



# EPILEPSYAFRICA NEWS

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



**Cover Picture: National Epilepsy Purple Week, RWANDA – September 2019**

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**About this newsletter: Editorial team:** Action Amos; Youssouf Noormamode; Betty Barbara Nsachilwa; Radcliffe Durodami Lisk. **Frequency:** bi-monthly  
**Distribution:** Email and other social media. **Email contributions to** [ibeafrika@gmail.com](mailto:ibeafrika@gmail.com) or [amos\\_action@yahoo.co.uk](mailto:amos_action@yahoo.co.uk). 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 associations. Coming soon, an email list for advocates/ambassadors! To join your list, send an email to [ibeafrika@gmail.com](mailto:ibeafrika@gmail.com). You can also catch up on missed issues on <https://www.ibe-epilepsy.org/publications/regional-news/> and [www.epilepsyafrika.org](http://www.epilepsyafrika.org)



## CHAIRPERSON & EDITOR'S MESSAGE:

Welcome to this 20<sup>th</sup> edition of Epilepsy Africa and a very warm greeting from all over our beautiful continent. It is with joy that we share highlights of Epilepsy work happening in Africa that our affiliates have been doing across the continent.

There is a key emerging issue that researchers and other stakeholders have written and talked about. It is about alternative healing which would include faith and traditional healing. What can be done to involve and collaborate with those that practice such healing? In this edition, we feature an article on how religious belief affects epilepsy treatment.

Six months ago we celebrated the birth of two affiliates in Rwanda and Lesotho. In these two countries, there has been a lot that has been happening and we have special coverage of their work in the past two months. Lesotho introduces us to our new “verandah” corner “Know Your Chapter”. In an effort to knowing each other and the work we are engaged in, we will be covering a continental leader who is leading or involved in Epilepsy work. This will not only feature those from our chapters but will include even ordinary citizens who are contributing to our cause of bringing epilepsy out of the shadows. This edition features a leader from Zimbabwe to get to know him and hear if there is anything good that comes out of Harare.

Let me thank all our 25 chapters for the good work that is being done and the support that you continue to render to our work as African Regional Executive Committee (AREC). We are excited as AREC with foreseeable prospects that our engagements in Africa are bringing.

We have lined up key strategic engagements and developments in our next article highlighting how we are gearing to have additional resources to support our work. We will feature two key developments in our 21<sup>st</sup> edition and urge you not to miss a copy.

Enjoy this article and don't forget to share what we like to hear from you!!!! Your work and stories!!!!

**Action Amos**  
**IBE Africa Vice President**

*If you have a story you'd like us to consider for publication, please contact: [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com),  
[amos\\_action@yahoo.co.uk](mailto:amos_action@yahoo.co.uk)*

## ARTICLE OF INTEREST

### How religion affects the treatment of epilepsy

By [Fredrick Beuchi Mboya](#)



Africa is on the rise to driving the epilepsy awareness agenda beyond borders. This is evidenced by the consistency with which

health professionals and stakeholders come together in Congresses to discuss issues regarding epilepsy in Africa. The most recent one was the 4th African Epilepsy Congress in Entebbe-Uganda. I was honoured to participate fully as one of the speakers presenting on the topic “Innovative Solutions for Epilepsy Awareness in Africa”.

As many issues of concern emerged during the congress, a couple of them, got me thinking. For instance, the relationship between epilepsy and religion.

Revered in some cultures but persecuted by most others, epilepsy patients have, throughout history, been linked with the divine, demonic and supernatural.

There is a wide variety of influences on people's beliefs about illness and treatments, including culture and religion. Religious beliefs can exert positive influences on health by acting as a source of inspiration. On the contrary, they can have negative influences when they are linked with guilt and punishment. Religious beliefs can also engender a sense of fatalism, a belief that someone or something is in control. This identification of an external locus of control can impact on health behaviour. Beliefs about health and illness affect people's decisions regarding their choice of treatments. Religious and complementary therapies are commonly used among communities in Africa.

Religion plays an important role for many individuals from Africa's majority ethnic groups in coping with, and understanding, their illness.



Religious and traditional therapies are commonly used in African communities. Little is known about how these traditional and religious forms of therapy are used in relation to conventional medicine. Although many people of African origin attribute their illness to the will of God or see it as punishment for sins of a past life. People often turn to spiritual and other traditional healing in desperation and as a result of family pressure, although some have doubts about its effectiveness. Religious and traditional therapies are used as an adjunct to, rather than a substitute for conventional medical therapy.

However, details about the type of therapies and how they are used in relation to conventional medicine are scarce; in particular, little is known about alternative treatments for epilepsy. It is important that health professionals are aware of their patients' lay beliefs about illness and the alternative treatments that they may choose.

Source:

<https://www.standardmedia.co.ke/evewoman/article/2001340655/epilepsy-awareness-how-religion-affects-the-treatment-of-epilepsy>,

4 September 2019



# Global Epileptic Connection – Rwanda (Volume 1 – Local Newsletter)



## National Epilepsy Purple Week



27th of October, 2019



Global Epileptic Connection/ GECO Rwanda 2019 initiative on epilepsy awareness and empowering patients through psychosocial, economic and financial inclusion has illuminated as a sunshine national NGO role model in the 5 major regions of the country during the epic weekly rally of *Rwanda National Epilepsy Week Celebration - Purple Week* from 14 to 19 October 2019. GECO has been previously operating in only one district among 30 districts of Rwanda. For this turn, we got a privilege to go throughout all 4 Provinces of our country including Kigali City which is comprised by 3 districts. This national event was organized by GECO in partnership and accompaniment of the Ministry of Health Representatives and Handicap International of which we are an implementing partner. It also involved Doctors and Nurses in charge of mental health at district main hospitals, Local Government Officials, Community Health Workers along with Patients' representatives.

We have completed this weekly rally visiting all largest district hospital. This event was characterized with talks on awareness of epilepsy accompanied with culture dance and patients from Namba Northern district hospital, Nyanza Southern district hospital, Kayanza Eastern district hospital and final Kibuye Western district hospital with special guest a mayor of the region /the Ministry of health representative, doctors and patients and the national conference for the closure of the event be held in Kigali city covering 3 health councils district hospitals (Kicukiro, Gasabo, Nyarugenge) from the capital city Kigali conducted by the Ministry of Health and GECO on Saturday 19/10/2019

GECO mission and testimony from patients and other beneficiaries has

promoted a positive hope among patients all over the country because we do promote the patient social welfare for fighting for their well-being in future: fighting against stigma, promote social counselling, advocacy in school and rural area, make strong opinion on drugs access, and social finance inclusion because for decay we find that patient abandoned their drugs due to lack of food, as we know every patient under the AEDS drugs need at least 3 meals a day based on quality balance diet. Each event get a media attention, and GECO visibility has improved more on national event from the results of our farming cooperatives groups in 12 Health Centres within our first intervention district.

GECO took advantage of that special rally day to inform patients and doctor the significant means of IBE and ILAE regards their mission and goals and how to join the international task force in collaboration with GECO as an IBE chapter and the ILAE Rwanda East Africa representative in order to help every patient to access SDG funds, improve number of youth in advocacy, make a league of doctor junior to join the yes youth ILAE and improve their professional journey in joining each month the Zoom meeting held by the Yes youth ILAE (international league against epilepsy).

For now statistics reflect that 400,000 patients in all country are under treatment where among 64% of people who visit hospitals for mental medical care, 58% are victim of epilepsy. We appreciate our Government concern and care for this challenge where about 8 EEGs were installed in 8 main referral hospitals

### Outcome

- \* Awareness of epilepsy at national level
- \* Hope and Encouragement for people with epilepsy and their caretakers.
- \* Alertness and stirring the government and entire community on epilepsy burden

### Thanksgiving

GECO / Rwanda Team offers its sincere thanksgiving to Government of Rwanda through the Ministry of Healthy and its implementing organ know as RBC for their active advice, accompaniment and guidance not only during this weekly event but also ever since GECO started. The team also acknowledge its partner Handicap International Rwanda of which we are implementing partner since 2017.

GECO Rwanda sent its heartfelt gratitude to the IBE, ILAE & WHO for the global burden on epilepsy that entirely aims at improving the wellbeing of people with epilepsy. Many thanks for adopting GECO as Rwandan Chapter. This increased our concern, confidence, courage and credibility.

## KNOW YOUR EPILEPSY CHAPTER

### Featuring



#### Background:

Epilepsy Lesotho is a non-profit organization established and registered in Lesotho in November 2017. The main purpose for which the association was founded is to generate awareness and increase advocacy for epilepsy in the country while also minimizing discrimination among people living with epilepsy. The mission of the Association is to improve the quality of life of the people with and affected by epilepsy. Epilepsy Lesotho aims to provide integrated services that are equitable, accessible and sustainable for people with and affected by epilepsy.

Epilepsy Lesotho currently has four members who operate in the capital city, Maseru, and the plan is to expand to other 9 districts when resources permit.

#### Success:

We have been able to introduce our organization to the Ministry of Health. The Ministry of Health welcomed us wholeheartedly and allowed us to visit the Mental Hospital where the epilepsy patients are checked. This will be the centre where we can start collecting the data of epileptic patients in the country

#### Challenges:

The biggest challenge is that we seem to be unable to take off from where we started. As a result, we are not able to attract members to the organisation. A major constraint is that we have not been able to acquire an office from which to operate. We are thus not able to acquire office equipment, therefore we can't attract members.

## LEADER OF THE MONTH



Taurai Kadzviti - Zimbabwe

**Taurai Kadzviti** is the advocacy officer at the Epilepsy Support Foundation and has been with the Foundation for **over 18 years** and risen through the ranks. As a person with epilepsy, he has faced discrimination and rejection by the community and employers. Part of the reasons for these negative attitudes, misconceptions, and perceptions about epilepsy. As a result of personal experiences, he became motivated and challenged to advocate and fight for the rights of persons with disabilities. Within the community set up, there are very high levels of misconceptions and negative attitudes brought on my myths and lack of knowledge and lack of adequate policies that enable access to education and rights.

The Minister of Public Service Labour and Social Welfare appointed Mr. Kadzviti as board member of the National Disability Board 2012 to 2016. Elected in as Secretary for Federation of Disabled People in Zimbabwe 2016 to 2108 and was re-elected as honorary Secretary from 2018 to 2020. He is also the current School Development Committee (SDC) Chair at Hatfield Girls High. In 2014, he was appointed to the organising committee of the 2<sup>nd</sup> Continental Round Table Conference by the Ministry of Public Service Labour & Social Welfare and National Disability Board under the Southern Africa Disability Alliance (ADA) project COPDAM "Communities of Practice in Disability Advocacy and Mainstreaming".

He holds a diploma in Counselling and several certificates in Human resources, computer programing, Epilepsy Management & pharmacology, resource mobilisation.





**A visit to Huruma Lions Health Centre, one of KAWE's outreach Centres in Nairobi - April 2019**

### **Contributing to the newsletter means Continuity:**

We are calling for chapters, their groups and members to contribute to the newsletter. You could share this with us:

1. Your local Newsletter
2. Your plans for 2020
3. Questions on epilepsy care
4. Photographs

**Did you enjoy reading our newsletter?** Please give us some feedback: **Email - [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com)**

If you have any other topics to suggest, please email us at [ibeafrica@gmail.com](mailto:ibeafrica@gmail.com) by 20<sup>th</sup> of each month

**Next Issue to feature:** Highlights on AREC visit to the Kingdom of Eswatini,  
Strategic Meetings in South Africa and Mauritius and an African Epilepsy  
Leader win a Prestigious Award.