



EPILEPSY AFRICA NEWS

Issue 10

June 2018

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

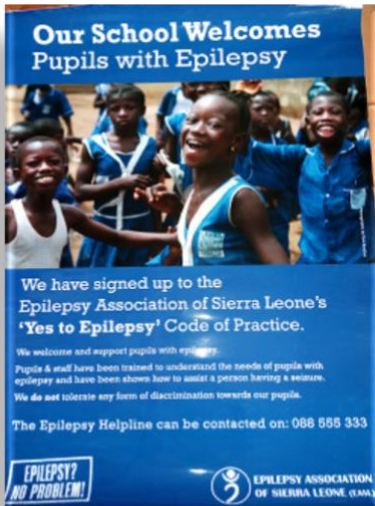


Image left: Epilepsy awareness in Sierra Leone. See report in next issue.

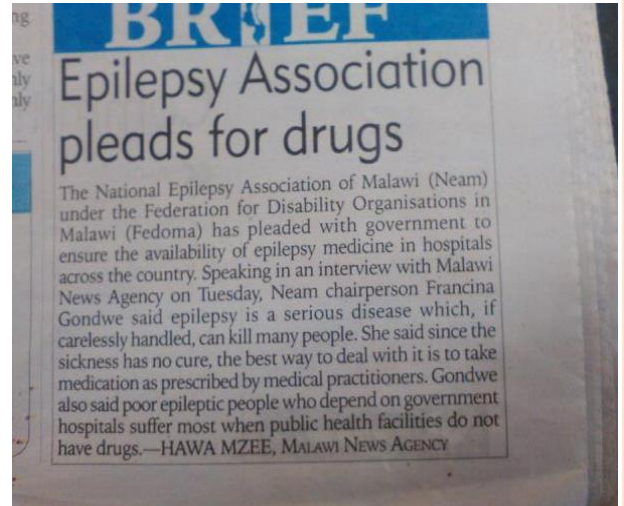


Image right: IBE member chapter in Malawi, the National Epilepsy Association, pleads with government to ensure the availability of medicine. The AREC has developed an advocacy project funded by the BAND Foundation to strengthen efforts like these.

Epilepsy Day	11 February 2019
Purple Day	26 March, 2019
4th African Epilepsy Congress, Kampala, Uganda	22-24 August 2019

<p>Contents of this Newsletter</p> <ul style="list-style-type: none"> • Youths projects: results and feedback. • Advocacy project information. • Epilepsy day. • Poster for epilepsy day.
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<p>About this newsletter: Editorial team: Jacob Mugumbate; Youssouf Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. Frequency: Monthly Distribution: Email and other social media. Email contributions to: ibeafrika@gmail.com. Enjoy your reading!</p> <p>How to join us:</p> <p>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. 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 ibeafrika@gmail.com.</p>
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Chairperson & Editor's message

This is the 10th issue of Epilepsy Africa newsletter. In this report you will find information about projects that were submitted by young people with epilepsy. You will also find reports from chapters and what to expect at the 4th African Epilepsy Congress to be held in Uganda from 22-24 August 2019. You will also find information about the Africa Epilepsy Advocacy (AEA) project. I want to encourage you to contribute to this newsletter by sending an email to ibeafrica@gmail.com. Enjoy your reading. *Jacob*.



Results for Young people with Epilepsy Support (YES) projects

The results of the YES project funding applications are now out. We received 11 applications from 9 countries. Most of the applications were of a high quality. In selecting those to fund in this round, we tried to balance regions, gender and type of projects. There were basically two types of projects, income generating initiatives (livelihoods or capacity building) and awareness activities. Sadly, we could not fund all of them and only 5 will be funded this time. We anticipate to fund the remaining projects in future starting in October this year. We will use the same projects for those who did not get funding this time around so there won't be any need to re-apply.

Country	Project type
Zimbabwe	Awareness
Kenya	Awareness
Kenya	Seedlings (Income Generating Project, IGP)
Malawi	Awareness
Mauritius	Green Garden – IGP/capacity building
Sierra Leone	Training (African Necklaces & Bracelets) - IGP
Cameroon	Soap making - IGP
DRC	Awareness
Zimbabwe	Awareness
Zambia	Training (Poultry rearing) - IGP
Rwanda	Tailoring - IGP

Before funding is made available, winning applicants are required to:

1. Provide a one-page document showing implementation plan, reporting plan and invoices/quotations. Implementation plans will include a few clear activities (three will do). Reporting plan can include photos, video, receipts, short write-up, publicity material plan (newspaper, radio or tv or YouTube or twitter or Facebook etc).
2. All projects that will involve training must submit their training manual so that we share with other countries.
3. All projects providing awareness must share their awareness document/resources so that we share with others.

4. Provide banking details.

The names of those who were funded will be published in the next newsletter because communication with them is ongoing.

AFRICA EPILEPSY ADVOCACY (AEA) PROJECT

PROJECT TITLE

Making Epilepsy a National Priority in African Countries

BACKGROUND

Epilepsy: an overview

Epilepsy is a common brain disease that affects people of all ages and in all parts of the world. More than 50 million people have epilepsy worldwide and three-quarters live in low-middle income countries. Epilepsy is characterized by recurrent seizures and though many causes are unknown, some of the known causes include: brain damage from peri-natal injury, head injury, stroke, brain tumours, neurological infections and genetics.

There are approximately 10 million people living with epilepsy (PWE) in Africa. While epilepsy can be a devastating and chronic condition, with basic treatment, more than 70% of cases can be controlled with one drug. Tragically, in Africa epilepsy is terribly misunderstood, deeply stigmatized, dramatically underfunded and most often ignored by the health care system. Over 75% of people in Africa with epilepsy live in rural and semi-urban areas where treatment is nearly non-existent. Knowing that there are affordable drugs and effective, low-cost programs it is especially egregious that people with epilepsy in Africa continue to suffer.

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.

OUR FUNDING REQUEST

Many African patient and family-based organizations are now organized and motivated to meaningfully change epilepsy understanding and treatment on the continent. These organizations are part of an international network called the International Bureau for Epilepsy (IBE). The IBE supports member chapters across the world to work collaboratively with professional and governmental partners to improve epilepsy care at the county level. Unfortunately, the capacity of such chapters in Africa is limited, yet there is a strong desire by these member chapters to build their infrastructure in order to narrow the knowledge and treatment gap.

The BAND Foundation has invested USD\$65,000 over 18 months to implement the first phase of a multi-year project. This initial support will strengthen the capacity of 5 African IBE chapters located in East and or Southern Africa. It will give these 5 chapters the tools and training to gather information to conduct a situation analysis and to form a national epilepsy coordination committee. In phase one of the project, each of the 5 chapters will develop a national action plan.

THE INTERNATIONAL BUREAU FOR EPILEPSY (IBE)

Our Mission

The International Bureau for Epilepsy improves the social condition and quality of life of people with epilepsy and those who care for them. We have a vision of the world where everywhere ignorance and fear about epilepsy are replaced by understanding and care. Established in 1961 and headquartered in Dublin Ireland, the IBE is an international organization (NGO) for national epilepsy organisations (IBE chapters) that exist to provide support for a strong global network, encourage the development of new chapters in underserved areas of the world, and to encourage communication and collaboration among all members so as to meet our mission and vision.

Our members are patient/family focused and driven organisations and we work collaboratively with our professional and government partners worldwide.

Our strategic priorities are to ensure that epilepsy is recognized as a health priority worldwide; that the human and civil rights of people with epilepsy are enhanced and protected where they might live; that people with epilepsy are empowered to maximize quality of life; and that research into prevention, treatment, care and consequences of epilepsy are promoted.

We work to achieve these priorities through a range of programs including: public information and health education; advocacy; international best practice exchange and helping build communities of care.

PROJECT GOALS AND ASSUMPTIONS

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).

By the end of phase one of this project 5 chapters will have undertaken the following activities:

1. Chapters will identify the burden of epilepsy in the country context and identify key stakeholders who will need to be contacted and engaged.
2. Chapters will gather information and conduct a situation analysis. A situation analysis provides a thorough understanding of the needs and resources available related to epilepsy in the country, and the coverage and quality of essential treatment. It helps identify any strengths and weaknesses of the current system and any barriers to expanding services.
3. Chapters will identify and inventory human, financial and material resources.
4. Chapters will engage partners at the local, national and regional level for strategic linkages and collaboration. Examples of such partners include ILAE chapters, disability groups, other NGO's, policy makers, elected officials, ministries of health, ministries of social development and the local and regional WHO office.
5. Chapters will form a national coordination committee responsible for the development and implementation of an action plan with goals and timelines.

Assumptions

Key to the success of this initiative are the following assumptions:

1. The epilepsy knowledge and treatment gaps can be reduced through the development and execution of a well laid out national action plan.
2. Associations of people with epilepsy, their families, and professionals have a significant role in advocating for a national epilepsy plan to be developed, adopted and implemented.

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 issues, for professionals and for associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to ibeafrika@gmail.com.
- Our Twitter account is here tweet to us: [@EpilepsyAfrica](https://twitter.com/EpilepsyAfrica)

In the next issues of the newsletter, we will talk about projects in Sierra Leone, call for expressions of interest for advocacy project, donation of medicines to Kenya and information about previous epilepsy congresses in Africa.

INTERNATIONAL EPILEPSY DAY, 11 FEB 2019

International Epilepsy Day, a joint initiative created by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE), is a global event celebrated annually on the 2nd Monday of February, to promote awareness on epilepsy right around the world. With IBE and ILAE representation in more than 120 countries, this is a powerful opportunity to highlight the problems faced by people with epilepsy, their families and carers, in every region of the world.

This is a day for everyone and every organization:-

- no matter where you are
- no matter how small your group or how wide your geographical spread
- no matter whether your focus is on the medical or on the social aspects of the disease

International Epilepsy Day is the opportunity for all stakeholders to join together and speak with one global voice. The objectives for International Epilepsy Day are:

- to raise awareness of the disease at international and government level as well as in the general public
- to strengthen the epilepsy movement by uniting epilepsy associations in a worldwide campaign
- to raise visibility on epilepsy and encourage discussion about epilepsy
- to provide epilepsy associations with a significant fundraising opportunity

See poster on next page. Please print for your notice board.

INTERNATIONAL EPILEPSY DAY



#EPILEPSYDAY

Monday, 11 February
International Epilepsy Day 2019

<https://internationalepilepsyday.org>