EPILEPSYAFRICA NEWS

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

Images: Training seminar for field doctors. Photo by Youssoufa

We now have an office in Nairobi, Kenya, what wonderful news!

Contents

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. 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.

Chairperson & Editor's message

This is the 16th issue of Epilepsy Africa newsletter. In 2018 we published 11 issues, then we took the decision to publish once in two months. In this report you will find information about the advocacy projects funded by the BAND Foundation. The exciting news is that we have so far done very well with our advocacy efforts. On 18 February, we opened our new office in Kenya, hosted by KAWE, the epilepsy association there. We did not only open an office, but we have contracted Justine Engole to run the office coordinating not only the advocacy project but the region. Presently, 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 including those registered with the IBE, those seeking registration, those starting, community groups, professional associations and training institutions. We believe, if we work together we will have meaningful impact. 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. Welcome Ms Engole. Lastly, I want to encourage you to contribute to this newsletter be sending an email to ibeafrica@gmail.com. Enjoy your reading. *Jacob.*

New year message

By Grace Moyo *(in photo)*, **Zimbabwe**

The year 2018 was an activity filled year for the International Bureau for Epilepsy (IBE) Africa. As the new year begins it is imperative to reflect on the things that took place during last year. It is notable that indeed, the year was a good one as shall be seen later on in the report. However, we faced our own challenges which are also going to be highlighted in this report as well.

To begin with, the IBE Africa received funding from BAND Foundation to implement the advocacy project on the WHO Resolution on epilepsy in some pilot countries in Africa. This was in a bid to help sensitize countries in Africa on issues to do with epilepsy and thus help lessen the challenges being faced by people with epilepsy in Africa. This was good for IBE Africa as it contributed positively to achieving one of the major goals of IBE Africa, which is to create awareness on epilepsy in Africa.

Also, as the IBE Africa we managed to have monthly publications for the newsletter which contain stories from the different countries within Africa. This was good since it helped in letting people with epilepsy know what is happening in other countries concerning epilepsy. This would encourage others to continue working hard to achieve the goals of IBE Africa.

Moreover, our Chairperson Dr. Jacob Mugumbate and our secretary Miss Betty Nsachilwa attended different seminars, workshops and conferences which enriched their experiences and knowledge. They shared these experiences and knowledge with other members of the Africa Regional Executive Committee who then shared these with other people with epilepsy in their respective countries.

This year, some countries received funding to implement YES projects for youths. These countries include Kenya, Malawi, Mauritius, Sierra-Leone, Cameroon, Zimbabwe and Zambia. Some countries such as Namibia, Swaziland and Rwanda are still working on their applications for funding for the YES projects with hope that they will also receive funding. These projects are meant to help people with epilepsy to be able to support themselves instead of being dependent on other people. However, as has been stated we faced some challenges during the year 2018. The first and biggest challenge was that of the slow responding nature of most of our associations. We are all encouraged to be more active this year.

The other challenge faced is that some projects were not endorsed by their chapters. DRC is one of the chapters that did not endorse the project for their country. We pray and hope that the chapter will eventually endorse the projects. We understand the challenge in that DRC that the contact person has not been in touch for quiteva long time. We hope a solution will be found soon so that our members in the DRC are not disadvantaged as is the current case.

Sadly, during the course of the year we lost our colleague, Augustine Mugarura who was Uganda Epilepsy Support CEO. It was sad indeed to lose our colleague who had made notable contributions to the growth of Epilepsy Africa. May his soul rest in peace.

In conclusion, we thank all the people who made positive contributions for the success of this year. We encourage each other to continue working hard for the success of IBE Africa. God will surely reward us. We are also reminded of important dates this year. These are the International Epilepsy day (11 February 2019) and the Purple day (26 March 2019) as well as the African Epilepsy Congress (August 2019). We are encouraged to prepare for these events to make them successful. We thank everyone for a job well done and we wish you a very happy festive season.

Livelihoods Lessons From Persons With Epilepsy in Malawi

By Action Amos

In the world today it is common knowledge that unemployment is a crisis. Unemployment for person with epilepsy is not an exception in Malawi. They are part of the massive unemployed people. However the problem of unemployed persons with epilepsy is coupled with lot of attitudinal and environmental barriers. Additionally, there is no readily available data to show the number of those not employed. This may not be a reflection of Malawi only but Africa at large.

How are then people with epilepsy making ends meet in Malawi? Malawi is an agro based economy. There is a saying from old times that, “if you want to keep a cow first learn to keep a hen”. Therefore many people survive by cultivating in their own small fields and doing small businesses. These are non commercial activities but “informal employment”.

In this report, I focus on two persons with epilepsy, Lameck and Golden. The selection is biased towards male citizens with epilepsy since females with epilepsy have a double disadvantage that will be reported separately. Many of them (women with epilepsy) cannot sustain themselves due to social barriers that we will also discuss in the future.

Golden, a father of two girls in his mid 30 years has lived with epilepsy for 16 years which he developed whilst he was in high school. Due to ignorance many in his family thought that there was no need to support him for further education hence he dropped school in form three. However a turnaround came through when the umbrella organisation for disabilities in Malawi supported him through National Epilepsy Association in Malawi to enrol in a vocational school and he acquired tailoring skills. He started a “veranda tailoring” work doing dresses for children and eventually adults. This allowed him to start farming and from the proceeds of the first year. Farming led him to opening a grocery shop. Today through the tailoring business, farming and grocery Golden is able to sustain himself and his family.

Lameck has never formally worked in his whole life. He is a typical village boy who has never had any opportunity to go to school due to the frequency of his seizures. He was remaining in the village whilst most young people of his age went to school and eventually leave the village. In 2012 with support from the National Epilepsy Association awareness Lameck started to receive medication. This stabilised his episodes and allowed him to concentrate on generating income through farming as this was the only and most viable livelihood option to him. As we speak Lameck is chairing the District support group and organises receipt of medication to others in the community. The example of Lameck is a booster in the community where he leaves and beyond as initially he was a “write off. He is now married, has 3 hectares of farming field allocated to him by a local chief in Zomba district. The Chief who allocated him the land was one of the people who used to discriminate him based on his epilepsy denying him subsidised farm inputs. Lameck is now in the record books of those receiving subsidy.

The two cited examples are an indication that with a good support base; community, financial and skills persons with epilepsy can sustain themselves. This also highlights that when persons with epilepsy are given an opportunity they can work beyond their perceived limitations. In Malawi as highlighted earlier most people including those without epilepsy are occupied with farming, fishing, handicrafts and any other small piece meal works. The Malawian experience also proves the community can help to develop skills by allowing such ones to have an environment that promotes skills training both in a formal and non formal way. The experience also shows that the best needs of persons with epilepsy can be met in their own setting or environment. Just in many low income settings there is need to be asking questions about the best community and traditional initiatives of family support that can help persons with epilepsy. This will assist in caring for both emotional and financial needs of persons with epilepsy. In Malawi lessons can also be drawn that if a person with epilepsy is assisted they can improve productivity and self-sustenance. This therefore helps the persons with epilepsy not to be dependent upon others and contribute to their wellbeing in a small way. In the Malawian experience persons with epilepsy are role models that motivate others to see the need to adhere to medication thereby stabilising the frequency of their seizures and engage in productive work. When they start to earn an income from small activities this helps others to follow suit.

In summary, it is a fact that self-employment of persons with epilepsy does offer a diversity of opportunities to pursue business enterprise or provide for family at a local level. It is time that we start thinking on village support in terms of skills, social contacts to ensure that there is self income generating activities for persons with epilepsy. The advantage is that they can do something they have passion, aptitude, and competence gained through informal and formal community trainings. This though must be noted that when we talk of livelihoods, it is only one leg among many other opportunities that are available in different environment with the aim of alleviating their lives. Consideration maybe made around group enterprises and pooling of resources and sharing responsibilities. This is yet to be a tested as a way of assisting persons with epilepsy to generate income here in Malawi if not in Africa. Without doubt therefore a lot needs to be done to help persons with epilepsy who have been marginalised economically for a long time.

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.

Youths projects applications

We are calling for applications for 2019 youths projects. Application forms will be available in March 2019. The maximum budget will be $200 per project. To start preparing, below are some ideas of projects that are likely to get funding.

1. Radio or tv program
2. Newspaper article
3. Internet blog, Facebook or twitter page
4. Music project
5. Epilepsy awareness at schools/college or community.
6. Income or enterpreneurship project
7. International or local epilepsy day project
8. Organising meeting with Minister of Health or First Lady
9. Printing and distribution of fliers
10. Youtube project
11. Sports
12. Community workshop or seminar

Choose projects are are:

- Easy to implement
- Quick to finish
- Easy to report
- Now expensive
- Promote people with epilepsy
- Have quick results
- Can be done in other countries
- Are innovative
- Advance the Intetrnational Epilepsy Day
- Advance the WHO Resolution on epilepsy

Email Betty to get more information.

If you stay in a country closer to Uganda or in Uganda, and you can travel there by bus or train, you can apply to attend the 4th Africa Epilepsy Congress that runs from August 21-24 this year. Your application can include conference registration (US$80), transport and accomodation. The maximum you get get is US$200.

International Epilepsy Day awareness project for Africa

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

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 ibeafrica@gmail.com.
- Our Twitter account is here tweet to us: @EpilepsyAfrica

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. We will also get a report from Zimbabwe.

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.