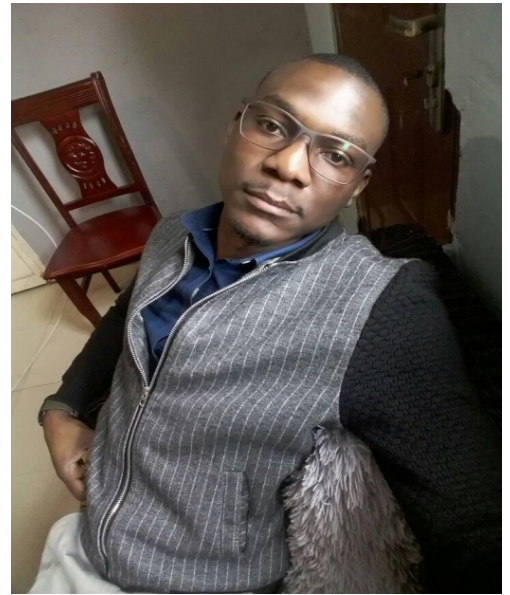


## ***“You don’t look like the kind”***

A statement I have gotten used to hearing whenever I introduce myself as someone living with a convulsive disorder. To some, I look too healthy, to others, too happy, and to an interesting bunch, well; I **just don’t look like the kind** – whatever that means.

**Hi!** My name is Bright M Bwalya, a 29 year old Epilepsy and Mental Health Advocate, Poet, Innovator, Pre-Entrepreneur living with a convulsive. I was diagnosed in March, 2016, a year before the completion of my studies at The Copperbelt University in Kitwe, Zambia, while pursuing my degree in Information Technology. The condition greeted me first as a series of auras triggered by excessive heat, sudden high pitch or monotonous sounds and tiredness. This introduced academic challenges, a life of constant fear, loss of esteem, mockery from others including the loss of the girlfriend who promised to be with me through it all just a month after I was diagnosed.



### **The Challenges:**

Medication affected my memory; remembering became partially selective. But being in a program as bulky as Information Technology, this became a strain, courses like Application Programming demands a lot of time and mental focus hence strained the very part needing rest the most. This led to a daily seizure count of close to five, with post-seizure effects demanding sleep and energy replenishment. But loss of appetite was an after effect of the medicine so it made experience even worse. I became home bound due to fear of suffering a seizure any time, so I couldn’t do the things I loved; Basketball, Poetry, Strolls, Christian Meetings and Just Visiting Friends. My energies had to be reserved for class; make my run there, find my way back before anything happened. This came with all sorts of mockery and rumors on campus about what was happening to me, some assumed I was demon possessed, others thought school had gotten too hard I went insane. My finale semester in school was extended because a lecturer did not believe I was sick and so he denied me the chance to present my graduation project.

### **The Moment of Recovery:**

A semester went by and as life would have it, the person next to me when I experienced my first seizure stepped forward and said she liked me! In my lowest moment where I thought I couldn’t be liked because the person who did left a month after my ordeal began. It was funny yet a great esteem booster which made me realize I was not the worthless human I thought I had become. That found friendship helped me realize I had to accept the condition was here as first step to healing, then begin to work out how to manage it. Since hospital didn’t provide information on what it was, I decided to record myself having a seizure, then a research to know what I was suffering from. “Simple Partial Seizure” was what my research revealed; with directions on trigger identification given and so the fight began.

### **The Initiatives:**

To graduate, I had to carry out a research and write a dissertation, building an innovation to address my case study; “Seizure Assistant” was born! A mobile application for people with epilepsy or convulsive disorders and for the general public.

**For the general public:** A learning tool providing information about various conditions which exist, common causes, First aid and known cures; Support groups for those with friends, relatives or loved ones living with these conditions.

**For the Patient:** Support groups; A pocket inventory with reminders for medicine; Pocket diary to keep track of convulsions; Information about seizure types and first aid needed; “Panic Mode” to notify a preset contact when a seizure occurs while giving first aid instructions to on sight respondents. This application has been developed and is soon to be launched for people to use. People rarely open up about these conditions, this platform allows sharing problems anonymously.

**Epilepsy and Mental Health Advocacy:** The American Corner (AMC) at The Copperbelt University, allowed for the hosting of Seminars with other advocates, addressing mental health and epilepsy issues. The number of people who came out saying they had epilepsy or convulsive disorder inspired me to do more. My work at the AMC in different programs made it hard for many to imagine I suffered what I spoke of; a shocking inspiration to them and a motivation for me to speak to even more people. Moving to Lusaka, I got chances to share my story and knowledge on how one can take care of themselves living with these conditions. Invitations came from Radio and TV Stations even Seminars; many questions founded in mythology were asked and they just drove my passion to do even more. As was my case, many patients are not given details by doctors during their sessions. I noticed this during sessions at The University Teaching Hospital. Many seemed Hopeless they just lived counting days, but having completed my studies, developed two applications and employed, I saw an opportunity to inspire someone among that bunch; Help them see they can have this condition and still do a lot! Entering the birth of “**Clinic 4 Wednesday 8:00hrs Talks**”. I was granted time to speak to patients before their doctors’ sessions. Questions I got revealed even more the need for my application, also, that people open up more to people they know relate on a first hand basis. My talks attracted consultant doctors from Harvard University, Dr. Charles, Dr. Anastasia and team and with them, podcasts were recorded and information provided to publish on the application. I was introduced to the Epilepsy Association of Zambia by Dr. Omar Siddiq, found at University Teaching Hospital and at one time held health talks at Clinic 4 together with the EAZ Liaison Officer, Mr. Godfrey Chisenga.



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My passion for advocacy lives on, fueled by the joy I see in those I have been able to help. Though challenges and struggle of living with the condition have not ended, citing the difficulties in carrying out work due to medicine side effects affecting my productivity at times. This has affected the development pace for my applications and cause a recent firing from my recent Job. Now jobless, I walk on bold knowing I can manage it and even do more. Even if I am not cured, I am proud to have the strength and be a beam of light to those still in the dark about this condition, for them, I will be strong and be Bright.