

## MY STORY – SOPHIE NABUKENYA

Hello, I am Sophie Nabukenya from Uganda. I am a volunteer with the Purple Bench Initiative. As an infant, I grew up with multiple concerns among them Epilepsy, a speech defect, and a cleft lip that mom suspects were all as a result of an accident she got with me in her belly. All these attracted ridicule from some children at school and in the neighborhood. Such mockery left me upset and out of place wondering why all these crowded a single individual.

I got my first seizure when I was a baby as was narrated by mom and later on at in primary school. The teacher didn't know what to do with me, so she decided to give mom a call. The next thing I knew, I was at home. Unable to understand clearly what had exactly happened, I asked what was wrong and all I was told is that I had fallen sick. Since I wasn't feeling pain on any part of my body this left me puzzled.

As years went by, I felt isolated for a reason I seldom comprehended but I suppose it was because of my cleft lip or inability to verbally express myself well enough. One day however, a classmate lamented to me, "Pupils say that whenever you think of your late father, your eyes become green and blue, you shudder and gnash your teeth." Thinking of such a statement, I imagine that it must have been one of those episodes of a seizure that neither I, nor my young and naive classmates had no idea about.

My mom and the teachers too did not understand why I got seizures. The frequency of seizures forced her to place me in a school near her new place of work. She thought the seizures would cease since I was in her vicinity, but the teachers often told her that I still got them. From the myths that Africans hold, she took me to a herbalist who would induce me to vomit so that I bring out the bad things I might have unknowingly consumed as a toddler, but herbalists didn't work. I was taken to a number of men of God for deliverance but the seizures would still occur.

We got a relief when my tests at a referral hospital proved that my brain was fine but had to start anti seizure medications, which I take up to today. The seizures greatly reduced though they didn't completely stop. When I was in high school, I got an attack and one of my new friends who had never witnessed me in such a situation got scared to death and cried thinking I was going to die. She was like, "You bit your tongue and spat blood". Embarrassed, I asked her how other students had taken it and she said that everyone had taken it calmly, but I imagined it was just a consolation for me not to get anxious and feel out of place.

My dream is the whole world to understand that Epilepsy is a disease like any other; people living with it are not bewitched, demon-possessed or insane. They can achieve every one of their goals if they seek and adhere to their medication, stop pity-parties, work hard and believe in themselves like I do. Personally, I graduated with a Bachelors degree in Development Studies and a postgraduate diploma in project planning and management. I've written poems and articles (though not yet published), acquired basic skills in sewing and jewelry making. I am using my academic experience and skills to serve the disadvantaged and marginalized groups in society

especially those living with Epilepsy. I am currently volunteering on the “Susan” project with Purple Bench. This project is supporting a schoolgirl who has epilepsy. I want people with epilepsy to live fruitful lives and get equal opportunities without being discriminated or stigmatized. They should get the courage and boldness to speak out about Epilepsy like I do to change the current situation. I look forward to a world where we can inspire, motivate and touch lives of those people whose disabilities have withdrawn them from being the best people they can be, where I too can make mom proud of me for all her tireless efforts and support she’s rendered me through this journey. I can’t wait to see Epilepsy considered as a public health priority.