolution is tremendously important in that it calls on all member countries to address epilepsy seriously by developing and implementing national plans of action. Despite this global declaration, none of the countries in Africa have developed an epilepsy national plan. There has been no political response nor has there been any financial investments in programs that could reduce the epilepsy treatment and knowledge gap at the country level. Previous international agreements like the African Resolution on Epilepsy (2000) were also never adequately implemented, despite research in some countries, such as Zimbabwe and Senegal, showing that the costs of managing epilepsy in resource poor settings were quite minimal.

The Africa Regional Executive Committee (AREC) has secured \$65,000.00 from BAND Foundation for the implementation of projects to advocate for the implementation of the Resolution WHA68.20. Initially, five countries will be selected to run the project. **This call is asking for chapters to express an interest in the project by 31 August 2018.** Those countries that show interest will be asked to submit full proposals. The projects are expected to begin this year and end in 2019.

Project goals

The overarching goal of this proposal is to reduce the epilepsy knowledge and treatment gaps in Africa. This goal will be achieved by providing IBE chapters in Africa with the tools to develop and execute country specific national action plans to implement the WHO Epilepsy Resolution (WHA68.20).

Funding and benefits of participating

For each selected country the project will provide \$3600 salary contribution for Liaison/Advocacy Officer, \$600 for workshops, reimbursement for administration costs related to the project. Advocacy Officers will be trained and mentored and will receive support from a Project Officer and a Project Steering Committee. The project provides an opportunity for associations to build capacity of their advocates, build advocacy networks and help their governments develop action plans.

Eligibility

All chapters of the IBE in Africa.

What to include in the expression of interest?

Write a ONE-PAGE letter on your letterhead using the following headings:

1. Our organization (brief history, vision or mission).
2. Our current programs (include how the WHO Resolution is being implemented in your country and challenges, if this applies to you).
3. Our current staff (include board/committee/volunteers).
4. Our willingness and capacity to implement an advocacy project.

Email your letter to ibeafrica@gmail.com before 31 August 2018.

What happens next?

After you submit your application, it will be acknowledged. A decision will be communicated by 14 September 2018. Full applications will be due on 28 September 2018. Successful applicants will start their projects from October 2018

In the next issues of the newsletter, we will talk about training project in Zimbabwe, conference in Cameroon (see picture) and information about previous epilepsy congresses in Africa.



REPORT FROM SIERRA LEONE

By Max Bangura

EPILEPSY ASSOCIATION OF SIERRA LEONE

(EASL)



Third Quarter Narrative Report

1. Introduction

The Epilepsy Association of Sierra Leone (EASL) is currently implementing a component of its strategic plan 2017 to 2020 entitled - 'Improving Access to Treatment and Support for People with Epilepsy in Sierra Leone.' This plan aims to directly transform the health status of 6,000 people with epilepsy in Sierra Leone through the promotion and facilitation of access to treatment, and enabling those affected to increase their participation in society.

This report summarizes work done and achievements (outputs) made for the period covering April to June 2018 presented under the following broad categories: Clinical management of epilepsy, Community Awareness-raising and sensitization, Community mobilization, Epilepsy peer support groups and School action on epilepsy.

2.1.1 Clinical management of epilepsy action

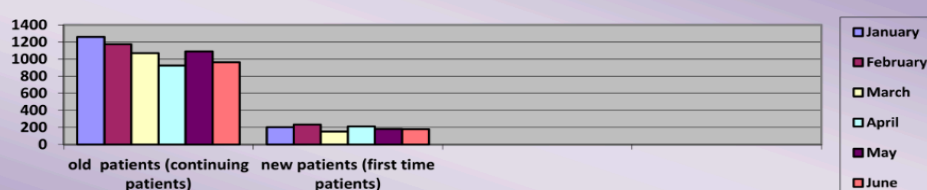


Figure 1: Chart showing patient attendance to all (22) EASL clinics in Sierra Leone

The chart above demonstrates to some extent the clinic attendance behavior of both old (continuing patients) and new (first time) patients that come to the clinics managed by the Association in order to access their anti-epileptic medication for seizure control for six months (January to June, 2018). The chart covers attendance for the 3 hubs in Sierra Leone, namely, the Freetown hub, Bo hub and Koinadugu hub. The actual total attendance for new or first time patients to all the clinics for April 211, May 182 and June 179 for new / first time patients respectively and for old /continuing patients, April 924, May 1,090 and June 963 respectively. This chart also demonstrates that we are retaining to some extent old and continuing patients while we are attracting new and first time patients at an approximate rate of 200 patients a month seen over a period of 6 months.

2.1.2. Community Awareness-raising and sensitization

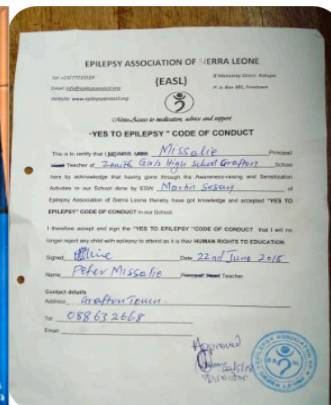
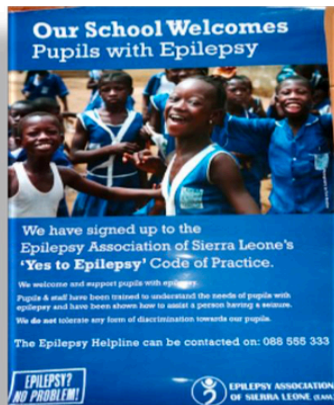
Community awareness and sensitization is primarily done through radio talk shows, faith based events (mainly churches and mosque services), community public events, community visits and home visits. In the period between April and June, 3 radio discussions were held for the 3 hubs (Freetown, Bo and Koinadugu), with 7 radio discussion participants, 1,767 persons were reached in 15 churches and 6 mosques benefitted from talks on epilepsy with 229 persons in attendance. Six (6) public events were reached with epilepsy messages with 638 persons attending. The social workers -ESWs paid 11 community visits to various communities and met with 645 listeners. They collectively visited 13 homes and spoke with 54 people.

2.1.3 Community mobilisation

EASL perceives its community mobilization action as a means to stimulate the communities in which mode to participate in a sustainable way to improve on the management of epilepsy and to enhance the inclusion of epilepsy patients into communal activities in order to enhance their collective standard of life. In other words, we try to provide a space for dialogue among persons living with epilepsy themselves as well as with other members of the communities that they live in.



As a community mobilization tool, the "Yes to Epilepsy" Code of practice' poster has been deployed in 92 schools nationwide in June 2018. Heads of schools sign the 'Yes to Epilepsy Code of practice before a poster is pasted on their school wall signaling their willingness to include children with epilepsy inside their classrooms



2.1.4 School action on epilepsy

The main activity with the school action on epilepsy are school visits to conduct school sensitization and awareness raising on the part of the school, mobilize the school to make the school environment welcoming for children and other school members who are living with epilepsy and to enhance the capacity of the children to undertake small projects to raise awareness on epilepsy among the school population.

In the reporting period, apart from 92 schools signing to the "Yes to Epilepsy" Code of Practice', 40 schools were visited during this quarter and 331 teachers and 18,212 pupils listened to presentations on how they can perform first aid on a person who experiences a seizure in school. Also, 15 health met with a total attendance of 175 pupils



School health club in session in a primary school in Koinadugu Northern Sierra Leone (picture above), Making a presentation during the morning devotion (middle picture) and sharing a message in a thatched classroom in Falaba district (picture to the far right)) which is one of the newest district in Sierra Leone.

2.1.2. **Epilepsy peer support**

The Epilepsy Support Group is designed to provide a platform for persons living with epilepsy to meet and share their experiences with one another. It is here too that they discuss coping strategies as well as undertake small projects in income generation.

During the period, the support groups for all the hubs met 51 times with a total attendance of 1,312.



Training in income generating skills as part of the peer support group in the Freetown hub



Epilepsy peer support group working on the groundnut farm in Tonkolili

Please contribute to the newsletter

We are calling for chapters, their groups and members to contribute to the newsletter. You could share this with us: Stories of members showing how they are overcoming epilepsy, Your local newsletter, Questions and Photographs.

We are on social media, join us today

You are encouraged to join these social media groups, and participate, follow, like posts, and comment regularly:

- WhatsApp Group for people with epilepsy and significant others: +260977789042
- WhatsApp Group for professionals interested in epilepsy: +260977789042
- Epilepsy Africa Facebook group: <https://www.facebook.com/Epilepsy-Africa-IBE-516237431779015/?fref=ts>
- Email list: We have three email lists – for social & advocacy issues, for professionals and for associations. To join your preferred list, send an email to ibeafrika@gmail.com.
- Our Twitter account is here tweet to us: [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica)

FUNDING OPPORTUNITY

IBE PROMISING STRATEGIES

PROMISING STRATEGIES PROGRAM

2018

Improving the quality of life for people with epilepsy in resource poor regions



The International Bureau for Epilepsy (IBE) is committed to finding new and innovative solutions to the problems impacting people with epilepsy and their families world-wide. As part of this commitment, under its Promising Strategies Program, IBE has been providing a limited amount of financial support to IBE chapters on a competitive basis for initiatives aimed at improving the quality of life for people with epilepsy in resource challenged countries or regions.

In the 12 years since it was established, Promising Strategies has provided US\$350,000 in funding to 83 projects in 37 countries. We are now pleased to announce the start of the next selection process, with successful projects being announced in January 2019.



This initial call for Letters of Intent invites IBE chapters to indicate their interest in submitting a proposal for consideration. As a first step, chapters should send a Letter of Intent to arrive at the IBE office no later than 15th September 2018. Successful candidates will then be asked to provide detailed proposals based on a Request for Proposals (RFP).

Please be aware that this is a competitive announcement and that only a very limited number of proposals will be funded based on overall merit as a Promising Strategy.



Members in developed countries may like to be involved in Promising Strategies in a supportive role.

This could be through the voluntary provision of technical support, staff training, or the provision of materials or equipment.

If this is something that is of interest to your association, please let us know.



Award process

Proposals will be scored by the IBE Executive Committee using 'blind scoring'. Two proposals will be selected to receive US\$5,000 each in funding. Applicants will be informed of their selection no later than end of January 2019. Please direct any queries to IBE at the address indicated below.

International Bureau for Epilepsy

7 Priory Office Park, Stillorgan Road, Blackrock
Dublin A94 FN26, Ireland
Email: annlittle@ibe-epilepsy.org

IMPORTANT DATES

Letter of Intent closing date:
15th September 2018

Announcement of approved Letters of Intent and Request for Proposals (RFP):
30th November 2018

Deadline for receipt of RFP:
30th December 2018

Announcement of successful proposals:
21st January 2019