

My story about epilepsy (716 WORDS)

My name is Fredrick Beuchi Mboya and I am 31 years old. Since 2013, I have volunteered in Epilepsy Awareness activities through the Foundation for People with Epilepsy (FPE) and the National Epilepsy Coordination Committee (NECC) Kenya.

My passion is greatly inspired by my last-born sister Mercy Kwekwe Mboya, who was diagnosed with Epilepsy at the age of 2 years following cerebral malaria. She is now 15 years, and has therefore lived with epilepsy for 13 years. I have not only cared for my sister, but I have also experienced first-hand, the challenges a person with epilepsy and their families go through.

For 6 years we watched helplessly as our sister's condition worsened, moving from one hospital to the other without improvement. Her seizure frequency increased each day, and she sustained physical injuries every time she had an attack. This greatly affected us as a family emotionally, psychologically and financially.

Five years ago, she was put under medication by an epileptologist, who was recommended to me when I first attended the epilepsy awareness initiatives by NECC, and this resulted in her seizure freedom for the last 4 years now. In most communities in Kenya, epilepsy is shrouded with a lot of myths, misconceptions, driven by cultural and religious beliefs. As a family we were stigmatized, discriminated and ostracized by members of our community who believed that we bewitched our sister to acquire riches and wealth.

These and many other mis-perceptions and false accusations from our community motivated me to educate and create awareness about Epilepsy.

For the last 8 years to date I have actively participated in raising awareness in our different Counties across Kenya, through NECC, FPE Community organization. Every year since 2013, I have organized a Kids festival and an Epilepsy walk for children and their family members to advocate for rights of people living with Epilepsy as well as give basic facts about the condition to members of the public.

I host and organize the Epilepsy Candlelight Kenya Concert and the coveted Epilepsy Afro Fashion Fair event where different musicians, creative art artists, fashion designers, the youth and young adults come together to explore talent, award, inspire, entertain, educate and fund raise to support children living with epilepsy access medication.

I Visit schools and conduct health talks to pupils and students as well as teachers about Epilepsy and most importantly demonstrating first aid do's and don'ts during an epileptic seizure. I create awareness in institutions of higher learning e.g. universities and colleges as well as religious institutions e.g. Churches. I also give epilepsy awareness talks in public health hospitals and health stakeholders' forums, and participate in training of Community Health Volunteers in the rural public health facilities.

In preparation for an epilepsy awareness initiative organized in Mombasa last year by National Epilepsy Coordination Committee (NECC), I walked a distance of 482km for 12 days in a sensitization campaign to encourage mothers to deliver in hospitals to avert the risk of infants getting head injuries which may cause epilepsy.

I write Epilepsy impact stories from different communities every fortnight on the Kenya National News Paper Magazine called “Eve Woman magazine” for print and online publication. Our local radio stations and National television stations have offered me opportunities to engage the public in Epilepsy awareness talk show dialogues which have been very effective mediums of communication with reach to thousands of people.

Recently, I organized and participated in an Epilepsy Awareness Challenge that involved; Cycling from Nairobi (Kenya) to Arusha (Tanzania) in 3 days covering 327km, rested for 2 days, then climbed Mt. Kilimanjaro (Tallest Mt. In Africa) for 6 days. As a result we reached out to 4.8 million people with information about Epilepsy across Africa.

With respect to these selfless efforts of breaking the silence and bringing Epilepsy out of the shadows, I got endorsed as the National Epilepsy Awareness Ambassador for the Nationwide Campaign dubbed “Shining light on Epilepsy”. I will use this award to consolidate epilepsy awareness efforts in Kenya that’s very much needed due to the engraved cultural beliefs that shroud epilepsy in Kenya.

Attached here are links to videos and articles of the Epilepsy impact stories in my journey while creating awareness;

<https://www.standardmedia.co.ke/evewoman/health/article/2001394129/epilepsyawareness-beuchis-mt-kilimanjaro-challenge-set-for-tomorrow>

https://www.ilae.org/journals/epigraph/epigraph-vol-22-issue-5-fall-2020/tackling-the-challenge-of-raising-epilepsy-awareness-in-africa?utm_content=Kakooza-Mwesige&utm_source=VerticalResponse&utm_medium=Email&utm_term=See%20photos%20from%20the%20Mt%2E%20Kilimanjaro%20Epilepsy%20Challenge&utm_campaign=Epigraph%202020%20Recap%20%7C%20Africa%20Awareness%20Challenge

https://www.youtube.com/watch?v=Nul0VD2vD_A

<https://www.standardmedia.co.ke/evewoman/search?q=fredrick+Beuchi>

https://www.youtube.com/watch?v=Jv4QaO_e-Fk&index=11&list=PL_urrkOxjMnG0R7vryuE1hl0s9VEQ93fE

<https://youtu.be/l0s9VEQ93fE>

<https://youtu.be/ULvKuBWTyhs>

https://www.youtube.com/watch?v=YVWmpLmzY_Q

<https://m.youtube.com/watch?v=CHFf61BW8c>