



EPILEPSY AFRICA NEWS

Issue 15

November-December 2018

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



Image: Report inside by Michael Che Kpuh and Kenneth Nsom.

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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!

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 ibeafrika@gmail.com.

Our website is coming soon: www.epilepsyafrika.org

Chairperson & Editor's message

This is the 15th issue of Epilepsy Africa newsletter that combines November and December. In this report, you will read about how the Kingdom of Eswatini is preparing for International Epilepsy Day. Michael and Kenneth have provide us with a detailed report that details how they are dealing with epilepsy in Cameroon. Betty has provided us an update of the advocacy project. I want to encourage you to contribute to this newsletter be sending an email to ibeafrika@gmail.com. Enjoy your reading. *Jacob*.



End of year message from AREC

By Kenneth Nsom, AREC member

The year 2018 has been a landmark in the history of epilepsy in Africa. This is because IBE Africa was lucky to have funding from BAND Foundation to implement the advocacy project on the WHO Resolution on epilepsy in some pilot countries. We thank BAND Foundation for the support. Also, our young persons with epilepsy in Africa also benefitted from their yearly project – YES project from the African Regional Executive Committee (AREC). These projects are usually sought through request for proposals. To the young persons with epilepsy whose projects were selected this year, we encourage you to carry out the projects diligently so that they can create an impact in your lives. We also thank our donors, the IBE for the YES project.

We wish to congratulate all the African IBE members who contributed articles into our newsletters this year; enabling us to be able to produce the newsletter throughout the year. We would also like members of IBE Africa in each country to always contribute so that we can keep bringing epilepsy out of the shadows; as well as giving our work visibility. We would not also forget to appreciate the members of the African Regional Executive Committee – AREC for their enormous suggestions that they made in any decision making as concerns epilepsy issues in Africa this year 2018. Again, some of our AREC members were invited to conferences and workshops abroad such our Chair Dr. Jacob Mugumbate and our secretary Miss Betty Nsachilwa. Their experiences and knowledge were enriched and we thank WHO/BAND Foundation for the WHO meetings and Edycs Mauritius for the invitation on disability and rights workshop respectively. Let's continue to build the capacities and skills of one another as we work.

Nevertheless, the year was not void of challenges. Our greatest challenge remains that of difficulties sorting funds for epilepsy work in Africa. Again, the slow active nature or inertia of most of our IBE member countries in responding to correspondences is also a huge challenge; as it makes our work sluggish, poor and we never meet up with time at the continent level or in our respective country Associations. We are challenged to improve in this area.

One other challenge that we continue facing is the lack of respect of rights of people with epilepsy. Early in the year, Abdullah Matola of Malawi was stoned to death after being accused of being a 'blood sucker' or witch. Abdulla had epilepsy and seizures were confused for witchcraft. Cases such as these are many on the continent. We urge governments to protect people with epilepsy.

During the year, we lost a key member, Augustine Mugarura who was the founder of the Epilepsy Support Association of Uganda (ESAU). Augustine was former Vice-Chairperson of AREC. We would like to wish his family and the ESAU family all the best in these trying times.

As this year draws to an end, we should not forget upcoming events which are very crucial on epilepsy. They are the International Epilepsy Day in February and the 4th African Epilepsy Congress in Uganda in August 2019 respectively. We should prepare well for these events and make them successful and beneficial to the persons with epilepsy and our countries we serve.

One important aspect of our work in 2018 and beyond is advocacy. We are glad to use the WHO Resolution on Epilepsy as the global epilepsy policy in our advocacy work. This enables our work to be truly aligned with that of the WHO, IBE and ILAE. The Resolution has one main objective: to ensure that each country has a policy on epilepsy. This policy will enable each country to fund epilepsy programs and services such as research, training and awareness. In 2019, we will scale up this work by having a regional office in Nairobi, Kenya. We will hire a Project Officer. This is a key step for our region, something that has never happened before. The coordinator will work with 6 countries that were selected to run advocacy projects, but will also work with all other countries in the region including new chapters such as Lesotho and Rwanda and upcoming associations in DRC and Mozambique.

Finally, we urge all members of the IBE African Region to continue to brave the odds on epilepsy as they work. God will surely reward us as He has started. We wish you happy holidays and a prosperous new 2019.

Eswatini: Yellow Open/Public Lecture & School Contest"

By Stanley Sangweni, Corporate Strategy Officer

The Swaziland Epilepsy Organization is preparing for the International Epilepsy Day and has scheduled a sequence of activities towards agenda setting, advocacy and resource mobilization. The Swaziland Epilepsy Organization will host a Public Lecture and a school contest during the epilepsy day. This discussion will set a way forward for areas of research social and clinical research about epilepsy in the Kingdom of Eswatini. Such an exercise will inform our programming for evidence based impact mitigation intervention. It will also enable us to further identify our constituents. Stakeholders in this activity will be the University of Eswatini, 8 schools drawn from urban and rural areas, The non-communicable diseases (NCD) department and NCD stakeholder alliance, the Eswatini National Youth Council. Each school will be given one WHA Resolution 68 to make a presentation on how well each resolution can be attained. They will present their strategies which shall inform our thematic areas in policy orchestration and research design. Find attachment of promotional poster.



Monday, 11th February 2019 is International Epilepsy Day

Start Preparing Now!

**What are you planning to do on this day, please
let us know.**



Find out how you can take part at
www.internationalepilepsyday.org

International Epilepsy Day awareness project for Africa

The AREC has a small budget for international epilepsy day awareness activities. We are asking chapters and individual members to submit a proposal for a project that could raise awareness in the whole of Africa. Ideally, this project must be in at least more than two languages widely spoken on the continent. It could also include collaborations across countries. This project must be implementable between January and 12 February 2018. The budget must not exceed USD3000. The proposal must have a key person.

The key person we are looking for must be:

1. Willing to speak (or sing, do a video etc) about epilepsy before and during International Epilepsy Day in February 2019.
2. Willing to appear in the media such as Youtube, television, radio and newspapers.
3. Ideally, the person should have a following on social media or other, or they must be prominent in their field of work.
4. We would prefer someone who can speak several languages or willing to work with others from other countries. The message we want to sell out, is drafted below.
5. A person who knows about epilepsy or who has epilepsy/family member with epilepsy would be prioritised.

If you know someone who can fit this criteria, please let us know.

Remuneration: Our budget is small, but we will cover all costs and pay a small fee.

Message in several languages: Epilepsy is treatable. But, many people with epilepsy are not on medical treatment in Africa. If you or a family member has epilepsy, go to the nearest clinic right now. If you know someone with epilepsy, ask them to do the same. Support the epilepsy association/group in your country or help form one. Epilepsy results from brain injury so you can't get it from someone. Remember, epilepsy affects anyone, at any time, in any place.

A story about the impact of CODEF's work on epilepsy in Cameroon my family testimony

By Pa Michael Kpuh & Edited by Nsom Kenneth Ninying

Am Mr. Michael Che Kpuh – a retired delegate for fisheries and animal industries in the North West Region-Cameroon. My son had epilepsy at his early childhood which started off like a joke. His epilepsy began with convulsions where my wife and I thought it was fever. So we took him to the hospital and he was tested malaria positive where treatment was administered. He took the anti-malaria medications and we were sure that everything was ok. But when we came home; the convulsions continued and aggravated where they remained on and off.

When he was of school age, we decided to register him into primary school - class one. He was performing barely fairly well in studies and made the usual seven (07) years and completed his primary education. Though he was schooling; the convulsions persisted and we had to rush back to the hospital and were told he had epilepsy. But we did not know what epilepsy is and his physical and psychological being started worsening followed by his mood and behavior that changed too.

With this epilepsy we were not discouraged to sponsor him in secondary education; so he was registered into secondary school. This epilepsy could not still allow him to study and he was only being promoted from one class to another using trial basis. In form four the epilepsy made him to always have incontinence - where he will always urinate on his mates in class whenever the epilepsy occurs in school.

Being a student in a secondary school, the school authorities and his peers were stigmatizing and discriminating him as they tagged him names and this demoralized him. As if it was not enough his peers and his teachers had to keep him seated alone on one bench at the corner of the classroom. At this time his epilepsy had gotten worse and I took him back to the hospital for check-up. The medics had to place him on carbamazepine tablets which could not still help him. The dose was increased to two tablets a day but there was no improvement at all. When we returned home he was barely going back to school and the epilepsy and incontinence became complicated with defecation. Then his school management took a decision to dismiss him from the secondary school where I was informed and this added worries to our

family and we were really traumatized. Our family nearly crumbled due to the taking care of our son and other siblings depending only on my little pension.

When we learnt of Community Development and Epilepsy Foundation – CODEF out-reach activities in Wum District hospital in 2015 from the American Peace Corps Volunteers working with CODEF and other projects in Wum; i decided to meet CODEF and presented our family ordeal to them. They immediately intervened by visiting the school authorities and stressing to the Principal and his four (04) Vice principals that it is the right of any child to be educated. So CODEF held several meetings with the school management and some teachers so that my son should not be dismissed. But the school management gave me one condition - that for them not to dismiss my son; i have to buy napkins and always pad him every morning before he comes to school. Imagine a 17 year old boy moving around with a napkin on his buttons. I followed their advice but it yielded no fruit.

CODEF again intervened and ask him to join the epilepsy mobile clinic activities in Wum District hospital where in collaboration with the doctors of the hospital; CODEF increased the carbamazepine tablets to a higher dose and also was seriously following-up my son on anti-epileptic drugs for compliance. This led to a huge improvement and my boy could not urinate nor defecate during his seizures again. Today my son is a flag boy in their school appointed by the same school authorities that was to dismiss him. His duty is to hoist the school flag every morning during assembly each day of the week. Telling our family story on epilepsy is to motivate you parents with children having epilepsy and countries in Africa to speak out about epilepsy and ring the epilepsy bell through out the world. Also we should try to be part of the education process in CODEF and IBE African region so as to bar the race of stigma and discrimination against persons with epilepsy promote knowledge gap.

Finally, since then I took it as a commitment to be a volunteer in CODEF and to educate villages about epilepsy wherever I find myself even in the markets and motor parks. I would like many parents in Cameroon, Africa and the world to join in this fight against epilepsy just by beginning within your home to talk about epilepsy, then in social groups-“Njangi” meetings, village Development Associations (VDAs) and this vision about epilepsy will spread helping many people in Africa and the world just like CODEF rescued our son from the epilepsy torments. CODEF keep the flag flying and Bravo!!

Project update: Young people with Epilepsy Support (YES) project

Two projects have so been successfully funded. The remainder are yet to access their funds. We have been trying to speed up the process but there are always challenges with bank transfers to Africa. In future, we also encourage our chapters to submit information quickly and to follow up with their banks. Where feasible, chapters should explore cash transfers especially where amounts are small. This option worked for Zimbabwe and Zambia. We wish these projects success and we will be calling for applications for next year soon.

Africa Epilepsy Advocacy (Aea) Project: countries that were selected for the project

By Betty Barbara Nsachilwa

1. Kindly note that we had twelve (12) Expressions of Interest to participate from: Cameroon, Eswatini (Swaziland), Kenya, Lesotho, Malawi, Mauritius, Namibia, Sierra Leone, South Africa, Uganda, Zambia and Zimbabwe.
2. Out of the Twelve, ten (10) were selected to submit Full applications with Implementation Plans considering their geographical location which would make it possible for the proposed Project Coordinator to visit and monitor. These were: Eswatini (Swaziland), Kenya, Lesotho, Malawi, Mauritius, Namibia, South Africa, Uganda, Zambia and Zimbabwe. (Kindly note that Malawi did not submit their plan as requested to).
3. Final selection: A total of 6 countries were selected to participate, including Kenya that will also host the office of the Project Coordinator but will not have a Liaison Officer: Eswatini (Swaziland), Kenya, Mauritius, South Africa, Zambia and Zimbabwe.

The selection committee consisted of 3 AREC members, representatives of IBE, ILAE and BAND Foundation.

I believe this information will help to understand how the selection was done.

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 issue....

- AREC new year message by Grace
- YES call for project proposals
- Introducing the Project Coordinator for the Advocacy Project
- And other stories

INTERNATIONAL EPILEPSY DAY 2019

VIDEO COMPETITION



DEADLINE: 14TH DECEMBER 2018



International
Epilepsy Day

AS PART OF OUR INTERNATIONAL EPILEPSY DAY CELEBRATIONS FOR 2019, WE INVITE YOU TO ENTER OUR VIDEO COMPETITION WITH CASH PRIZES FOR THE WINNING ENTRIES!

The winning videos will be selected based on their success in telling an inspiring personal story or in using a novel means of increasing knowledge and awareness of epilepsy. In each category, there will be one 1st Prize of US\$500 and five Runners' Up prizes of US\$100.

CATEGORY ONE:

My Personal Story

People with epilepsy, their families, friends and carers, can create non-professional individual short videos, using a smart phone or personal camera, to inspire others or to highlight problems faced.

CATEGORY TWO:

Educational Video

Open to organisations and support groups who have developed professionally produced videos to educate the public, policy-makers, and people with epilepsy themselves, about epilepsy during the past 3 years.

VISIT WWW.INTERNATIONALEPILEPSYDAY.ORG FOR MORE