



# EPILEPSY AFRICA NEWS

Issue 13

September 2018

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



*Images: Donation of medication to KAWE in Kenya. Left: Ms. Rosemary Gathara (Program Coordinator-KAWE) receives donations from the Epilepsy Foundation. Right: Ben Slack and Richard Calvette at KAWE's Riruta Epilepsy Clinic.*

## Contents of this Newsletter

- Donation of medication to Kenya.
- Job vacancy: project officer for Advocacy project.
- Poster: Golden Light Awards.

## SAD NEWS FOR OUR REGION

We wish to announce the death of our beloved brother Augustine Mugarura of Uganda (in picture) who passed on Monday, 15th October, 2018. A requiem mass was held on Tuesday, 17th October, 2018 in Kampala, and burial was held on Thursday, 18th October, 2018 in his home village.

The AREC Team sends its heartfelt condolences to the bereaved family and the Epilepsy Support of Uganda.



**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:** [ibeafrica@gmail.com](mailto: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](mailto:ibeafrica@gmail.com).

## Chairperson & Editor's message

This is the 13<sup>th</sup> issue of Epilepsy Africa newsletter. In this report you will find information about the donation of medication to the epilepsy association in Kenya, KAWE. The report was prepared by Thelma Njamwea and I wish to thank her. The medication was donated by Ben and of the Epilepsy Foundation in the USA. You will also find information and posters for distribution. I want to encourage you to contribute to this newsletter by sending an email to [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com). **Epilepsy awareness is very important in our African region. Remember to prepare for International Epilepsy Day, 11 February 2019 to increase awareness of epilepsy and reduce stigma.**

Enjoy your reading. *Jacob.*



## Donation of medication to Kenya



REPORT ON THE VISIT BY REPRESENTATIVES FROM THE EPILEPSY FOUNDATION NORTH/CENTRAL ILLINOIS 18-24 MAY 2018.

*Written By: Thelma Njamwea, Project Officer Assistant, KAWE, 28/5/2018.*

In line with the mission to improve the quality of life for people living with epilepsy, KAWE partners with various stakeholders both local and international. With this in view, KAWE had the privilege of hosting Mr. Ben Slack (Executive Director) and Mr. Richard Calvette (Service Coordinator) of Epilepsy Foundation North/Central Illinois. The aim of the visit was to inform the representatives on the epilepsy work that KAWE is involved in and strengthen the partnership.

On 18th May 2018, they made a visit to KAWE office and met some of the staff. After an introduction and pleasantries, the Epilepsy Foundation made a donation of 2 boxes of epilepsy medication\*. Afterward, a schedule for the next week's activities was agreed on.

On 21st May, a meeting was held at the KAWE office where Mr. Slack and Mr. Calvette met the KAWE team. It was not only an informative meeting but an avenue where ideas and suggestions were made to improve efforts towards epilepsy management.



*Picture to the right: This is my epilepsy story: The Njoroge family*

The following are highlights from the meeting:

- Staff shared the KAWE brochure that highlighted KAWE history and programs. With regards to health care, Mr. Slack hoped that more drugs in future could be donated to enable more patients access medication. He cited delays in importation clearance as a challenge. Further discussions are to be held with Dr. Miyanji.
- They took note of the Fafanuka project and how easily one can get epilepsy information on their mobile phones. They are considering ways they could initiate the same/similar project. They hope that Dr. Miyanji could be invited to speak on the project in one of the epilepsy conferences.
- To raise awareness of various awareness and fundraising initiatives, both teams were willing to assist with sharing the same through various channels like online/ social media platforms.
- Epilepsy medical training content; Ms. Judy Kariuki (KAWE Medical Manager) briefly highlighted contents that are covered in training of primary health care workers. Mr. Calvette also shared training content. This was in efforts to exchange ideas and highlight issues/ needs that both teams experience during training and find approaches to handling them.
- KAWE has faced challenges in funding of the public awareness project since February 2018. A donation of Ksh 10,000 was made towards this program by the Epilepsy Foundation. It was noted that while in Kenya, schools are receptive and in some cases request for epilepsy awareness sessions, in the United States, majority of the requests were made on a need to know basis perhaps after a child has had a seizure in class.
- A donation of about 50 children's comic books was received by KAWE.

They were then invited to the clinics on 23rd and 24th May 2018 to witness the KAWE clinics model.

At the clinic they were able to assist with registration of patients, dispensing of drugs, interacted with the patients on a personal level and they distributed epilepsy awareness comic books to patients.

A home visit was arranged with the family of Tenorio Njoroge. The family was able to relate how father and son are living with epilepsy. The family was able to share the challenges and successes over a warm cup of tea in their home in Kabiria.

KAWE was privileged and honoured to host Mr. Slack and Mr. Calvette who demonstrated humility, diligence and generosity towards KAWE and its patients. We are confident that such collaborations enable us to improve our services, gain new insights to improve on old methods and chart new paths.



*Mr. Richard Calvette counting medication for drug dispensing*





Mr. Slack (seated on the left) and Mr. Calvette (standing) handing out a comic book to Alphonce, a 4yr old KAWÉ patient



Left: At the Riruta Epilepsy Clinic. Right: Mr. Slack registering patients for their appointment



Left: Reaching young minds through comic books. Right: Ms. Rosemary Gathara (Program Coordinator-KAWÉ) receives donations from the Epilepsy Foundation

\*The Pharmacy and Poisons Board (PPB) Kenya, needs to approve the donated drug first for it to be issued.

# Africa Epilepsy Advocacy (AEA) Project

## VACANCY ANNOUNCEMENT

### **JOB DESCRIPTION**

**Position:** Project Coordinator (PC)

**Project:** Africa Epilepsy Advocacy (AEA) project

**Location:** Nairobi, Kenya

**Type:** Fixed term, fulltime, 15 months contract.

**Reporting to:** Chairperson (AREC and Project Steering Committee, PSC)

**Supervising:** Liaison Officers (LO).

**Salary details:** Will be disclosed to shortlisted candidates.

**Project sponsors:** BAND Foundation and International Bureau for Epilepsy (IBE).

**Closing Date:** To be advised

**Contact:** [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com)

**Duties:**

1. Generally, to promote implementation of the WHO Resolution on epilepsy in the region with a focus on 5 selected countries.
2. Overseeing the regional office in Nairobi, Kenya.
3. Training, supervising and coordinating LOs.
4. Submitting reports to Chairperson.
5. Coordinating the regional communication strategy (website, newsletter, etc.).
6. Coordinating PSC meetings or workshops.
7. Coordinating fundraising work for the region.
8. Coordinating needs and situational analysis.
9. Engaging with regional stakeholders from NCDs, Disability, Mental Health, etc.
10. Any other duties as desirable or agreed from time to time.

**Minimum requirements:**

11. Bachelor's degree in social science disciplines, health or related fields.
12. Proven experience of work in related field.

**Selection criteria:**

1. Demonstrated understanding of epilepsy.
2. Demonstrated understanding of the African region.
3. Experience working in related environment.
4. Suitable qualifications.
5. Proof of suitability and willingness to work in Kenya.

### **SUBMISSION INFORMATION**

**What to include in your application?**

1. Cover letter (not more than 1 page). Include your expected salary.

2. Your CV (not more than 3 pages). Include your qualifications, work experience and traceable references.
3. Statement addressing the selection criteria (not more than 2 pages).
4. Proof of identify and suitability to work in Kenya and travel in Africa.
5. Supporting documents (not more than 5 documents).

### Submission instructions

1. Combine all your documents into one PDF application document.
2. Email your attachment (one document) to [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com).
3. The subject of your email must be **Application for Project Coordinator Position**.

### What happens next?

After you submit your application, it will be acknowledged. Our decision will be communicated by within a month. Online or tele interviews will be held for shortlisted participants in October/November 2018. The successful applicant will start work in November/December 2018.

## PROJECT DETAILS

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. 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).

## 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](mailto: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 our human rights project in Mauritius, the advocacy project and other issues. Please feel free to submit articles.**

## **IBE Promising Strategies Funding**

Remember to submit a letter of intent before 15 September 2018 to [annlittle@ibe-epilepsy.org](mailto:annlittle@ibe-epilepsy.org). Let us know if you need help. PLEASE SEE POSTER ON NEXT PAGE.



# GOLDEN LIGHT AWARDS

The Golden Light Award honours young people with epilepsy who have been a 'shining light' for others and deserving of recognition. First introduced in 2004, the awards have been presented at each Asian Oceanian Epilepsy Congress since then. Now we plan to roll them out at the other regional epilepsy congresses, in which IBE is a partner in the African, Eastern Mediterranean and Latin American regions. The awards recognise the fact that people with epilepsy should not be defined by their condition but, instead, embrace the call of the IBE to 'bring epilepsy out of the shadows and into the light'.

## CANDIDATES

Candidates must be under the age of 35 years in the year in which the award is presented and must submit a short, written article telling their story about living with epilepsy. Those with the three best submissions will be invited to present their story during the Epilepsy and Society Symposium, that will take place during the relevant congress. They are also posted on social media and on the IBE website to highlight success in the face of adversity.

All candidates selected for a Golden Light Award will be presented with a trophy and scroll during the opening ceremony at the congress.

## NOMINATIONS

Each IBE chapter in the region in which the congress is taking place may nominate one recipient for the award bearing the following in mind:

- Contribution to community service
- Support for people living with epilepsy
- Individual achievement (personal, professional, educational, sporting, creative)
- Advocacy for epilepsy (community, political, media)
- Distinguished service to a local epilepsy support organisation

## PRIZE ENTITLEMENTS

In addition to the trophy and scroll, each candidate will receive support for travel to the congress in which the award is being presented, hotel accommodation, and free registration to the Epilepsy and Society Symposium.