

MY JOURNEY AND RESEARCH INTO EPILEPSY: A GLOBAL CALL TO ACTION

Introduction

My name is Millicent Misango. I am an independent certified epilepsy trainer from the Epilepsy Foundation of America. My personal and professional journey with Seizures began after being involved in a motorbike accident. Months later after successfully treating the leg injury is when I had my first seizure. Through my experiences and research, I have developed a deep commitment to raising awareness, advancing knowledge, and improving the quality of life for those affected by this condition.

The Beginning of My Journey

I first encountered a seizure when working in a corporate company—my diagnosis was not immediate and was quite a process. Myself, colleagues and family were wholly confused and scared because it was nothing we had experienced before. Personally, not even fainting, and the seizures kept recurring day after the other at work. I expected treatment to be done and the body to regain stability as the normality of getting unwell and visiting the hospital for treatment. Instead, it got worse and more confusing for the fact that getting the right, balanced anti-seizure medication also took a few years. I had to resign and drop off everything to focus on treatment and getting better. I struggled mentally, emotionally, and spiritually and battled from within having lost everything literally, suffering rejection and even termination from work with a few companies when I tried getting back to employment, despite being amongst the best performing employees. Nothing was clear on what to do next with my life apart from the regular doctor's checkups. It was during this time that I realized how little information and support were available. This lack of awareness motivated me to dig deeper and become actively involved in researching and advocating for better understanding, treatments, and support systems.

My Research and Findings

Over the past few years, I have dedicated myself to studying Epilepsy. Here are some of the key areas I have focused on:

1. Symptoms and Diagnosis Challenges

- The common symptoms include seizures, aura, loss of awareness, and post-seizure symptoms. Some of the major difficulties people face in getting an early and accurate diagnosis are varied seizure presentation, intermittent nature of seizures, misdiagnosis with other conditions, lack of awareness among patients and families, limitation of diagnostic tools, social stigma and emotional barriers, and access to hospitalized care.

2. Innovative Treatment Options

- Innovative treatments like neuromodulators, gene therapy, and medical cannabis offer new hope for people with drug-resistant epilepsy. Alongside advanced monitoring systems and non-invasive surgery alternatives, these therapies represent a shift toward more personalized and less invasive care. Research in optogenetics, VR, and brain computer interfaces continues to expand the frontier, potentially leading to even more effective treatments in the future.
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Challenges and Insights Gained Along the Way

Throughout my journey, I have encountered numerous challenges, just to mention but a few including social barriers—such as deep emotional stigma, deep lack of awareness, hopelessness, suicide attempts, diagnostic and treatment issues, the financial burden due to high treatment costs, complete sudden change of lifestyle due to restrictions and strain on family and relationships. However, these obstacles have strengthened my resolve to advocate for change. My research has shown that:

- **Public Awareness is Key:** essential for changing attitudes, promoting safety, encouraging timely treatment, and improving the quality of life for people with epilepsy. When society understands epilepsy better, it fosters acceptance, inclusion, and support, enabling individuals with the condition to live more fulfilling lives. Public education campaigns, policy advocacy, and community involvement are all vital components in creating a world that is safe and inclusive for those living with epilepsy.
 - **Collaboration Can Drive Progress:** The partnerships I have as an independent agent with health agents have greatly helped raise community and social awareness of the condition. They have also largely helped me increase my knowledge.
 - **Every Story Matters:** My personal experience and journey with epilepsy has empowered me to help someone else with the condition and the people involved in taking care of them.
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A Call for Global Awareness and Action

The fight against epilepsy is far from over, but with collective effort, we can make a significant impact. Here are a few ways you can help:

1. **Spread the Word:** Share this story and other resources to raise awareness.
 2. **Support Research and Funding:** Consider donating to or supporting Binti First Aid Team NGO, set up on the platform of my personal experience focused on epilepsy awareness and training.
 3. **Engage Community:** Get involved with support groups, events, or advocacy campaigns.
 4. **Advocate for Policy Change:** Help promote healthcare policies that improve access to care and support services for individuals affected.
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My Vision for the Future

I envision a future where no one suffering from epilepsy feels isolated, misunderstood, or without access to the care they need. I believe that through continued research, advocacy, and public engagement, we can:

- Improve diagnostic tools for early detection.
 - Ensure equitable access to innovative treatments worldwide.
 - Foster a global community that supports individuals and families dealing with epilepsy.
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How You Can Connect and Support

If you would like to learn more about my research or join me in advocating for epilepsy, please feel free to:

- **Follow My Work:** Binti First Aid Team NGO
 - **Contact Me:** +254 786 711 531
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Conclusion

Thank you for taking the time to learn about my journey and epilepsy research. Together, we can create a world where individuals affected by epilepsy receive the support, treatment, and recognition they deserve. Let's work towards a brighter future—one where awareness, compassion, and action lead the way to change.

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