



EPILEPSY AFRICA NEWS

Issue 9

May 2018

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



Image: Participants of a rabbit project in Cameroon showing their rabbits in front of the rabbit house. See report inside.

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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.



Chairperson & Editor's message

I warmly welcome you to our 9th issue of Epilepsy Africa newsletter. And I have exciting news for all our young people with epilepsy: the IBE is funding projects this year again. Thank you IBE for this kind of support that will allow the region to promote projects by its future leaders. My own vision is for these projects to focus on advocacy through showcasing capabilities (e.g. income project), doing awareness or direct lobbying. Inside this newsletter, you will find suggestions on how you can achieve this. You will also find a report of a previous project in Cameroon. By sharing the report, we hope that you will pick important lessons for you to improve your project. Further about advocacy, you will find information about a meeting that I attended in Geneva in May 2018. The meeting was about reducing the challenges people with epilepsy face globally. I am also happy to inform you that while in Geneva, I had a meeting with Mary Secco (IBE Secretary General) and Gardiner

Lapham from BAND Foundation, a USA based foundation that has agreed to fund our advocacy project. BAND will fund us through the IBE and I want to encourage you to apply to run this advocacy project in your country when calls for applications open. I had several other meetings and conversations. I would want to welcome Grace Moyo (youths representative in our committee) and Kenneth Nsom (representing West Africa). I want to thank all those who have been communicating with us through emails, Facebook, twitter and calls. I will be happy to hear from all our associations. Lastly, please see the WHO resolution poster at the end. As you know, this is the current global policy on epilepsy and we have to push for its implementation in our countries and the African region. Let's us hear how we can work with you to achieve the objectives of the resolution. Enjoy your reading.

Call for funding application: Young People with Epilepsy Support (YES) projects

The IBE African Regional Executive Committee (IBE AREC) has *funds* available for projects specifically run by young people with epilepsy in Africa to a maximum amount of US\$250 per project. Applications should reach the IBE AREC Secretary's Office no later than 17h00 CAT on **Friday, 29 June 2018** by email: epilepsyafrika@gmail.com. Funds will be allocated by 13 July 2018. Projects will be implemented between August/September 2018 and February 2019. Projects submitted must comply with the following **criteria**:

1. We are looking at innovative projects that will showcase the capacity of people with epilepsy, help to reduce epilepsy stigma, increase people with epilepsy on treatment and raise the profile of young people with epilepsy.
2. We are looking for projects that have immediate and measurable impact or outcomes or results (see last page for more details).
3. The project leader must be a young people with epilepsy between the ages of 18 and 35 years.

4. Funds will be granted to projects with a duration up to six months.
5. The project should not benefit a single individual or a single family.
6. Projects that have potential for replication in other countries will have an added advantage.
7. The project should be implemented by young people with epilepsy who belong to the local IBE affiliated association.
8. The Local IBE association should approve the project before applying.
9. Beneficiaries will report on the implementation of their project to the IBE AREC, inclusive of activities, challenges, successes and lessons learnt. This report will be illustrated with a variety of photographs and counter signed by local IBE member.
10. All allocated funds should be kept in the local Association account and only withdrawn and spent for the benefit of the youth. Where there is valid evidence that the local Association is not able to play this role, applicants are encouraged to suggest a suitable arrangement.
11. Projects and young people funded before must demonstrate strongly why they need funding again and must have met or reporting requirements.

Ideas for innovative projects

1. Radio or tv program
2. Newspaper article
3. Internet, Facebook or twitter page
4. Music project
5. Awareness at schools/college/village
6. Income or entrepreneurship project
7. Epilepsy day project
8. Meeting with Minister or First Lady
9. Printing and distribution of fliers
10. YouTube project
11. Sports
12. Community workshop or seminar

Choose projects that 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 Epilepsy Day
- Advance the WHO Resolution



Rabbit Rearing in Cameroon: Awesome Project progress report 2018.

Report by Kenneth Nsom



Activity: Rearing of rabbits in Bali and Bafut communities in North West Regions by young persons living with epilepsy in Cameroon. \$246 was received from the IBE.

Success: These epilepsy support groups were assisted by IBE AREC young persons with epilepsy funds which supported their rabbits rearing in 2016. Since then the 15 rabbits have delivered seven (07) times amounting to 42 rabbits. Twelve (12) were sold for 80.000Fcfa (US\$160). So, no money is neither at hand nor kept in the bank meaning there is no balance. But 09 rabbits are still to be crossed in their keeping. Four (04) young persons with epilepsy used the money to buy their anti-epileptic drugs for one (01) year with less difficulty. The rest of the members had their drugs only for 08 months. Three (03) families visited the young persons with epilepsy group to join. One with no epilepsy visited just because of curiosity for they learnt in the community that young persons with epilepsy were rearing rabbits. While the 02 others were families with adults who had epilepsy that wanted to join and own rabbits.

On the other hand, one hard working beneficiary young person with epilepsy in the group – Samjella Esau said “Am grateful for the support of IBE AREC. It has taken away my seizures for 12 months. I pray that this ‘fainting sick’ goes forever and ever. Amen”

Challenges: Some members abandoned the group. And said they wanted to be caring only for their own rabbits and that rabbits should be shared. This misunderstanding came up because only a few members were committed and dedicated in caring for the rabbits while others were only lazing about. This misunderstanding tore the group apart. Because of this behaviour and attitude some rabbits died. Unwillingness to follow the expert advice on rabbit caring was also a cause for the rabbits to die. Some young persons with epilepsy wouldn’t want anybody to alter their decision. Some don’t want the money to be kept in the bank but be given them. This poor relationship with one another brought friction and poor handling of the groups’ property.

Lessons learnt: That though from the start group members were very excited to engage in the rabbit rearing they later wanted to be independent. That no rules were made from the start to guide the participants. That their carers or parents at one moment need to be incorporated into the activity to help in case of seizures. That the ‘lazy’ persons with epilepsy are usually the ones who tear the group. That the group is only made of young men with epilepsy and do not give chance or listen to the lone young woman with epilepsy among them-male chauvinism hence violence against women and gender bias.

From the Editor

Thank you for providing this report. There are very important lessons from your project. I would like to encourage others who benefitted from the IBE fund to provide reports. We will use the reports to improve application guidelines and to support projects to run smoothly. Please keep on doing the good work and for all our other project applications. I encourage associations to develop project guidelines with your members and to train members in managing projects. Best wishes to all.



Left: Grace
Nkazana Moyo,
from Zimbabwe.
Right: Kenneth
Nsom from
Cameroon.



INTERNATIONAL BUREAU FOR EPILEPSY (IBE)

Africa Regional Executive Committee

Email: ibeafrica@gmail.com Facebook: <https://www.facebook.com/Epilepsy-Africa-IBE>

Twitter: @EpilepsyAfrica

Webpage: <https://www.ibe-epilepsy.org/about/regional-committees/africa/>

IBE AFRICA REGIONAL EXECUTIVE COMMITTEE 2017-2021

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Senegal
Sierra Leone
South Africa
Swaziland
Tanzania
Togo
Uganda
Zambia
Zimbabwe

May 14, 2018

To: All Africa Region IBE Chapters

RE: INTRODUCTION OF ADDITIONAL MEMBERS TO THE EXECUTIVE COMMITTEE

It is with great pleasure that the Africa Regional Executive Committee (AREC) informs you of the addition of two members, as intended from inception.

The two members are:

1. Mr. Kenneth Nsom of Cameroon, **Member** of the Committee
2. Ms. Grace Nkazana Moyo of Zimbabwe, **Youth Member**.

As you may be aware, Mr. Kenneth Nsom responded to our announcement to all Chapters to have an additional member from a different sub-region other than the south. While, Ms. Grace N. Moyo was the successful candidate among three applicants to our call for a Youth living with Epilepsy to join the Committee. After repeated calls, there were only three applicants from Zimbabwe and to select the successful candidate the Committee conducted an elective selection with points given to each candidate. Resulting in the candidate with the highest score being offered the position.

By copy of this memorandum, we wish to welcome the two members to the AREC and wish them a successful tenure of office.

Yours faithfully,

Betty B. Nsachilwa
Secretary
For/Chairperson

Improving the quality of life of 10 million people with **EPILEPSY** in Africa

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

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)

4th African Epilepsy Congress, Uganda 2018

4th African Epilepsy Congress 2019 – Call for Session Proposals

Inbox x



4th African Epilepsy Congress <aec@epilepsycongress.org>

Jun 23 (1 day ago) ☆



to 4th ▾

Dear ILAE Chapter,

Preparations are now underway for the 4th African Epilepsy Congress 2019, taking place in Uganda in late August 2019.

We would like to provide you with the opportunity to submit a proposal for a session to form part of the scientific programme.

Full proposals including names of speakers and suggested titles should be submitted, using the official online form (available at <https://goo.gl/forms/zhG5QcBUDrFGcKba2>) no later than **Thursday 2nd August 2018**. Please refer to the instructions and recommendations before submitting a proposal.

The aim of the Scientific and Organising Committee is to create a comprehensive programme which will encompass topical and varied themes. Please note that the SOC will be responsible for the final selection of sessions and that presentations and/or speakers may be changed or amended whenever it is deemed appropriate.

If you have any questions or require further details about the submission procedure, please do not hesitate to contact the congress secretariat at aec@epilepsycongress.org.

We hope that you will all consider contributing to this important congress, and we look forward to welcoming you to Uganda in 2019.

With best regards,

Angelina Kakooza
Chair, ILAE Commission on African Affairs
Congress Co-chair, 4th AEC

Jacob Mugumbate
Chair, IBE African Regional Committee
Congress Co-chair, 4th AEC

4th AEC Congress Secretariat
ILAE-IBE Congress Secretariat
7 Priory Office Park, Stillorgan Road, Blackrock, Co. Dublin, A94 FN26, Ireland
E-mail: aec@epilepsycongress.org | Tel.: +353 1 2056720

IMPORTANT - Instructions for Session Proposals

Please review the following important points before preparing a session proposal:

1. The Organising Committee welcomes all presentations by eminent people in the field. Proposals from young people in the early stage of their career are especially encouraged.
2. Include the name and contact details of the person making the proposal.
3. The person making a proposal does not have to be included in the programme proposed.
4. The person proposing a session should have substantial experience in the proposed topic.
5. Proposals for sessions should allow for time for discussion and interaction with the audience.
6. When suggesting speakers, please consider the need to ensure regional geographical diversity.
7. With a few exceptions, each individual may only appear twice as a speaker and/or a Chair during the congress sessions (not including satellite symposia).
8. Whenever appropriate, sessions should cover both paediatric and adult aspects of a specific topic or even reflect the evolution of the specific problem throughout the lifetime. Where applicable, the inclusion of complementary presentations addressing clinical and basic science is encouraged.
9. Please provide a short summary (up to 300 words) for the proposed session including: objectives, reason for choosing the topic, anticipated learning outcome for the audience.
10. Please use the official form when preparing the proposal.
11. The deadline for submission of proposals is Thursday 2nd August 2018.

Please note:

- ☒ The submission of a proposal does not guarantee approval by the Scientific and Organising Committee. All proposals will, however, be given due consideration.
- ☒ The SOC will review all proposals and will be responsible for the final selection/creation of sessions. Presentations and/or speakers may be changed or amended whenever it is deemed appropriate.
- ☒ Notification of the SOC's decision will be made following the review process.

In the next issues of the newsletter, we will talk about funding that has been made available for our advocacy project and donation of medicines to Kenya.

MESSAGE DELIVERED BY THE IBE AT THE 70TH WORLD HEALTH ORGANISATION MEETING IN GENEVA

International Bureau for Epilepsy

Printer-friendly version

Meeting:

Seventy-first World Health Assembly (A71/1)

Agenda Item:

20.3.2.3 F. Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications (resolution WHA68.20 (2015))

Statement:

The International Bureau for Epilepsy envisions a world where understanding and care replace ignorance and fear of epilepsy. Epilepsy affects people of all ages and all ethnicities. Close to 80% of the 50 million people living with epilepsy live in low and middle-income countries. It is unacceptable that 75% of people with epilepsy living in low and middle-income countries do not have access to treatment. Approximately 65% of these individuals could be treated easily with inexpensive daily medication that costs as little as US \$5 per year. Without access, these people will continue to live in poverty and be at risk. Worldwide the number of cases of unexpected death in epilepsy is estimated at 60,000 per year. In low and middle-income countries the mortality and morbidity rates are even higher because of status epilepticus and drowning. In every part of the world, people with epilepsy and their families suffer from human rights violations, stigma, social isolation, seizure related injuries and discrimination. Persons with epilepsy have access barriers in schooling, employment and health care. WHO demonstration projects have indicated that it is possible to diagnose and treat most people with epilepsy at the primary health-care level without the use of sophisticated equipment. To do this we need to have a commitment from governments that epilepsy is a public health priority. Progress towards achieving the goals of WHA68.20 has been slow. On behalf of persons living with epilepsy and their care providers we ask (1) for a new report on the implementation of the resolution WHA 68.20 to be prepared and discussed again at the 74th World Health Assembly in 2021 and (2) for the development of a Global Action Plan on Epilepsy.

This statement was prepared by IBE Secretary General, Mary Secco and read by Jacob Mugumbate. Other events at the meeting included a discussion on improving epilepsy care globally and a meeting with Gardiner Lapham from BAND Foundation, funders of our advocacy project. *Photos: right: Jacob, and ILAE VP & WFN President. Bottom: participants of the WHO resolution discussion.*



THREE SIMPLE STEPS TO IMPLEMENT THE WHO RESOLUTION ON EPILEPSY

Every government is obliged to implement the WHO resolution on epilepsy. There are THREE simple steps that the government of each country should take:

136th session
Agenda item 6.6

EB136.R8
2 February 2015

Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications

ONE: Forming a national taskforce that includes epilepsy associations, local League, Ministry of Health, local WHO office and other stakeholders.

TWO: Developing a national action plan for epilepsy that includes activities and funding for:

- a. Awareness
- b. Training of health and social care workers
- c. Research
- d. Medicines

THREE: Implementing the national action plan

Where to start? Take a copy of the Resolution and meet the officials responsible for epilepsy in your country. Inform them about the three simple steps and ask them what they think about implementing the Resolution in your country.

1. URGES Member States:¹

- (1) to strengthen effective leadership and governance, for policies on general health, mental health and noncommunicable diseases that include consideration of the specific needs of people with epilepsy, and make the financial, human and other resources available that have been identified, as necessary, to implement evidence-based plans and actions;
- (2) to introduce and implement, where necessary and in accordance with international human rights norms and standards, national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social and other related services, paying special attention to people with epilepsy living in conditions of vulnerability, such as those living in poor and remote areas, including by strengthening public health care services, and training local human resources with proper techniques;
- (3) to integrate epilepsy management, including health and social care, particularly community-based services, within the context of universal health coverage, including community-based rehabilitation, into primary health care, where appropriate, in order to help to reduce the epilepsy treatment gap, by training non-specialist health care providers to provide them with basic knowledge for the management of epilepsy so that epilepsy can be diagnosed, treated and followed up as much as possible, in primary health care settings, as well as by empowering people with epilepsy and their carers for greater use of specified self and home care programmes, by ensuring a strong and functional referral system and by strengthening health information and surveillance systems to routinely collect, report, analyse and evaluate trends on epilepsy management;
- (4) to support the establishment and implementation of strategies for the management of epilepsy, particularly to improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines and include essential antiepileptic medicines into national lists of essential medicines;
- (5) to ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, in order to help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions;
- (6) to promote actions to prevent causes of epilepsy, using evidence-based interventions, within the health sector and in other sectors outside health;
- (7) to improve investment in epilepsy research and increase research capacity;
- (8) to engage with civil society and other partners in the actions referred to in subparagraphs 1(1) to 1(7) above;

