



EPILEPSYAFRICA NEWS

Issue 17

Mar-Apr 2019

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



Images: Supporting children with epilepsy in Eswatini/Swaziland

We now have a website, developed as part of the advocacy project <https://epilepsyafrika.org>

Contents

- Editor's message
- Inte. Epilepsy day reports
- Reports from Eswatini
- Golden Light awards results
- Youths project report from Zambia

About this newsletter: Editorial team: Jacob Mugumbate; Youssouf Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** Once in two months **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. **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.

Our website: <https://epilepsyafrika.org>

Chairperson & Editor's message

This is the 17th issue of Epilepsy Africa newsletter, now published once in two months. In this report you will find information about the advocacy project funded by the BAND Foundation. The exciting news is that we have contracted Ms Justine Engole to coordinate the project. The project is based in Nairobi, hosted by KAWE, the epilepsy association there. The office will work mainly with five associations that are piloting the advocacy program but in future we want it to work with all associations in the region. So, I wish to take this opportunity to introduce Ms Justine Engole. Ms Engole was employed by the epilepsy association in Uganda, ESAU before we appointed her through competitive interviews. You will hear more about the advocacy project, including a workshop held recently in Nairobi in future issues. Elections for Vice-President/Chairperson are currently ongoing and more information will be provided in the next issue. As some of you already know, I have not made myself available for re-election. It is my hope that the region will elect someone who share a vision of building capacity of our region. In this issue, you will also read about the important work happening in Eswatini. The outcome of Golden Light nominations is out, and you will read about the applications from Africa. Lastly, I want to encourage you to contribute to this newsletter by sending an email to ibeafrica@gmail.com. Enjoy your reading. *Jacob*.



Correction

In our previous edition of the newsletter, it was mentioned that Cameroon received funding for the youth with epilepsy project in 2018. We wish to state that Cameroon did not receive funds in 2018 but 2017. We regret the inconvenience this error might have caused.

International Epilepsy Day awareness project for Africa

The AREC has provided \$1500 each to Cameroon and Eswatini to produce awareness material for the regional in multiple languages. Congratulations to Mr. Kenneth Nsom and Mr. Mbuso Mahlalela, the leaders of these associations.

We now expect these projects to be funded before the end of this year.

International Epilepsy Day (IED) 2019

This year, we had several activities to mark IED 2019. In this issue, we will feature activities from Sierra Leone and Zambia (next 3 pages). Reports from around the world are available from the IBE website here: <https://internationalepilepsyday.org/wp-content/uploads/2019/03/IED-Report2019.pdf> as well as in the latest newsletter available here: <https://www.ibe-epilepsy.org/international-epilepsy-news-issue-1-2019/>

Activities in Sierra Leone

There was a month-long awareness campaign.



STATEMENT BY THE HEAD OF TRADITIONAL HEALERS



PA Unisa F. Fofanah thanked EASL for treating them as people very important in the health sector. He said the orientation provided over the years have helped them to understand the dangers associated with the healing method they have been using to cure/control epilepsy. He stated that they have held meetings with traditional healers with the aim of controlling the use of traditional methods to cure epilepsy. He accepted that fact that they have been using a whole lot of methods to help people with epilepsy but this has not been working. He told the gathering that he and his team are now convinced that epilepsy is a medical condition considering the successes the medication has scored over the past year. He concluded by saying that they will continue

to work with EASL, the medical personnel to ensure that persons with epilepsy get the best of treatment by way of referral. They will also work with traditional leaders to help fight against provocation and discrimination in the communities as they are the first point of call.

TESTIMONY BY HASSAN BARRIE'S MOTHER

The mother thanked God for his son and EASL for what the Organization has been doing in the district. She narrated the story that her son was at attending at the Islamic Bankolia where he had a seizure. They called her immediately to the school; she met him in a sad state. Everybody including the teachers had deserted him. Madam Kamara carried Barrie on her back and took him home. An old woman close to our house said her son was borne with a hat which has been removed from him that is why he is now suffering from

epilepsy. The old woman claimed to have seen this for a very long time but couldn't sum up the courage to tell Barrie's the mother.

'My son suffered seizure after seizure in school, so one day I wanted to take him to the hospital but was admonished that the disease is not a medical condition. I took him to a village called Seredugu. He was there for three months without improvement, scares all over his body, received very little attention and no medicine. I spent well over three hundred thousand Leones excluding food. I took him to more than five traditional healers, in villages and even Kabala town ship. I have no money and the market is gone trying to save my child. I have sold all of my valuable possession. The money I used to do my marketing she said. She told the people that she met Mr Tucker who admonished her to stop taking the child to all the different traditional healers and concentrate on the clinic. 'I did all what I was told' she said; she was given some drugs and educated her on how to administer the drugs, care taking etc. Two months after taking the medication, my son has not only stopped have seizures five or ten times a day, but the scars on his body have completely gone. S o I say thanks to EASL and God for the improvement.

SUCCESS STORY BY MARIAMA JALLOH

This is Mariama's (pictured) testimony:

'Good morning my fellow pupils, I am also a victim of epilepsy. I got the condition when it was almost two weeks before I took my Basic Education Certificate Examinations called BECCE. It was one night when I was lying in the parlour that I got the attack. My friends deserted me since I got the attack, no friends, everybody went far away from me, because they had the feeling that the disease is transferable, that if someone steps on the spittle of an epilepsy person he/she will also contract the condition. My parents took me to many traditional healers each with his diagnosis- some said I have a demon, others said I was bewitched, while one traditional healer said I have something to say. My mother told me that I did not cry when I was delivered and so she has to beat and pinched me before I could cry.'

Mariama told participants that people are with the notion that a woman with the condition would not give birth because the sick will transfer to the child through breast feeding. 'I am glad to inform you all that it is not true because I have a son'. Finally, she thanked God for the arrival of Mr Yavana the Epilepsy Support Worker in Bo. He encouraged me, gave me hope that as long as I continue to take the medicine things will be fine. I thank God now she ended.



The Chikankata Epilepsy Care Team (ECT), a department under Chikankata Mission Hospital in Southern Province of Zambia founded in 2000 under the leadership of Professor Gretchen Birbeck, commemorated International Epilepsy Day 2019 on 11th February. The day was commemorated under the theme: ***Educating the Public about Epilepsy, Seizures and Social Stigma.***

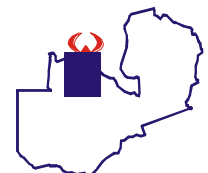


The event was preceded with a match past from the Hospital to the nearby (~1 km) school. Chikankata Day Secondary school hosted the event. The day was characterized by poems, role plays, dances by different drama groups from both local and out of town.



A detailed history of how the Epilepsy Care Team came to be was given at the function and so was a detailed health talk on epilepsy. The talk included facts about epilepsy, the causes of epilepsy, what treatment is available, epilepsy not being contagious, types of epilepsy etc.

See report on a project being run by young people with epilepsy in Zambia from page 7.



Upcoming: 4th African Epilepsy Congress, 22-24 August, Uganda

A person with epilepsy narrated how she has lived with the condition for over ten years. She went further to explain how she lost her first marriage due to having continuous seizures, and how medication has helped her control her seizures. How she got married again and is living a happy life. She advised the general population on how to care for a person living with epilepsy.



Chieftainess Mwenda (Ellie M. Kalichi, Nurse by profession) graced the occasion. She was invited as guest of honor. She expressed her pleasure in seeing a Project (ECT) that she worked for at its inception flourish to this stage. She ended her speech by thanking the funders of the project and urging the Zambian government to support such projects.

Other members present in the gathering where the representative of the Area Member of Parliament, the Acting District Commissioner, the Council Secretary, the Acting Mission Director/Health Services Administrator, the Mission Captain, the Acting Medical Superintendent-Chikankata Mission Hospital, the District Director of Health, Principals - Chikankata Collages of Nursing and Biomedical Sciences and two village Headmen.

As such we urged the pupils to go and teach their parents and siblings what they had learnt on this very special day. Over 200 people were in attendance. Overall, the general public was educated on epilepsy, seizures and dangers of social stigma. We had a colorful purple day!



eSwatini Epilepsy Organization clothing distribution at ka Ndzangu, Mpolojeni Siteki

By Stanley Sangweni

On the 26th of March 2019 the eSwatini Epilepsy Organization visited ka-Ndzangu Area in the Lubombo Region where it donated clothing worth \$ 6905.50. This follows distribution that was done by the organization during its Yellow Epilepsy Half-Marathon at Sikhuphe on the 17th of

February 2019 where a total of 300 children received clothing. The Items were shoes, t-shirts, and shirts.

The National Director Mbusomuni Mahlalela liaison with rural health motivators and royal kraal representative Ganekuseni Shongwe in identifying, orphaned and vulnerable children, people with disabilities, people with epilepsy the aged and the feeble also benefited. This clothing was donated by World Vision eSwatini to the Epilepsy organization in its endeavor to raise funds and material benefits to help the situation of children with epilepsy and disability, mainly in the Lubombo and Shiselweni Regions where epilepsy is more affecting people because of warm temperatures. The National Director also raised awareness through sending key messages and urged people to shy away from myths about epilepsy. He emphasized that, "Epilepsy is treatable, and a result of brain injury. Epilepsy is non-communicable. He further urged anyone who has a family member with epilepsy or know someone with epilepsy to encourage her to visit the nearest health centre. He further mentioned that epilepsy affects anyone, at anytime and anywhere.



Zambia poultry project report

Report by Rebecca Mwale

My name is Rebecca Mwale, leader of the Zambia Epilepsy Poultry youth project. The project was selected to be one of the beneficiaries of the Youth Epilepsy Support (YES) Projects funding under International Bureau for Epilepsy (IBE) in 2018. Immediately after the announcement that our application was successful, my group held a meeting at the Epilepsy Project Site to discuss on how we could achieve objectives to train youths in chicken rearing and advocacy. It was then realized that training had to start with the group involved in conducting the project. Thus, the Executive Committee members of the Association held a training session for us on August 6th, 2018.

We were trained in the following areas:

1. What epilepsy is, diagnosis and treatment
2. Awareness delivery on epilepsy through Effective Communication
3. Brooding and Chicken Rearing
4. Entrepreneurship



The training was attended by eight youths, namely:

1. Rebecca Mwale (Leader – living with epilepsy)
2. Eric Mumba (Living with epilepsy)
3. Joel Nsachilwa (Living with epilepsy)
4. Haggai Nsachilwa (Living with epilepsy)
5. Beatrice Bupe (Living with epilepsy)
6. Rose Mwanza (Living with epilepsy)
7. Cindy Zimba (Social Worker)
8. Annie Mwanza (Social Worker)

The speakers were:

1. Ms. Betty B. Nsachilwa - Topic: What Epilepsy is and Campaign Guidelines
2. Mrs. Leocardia Miti Mukamo – on Brooding and Chicken Rearing
3. Mrs. Monde Kampala – Entrepreneurship

1. What Epilepsy is, Diagnosis and Treatment:

The group was enlightened on the causes of epilepsy, diagnosis and treatment. This information was timely because some of the members were newly diagnosed with the condition and the topic enabled them to understand epilepsy in detail. The topic was extremely interesting ensuing into a lengthy discussion with questions from participants as they wanted to fully understand their ordeal and why they are considered differently by society or family members

2. Campaign Guidelines on Effective Communication

This topic helped all to know why it is important to disseminate information on epilepsy and allow society to accept epilepsy as a common neurological condition that is treatable. It also helped us prepare a campaign, while keeping in mind the type of audience one is addressing. (Notes on the topic attached as Appendix I)

3. Brooding and Chicken Rearing

The speaker, former Youth Leader for the Epilepsy Association, Mrs. Leocardia Miti Mukamo gave details on how to budget for a poultry project, preparing a poultry house and all the necessary care to be given to the birds. Slides were shown on this topic

4. Entrepreneurship

Ms. Monde Kampala, a business lady, taught the group on how to explore the market for competitors, costs and opportunities before engaging into any business venture. The poultry business in Zambia is very common and all that is needed is being focused on what one is doing to succeed.

Through this topic, my colleagues and I were enlightened on how to keep a simple sales book, to record how money has been spent against what is gained through sales and to see if there is any profit or not.

Most of all, to engage partnership with other experienced similar business venture players.

To take advantage of the Government established Youth Development Programmes that help youths come up with Small and Medium Enterprises (SMEs). The Government of the Republic of Zambia, through the Ministry of Youth and Sport, its implementing agencies, including the National Youth Development Council, Youth Development Fund, Zambia Development Agency, the Citizens Economic Empowerment Commission and National Technology Business Centre, is interested in assisting youths to be empowered and find gainful occupation by 2020.

Photos: Rebecca and Lubinda holding dressed chickens



Outcome

1. My group decided to turn the project into a fundraising venture by buying already fully-grown chickens, dressing them and selling the same at the Project Site.
2. A shop and deep freezer has been allocated to the project by the Association.
3. Members of the project have assigned days to sell the dressed chickens.

Conclusion

Considering the high cost of rearing chickens due to the current down trend of the Zambian currency against the US Dollar, the committee decided just to be buying and selling already grown chicken till sufficient funds are raised then our team will start rearing chickens as per the original plans. Consultation was made with the Chairman who agreed with the proposal. A financial report will be prepared as soon as the business is fully functional. I am so happy doing something so far and not worried all the time about my condition. I used to be extremely quiet, thinking about my welfare and what others think about me. However, the Youth Epilepsy Support project has already shown from inception that I am a changed person. I also wish my colleagues would feel the same. I hope to see a success of my project soon.

Youth projects applications - results

After careful consideration, the following projects were selected for funding:

1. Rwanda – pig farming
2. Cameroon - Community inclusion of persons with epilepsy in Nseh village.
3. Sierra Leone - To train 10 youths living with Epilepsy in making paracord bracelets, Africana cord necklaces and stone bead necklaces as a means of their income-generating activity and sustenance

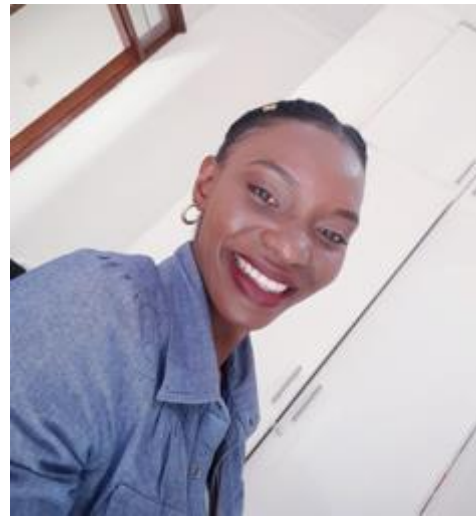
We wish to thank the IBE for funding these projects and wish these associations the best as they implement their projects. It is our wish as AREC to fund more small projects, costing about USD200 each but we do not have adequate resources. Any support from well-wishers would be very welcome.



More information: <https://www.ibe-epilepsy.org/wp-content/uploads/2019/05/Issue-1-2019.pdf>

The IBE has announced winners for the Golden Awards. You can get further information by following the link above. Two applications were received from Africa. We would have wanted to see more applications from our region. The two applications were from Fredrick Beuchi Mboya in Kenya and Nina Mago from Uganda (both pictured below). They applicants detailed the kind of work they are doing. They all had very

powerful stories to tell. Unfortunately, only one person could be selected. The person was Nina Mago. Congratulations Nina Mago and best wishes in future to Fredrick Mboya. Nina Mago will tell her story in Bangkok at the 33rd International Epilepsy Congress but we also wait to hear her story in Uganda during the 4th African Epilepsy Congress.



Nina has epilepsy while Fredrick cares for a sister (12 years) with epilepsy. Follow the link below for further information about Nina's work: Purple Bench Initiative: <https://www.facebook.com/purplebenchug>
<https://www.epilepsysparks.com/Epilepsy-Education-Culture-Change-in-Uganda>

Below are links to videos and articles that showcase the work of Fredrick while creating awareness about epilepsy. **Fredrick walked for 482 kilometres to raise awareness about epilepsy.**

<https://www.standardmedia.co.ke/evewoman/search?q=fredrick+Beuchi>

<https://youtu.be/I0s9VEQ93fE>

<https://youtu.be/ULvKuBWTyhs>

https://www.youtube.com/watch?v=YVWmpLmzY_Q

<https://m.youtube.com/watch?v=CHFf61BW8c>

<https://m.youtube.com/watch?v=vPn0wKoC6UE>



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.

In the next issue of the newsletter, we will talk about progress with the advocacy projects and the upcoming 4th African Epilepsy Congress in Uganda. If you visit our website, you will see a new logo for Epilepsy Africa, we will have a description of that logo in the next issue. We will also give a YES project report from Zimbabwe (see photos)



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)
- **At last, we now have a website.** <https://epilepsyafrica.org>

