



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



About this newsletter

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Enjoy reading! How to join us:

WhatsApp group for people with epilepsy and significant others group for professionals interested in epilepsy: Epilepsy Africa Facebook group: Epilepsy-Africa-IBE; 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 the list, send an email to ibeafrika@gmail.com. You can also catch up on missed issues on <https://www.ibe-epilepsy.org/publications/regional-news/> and www.epilepsyafrika.org

Cover photo

Dr. Joyce Banda, Former President of Malawi with Mr. Action Amos – full story on page 5

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Chairperson/Editor's Message

Dear Friends,

Welcome to the September/October issue of our Newsletter.

It has been an exciting few weeks for us with the campaign towards the World Health Organization 73rd Assembly to towards endorsement of the Global Plan on Epilepsy and other Neurological Disorders resolution. The Advocacy team continued with it work on developing a specific Advocacy toolkit to be used by all epilepsy stakeholder to ensure that there is systematic engagement with duty bearers. The Making Epilepsy a Health Priority in Africa project made strides in reaching putting up a situational analysis framework to be used to assess epilepsy status quo within Africa.

In this article we highlight high-level engagements done by IBE Africa in engaging a former Head of State to be part of our work as an Ambassador of IBE Africa. We also highlight her call for action towards the WHO 73rd Assembly to endorse the amended WHA 68.20 resolution. In the article we look at a life of a University student in Cameroon and her achievement and challenges Cameroon is facing to address epilepsy challenges. We also go back to basics and discuss the causes of epilepsy to help our readers and public on the Know Epilepsy section. In the next issue, we will visit Zambia where the Epilepsy Association of Zambia is part of the founding organizations forming the Zambia Non Communicable Diseases Alliance.

We want to recommit ourselves as IBE Africa to continue serving all people with epilepsy in raising awareness about epilepsy at international and local levels and also provide an opportunity for IBE Chapters to build their capacities in many strategic pillars of our work such as advocacy and political dialogue. We are looking forward to exciting stories in our next feature about continued work from our Chapters, Mt Kilimanjaro venture, the 50 million Steps Challenge, our webinars review and the strategic partnership with BAND foundation and new work in the offing.

We want to encourage you all to interact with our editorial and communications teams through our social media platforms. Enjoy your reading and don't forget to visit our website www.epilepsyafrika.org !!!!!!!

Zikomo !!!! Tatenda !!!! Asante !!!! Dankie !!!! Siyabonga !!!! Enkosi !!!! Obrigado !!! Merci !! Thank you !!! Webale !!!!

**ACTION AMOS - IBE
AFRICA VICE PRESIDENT**

If you have a story, you'd like us to consider for publication, please contact: ibeafrica@gmail.com, amos_action@yahoo.co.uk



Chapter News: Cameroon

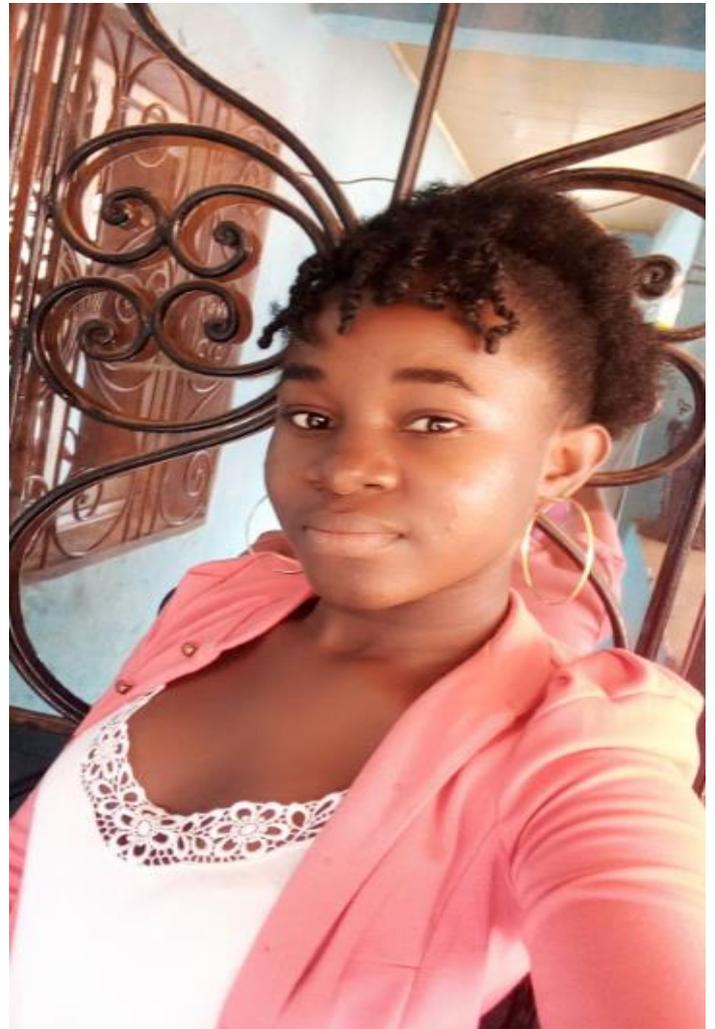
MY EPILEPSY STORY AND EXPERIENCE FROM CODEF CAMEROON

My epilepsy originated as a result of falling and hitting my head at the age of one year six months. This marked my first experience with epilepsy. This health condition negatively affected my psychology and reasoning capacity where I could not lead a normal life like my age mates or other people I could see around. As time went on I became aware that I was not as healthy as my brothers and sisters.

Whenever I was to experience seizures I will start feeling dizzy, my right hand will be jerking and I may fall unto the ground. I will go unconscious during the crisis and become conscious thereafter. I could also feel some internal vibrations within me where I will start crying unconsciously. These signs and symptoms would intensify whenever I was stressed up. The signs and symptoms could diagnose epilepsy but were **“Warning signals”** to me that gave me a mastery of my epilepsy. This helped me a lot as I could know when I was to have seizures and will not go out of home or to the public until the day I feel am fine.

I was first consulted and given epilepsy treatment when I was 05 years old in l’hospital Generale in Douala. My condition started improving. But my anti-epileptic drugs (AEDs) or treatment and other tests like scanning costed my parents a lot of money. They were spending more than **US\$600** or **300,000FCFA** per month.

Epilepsy brought me low self-esteem, lack of confidence, stigmatization, abandonment, traumatization and demoralization a lot. For instance, at one moment I felt like my parents were wasting their money on me; whereas they could have rather used it on something else



productive than throwing it away in the hospital. My mother could not withstand the scene. My Mum would prefer staying out the whole day to later return home in the evening when she suspects that I might have recovered from the epilepsy crisis.

Socially, I saw myself as an outcast in society because at one time I could feel like not being capable and not qualified but that I was a “good for nothing thing” – useless in life. My great ambitions and future plans were all shattered by epilepsy. My junior sister could study their subjects well plus mine and would answer questions so excellent in my subjects than I could do. I was in class 4 and my kid sister was in class 2 in primary school. My parents restricted me from doing household chores like fetching water, carrying out manual labour like clearing. They even banned me from sporting activities. I was barred from eating Okro and snails for my mother wrongly thought these could provoke epilepsy crisis.

It was in an absurdity manner that epilepsy crisis affected my menses and menstrual cycle. So I was terribly worried and began to ponder whether I would ever get married, have my own children, complete my education and be employed to have a job.

But I meticulously took my anti-epileptic drugs (AEDs), do my hospital routine checks and the doctor changed my AEDs from Depakin Chrono 500mg to Tegretol LP 200mg in Centre Pasteur hospital Yaoundé. Today there is a huge improvement on my seizure and frequency levels. This has made me proud as am in the university currently studying English Modern Letters.

Finally, I would like to give out this advice to my friends and their families that have epilepsy. I urge you to keep having hope and to continue having your greater life ambitions for you shall one day achieve your objective. Never you be tired of taking your AEDs because after God are the anti-epileptic medications. To parents of persons with epilepsy do not relent your efforts in getting drugs for your children for they shall surely help your children as they helped me. I hope my epilepsy story and personal experience will assist someone somewhere in school or community in Cameroon. Do not hide but come out of the epilepsy shadows!! **By Bessong Takang Eyang-Obasi Praise 19 years old- University student Yaoundé**

‘.....keep having hope and continue having your greater life ambitions for you shall one day achieve your objective.’



Global Action Plan on Epilepsy and its Synergies with other Neurological Disorders

In our conquest to push our Governments in Africa to support the WHA 68.20 Resolution fully, the Africa Region added a Voice of a prominent person to give a **CALL TO ACTION** and that was none other than the Former Head of State of Malawi Dr Joyce Banda. Additionally, a group of youths developed a Petition to be dropped with all Ministries of Health in respective countries.

During the 2nd IBE Africa Webinar, the region saw great support from an African Leader and mother, Former President of Malawi, Dr. Joyce Banda, who is also International Bureau for Epilepsy Africa Ambassador. Dr. Banda in a pre-recorded message urged Health Ministers on the African continent to support the WHA 68.20 Resolution. Recognizing that epilepsy is overshadowed by other conditions or aligned with other major non-communicable diseases, thus rendering the impact of epilepsy non-essential

At the time of putting this edition WHO endorsed the new resolution WHA73 11.6 and will discuss this in our next issue

We say ZIKOMO to you Mum for your support !!!!!



Causes of Epilepsy

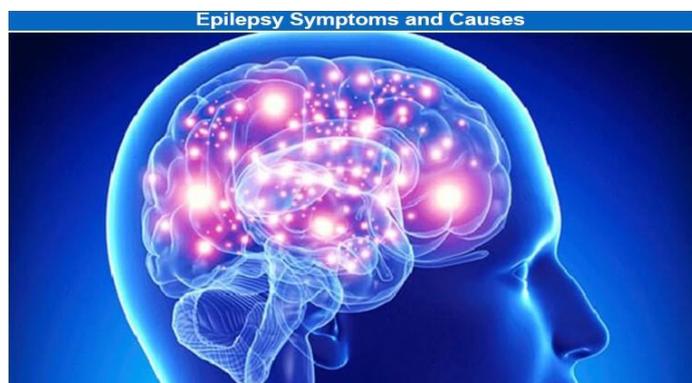
WHAT ARE THE CAUSES OF EPILEPSY?

[Epilepsy](#) is a general term for the tendency to have [seizures](#). [Epilepsy](#) is usually diagnosed only after a person has had more than one seizure.

When identifiable, the [causes of epilepsy](#) usually involve some form of injury to the [brain](#). For most people, though, epilepsy's causes aren't known.

What Are Seizures?

A seizure occurs when a burst of electrical impulses in the [brain](#) escape their normal limits. They spread to neighboring areas and create an uncontrolled storm of electrical activity. The electrical impulses can be transmitted to the muscles, causing [twitches](#) or convulsions.



Types of Seizures

There are two types of seizures:

Focal seizures. These seizures involve abnormal activity in just one part of your brain.

You may lose consciousness, or you may stay alert when you have them.

- **Without loss of consciousness.** These seizures may just change your emotions, or alter your sense of sight, smell, taste, or sound. You might also jerk an arm or a leg without meaning to, or feel tingling, dizziness, or see flashing lights.
- **With loss of consciousness.** During these seizures, you aren't quite aware of your surroundings as usual. You may stare into space, or move repetitively by chewing, rubbing your hands, or walking in circles.

Generalized seizures. This type of seizure tends to involve all the parts of your brain. There are six kinds of generalized seizures:

- **Absence seizures** happen mostly in children and involve small movements such as lip smacking or eye blinking.
- **Tonic seizures** make you stiffen the muscles in your arms, legs, back and sometimes fall down as a result.
- **Atonic seizures** take away your muscle control. They're also called drop seizures, because they can make you collapse onto the floor.
- **Clonic seizures** often make you repeat jerking movements in your neck, face, and arms.
- **Myoclonic seizures** involve short, twitching and jerking motions in your arms and legs.
- **Tonic-clonic seizures**, which used to be called grand-mal seizures, can make you lose consciousness, stiffen your whole body, and shake. You may also bite your tongue or lose control of your bladder.

Causes of Epilepsy

There is a clear cause for epilepsy in only a minority of the cases. Typically, the known causes of seizure involve some injury to the [brain](#). Some of the main causes of epilepsy include:

- Low oxygen during birth
- [Head injuries](#) that occur during birth or from accidents during youth or adulthood
- [Brain tumors](#)
- Genetic conditions that result in [brain](#) injury, such as [tuberous sclerosis](#)
- Infections such as [meningitis](#) or [encephalitis](#)
- [Stroke](#) or any other type of damage to the brain
- Abnormal levels of substances such as sodium or blood sugar
- Developmental disorders, such as autism and neurofibromatosis
- Injury before birth, such as brain damage from an infection in the mother, poor nutrition or oxygen deficiencies

In up to 70% of all cases of epilepsy in adults and children, no cause can be discovered.

Causes of Seizures

Although the underlying causes of epilepsy are usually not known, certain factors are known to provoke seizures in people with epilepsy. Avoiding these triggers can help you avoid seizures and live better with epilepsy:

- Missing medication doses
- Heavy alcohol use
- [Cocaine](#), ecstasy, or other illegal drugs
- Lack of [sleep](#)
- Other medicines that interfere with seizure [medications](#)
- Flashing lights, images, and repetitive patterns may cause seizures in persons with photosensitive seizure disorder.

For about 1 in 2 women with epilepsy, seizures tend to occur more around the time of menstrual periods. Changing or adding certain drugs before menstrual periods can help

KEY FACTS

- **Epilepsy is a chronic non-communicable disease of the brain that affects people of all ages.**
- **Around 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally.**
- **Nearly 80% of people with epilepsy live in low- and middle-income countries.**
- **It is estimated that up to 70% of people living with epilepsy could live seizure-free if properly diagnosed and treated.**
- **The risk of premature death in people with epilepsy is up to three times higher than for the general population.**
- **Three quarters of people with epilepsy living in low-income countries do not get the treatment they need.**
- **In many parts of the world, people with epilepsy and their families suffer from stigma and discrimination.**

<https://www.who.int/news-room/factsheets/detail/epilepsy>





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. Newsletter
2. Your plans
3. Questions on Epilepsy Care

Did you enjoy reading our newsletter?

Please give us some feedback –

Email: ibeafrika@gmail.com

next issue to feature:

- Global Action Plan on Epilepsy and its Synergies with other Neurological Disorders
- Local Chapter News: Zambia Non-Communicable Diseases Alliance Launch of Strategic Plan 2021-2025
- West Africa Funding Efforts
- Advocacy Toolkit

