

Epilepsy  
Alliance  
Africa  
(EAA)



Stripes Week  
2024

**STORIES OF  
LIVING WITH  
EPILEPSY**  
**JOURNEYS OF  
CAREGIVING**  
**NARRATIVES  
OF ADVOCACY**



**EMPOWERING CAREGIVERS: A JOURNEY  
OF GIVING, RECEIVING AND VALUING CARE**



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## Empowering Africa *A Journey to Raise Epilepsy Awareness*

In Africa, there is a hidden challenge that often goes unnoticed—epilepsy—a neurological disorder characterized by recurrent seizures. Due to stigma, misinformation, and limited access to healthcare, many individuals living with epilepsy face significant challenges in managing their condition and integrating into society.

Meet Fiona Night, a young woman from Kenya who has been living with epilepsy since she was a teenager. Through her journey, she has encountered countless others like her, each with their own struggles and triumphs.

Fiona is a passionate advocate for epilepsy awareness. Through her organization, Epicare Africa, she organizes community workshops and educational campaigns..

Access to affordable medication, specialized care, and trained healthcare professionals are still limited in many parts of Africa.

But amidst these challenges, there is hope. Through education, advocacy, and support, the narrative around epilepsy in Africa is slowly changing.

*At Epicare Africa, we see beyond the seizures*  
*Fiona Night*

# FIONA NIGHT



Story  
Moja  
(1)





## Acceptance, avoiding triggers, and adhering to medicines

# GEOFFREY HINGA



Story  
Mbili  
(2)

My name is Geoffrey Hinga. I am 30 yrs old. I come from Kiambu County in Kenya. I am a husband and a father of 2 adorable kids (a boy & a girl). I am a Cosmetologist by profession and I have been living with epilepsy for 18 years.

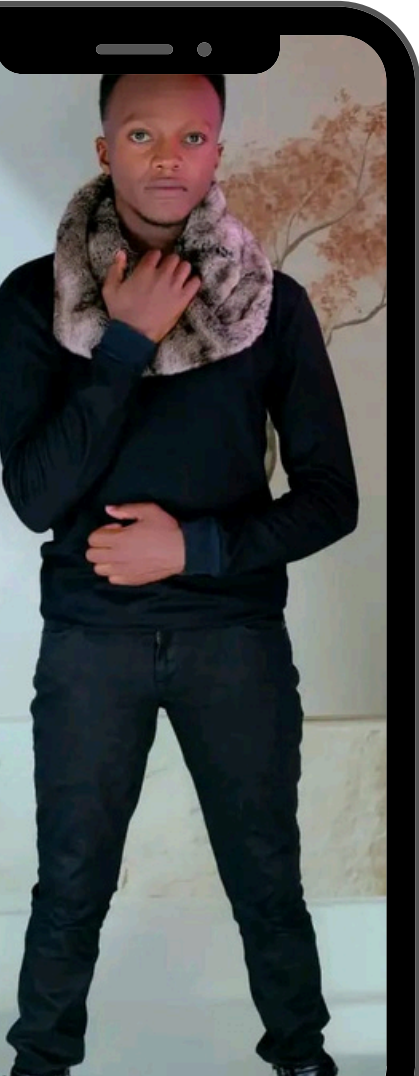
When I was 12 years old, I lost my dad due to a short illness. I never got time to say goodbye nor mourn as I was sitting for my national exams. My dad and I were so close and losing him gave me a great shock which made me fall into depression. I started experiencing absence seizures of which I didn't understand what was going on. The other students would laugh at me. The teachers would punish me because they thought I am being hard headed and disrespectful as I was in adolescence stage.

It later got serious to a point I started experiencing seizures (epilepsy attacks). The students started isolating themselves from me as they would say I am bewitched and the most painful part is not even my mum believed me when I told her what I was going through because she believed I was pretending so that I would not go to school.

It got serious to a point I would fall down, get injuries because of the attacks. It is at that point my mom took me to the hospital and I was referred to Kenyatta National Hospital (KNH). They took blood samples, did CT scan, MRI and I was diagnosed with epilepsy.

KNH was very expensive for the management of epilepsy so we opted to go to Kenya Association for the Welfare of People Living With Epilepsy (KAWE), a facility that deals in management of neurological conditions such as epilepsy where we were referred by a friend. Where I have been going for follow up and to pick my drugs.

Healing is a process and it starts with you as an individual which involves accepting yourself and medicine adherence because as for me it's hard to notice I have epilepsy unless I let you know. I would urge everyone to create awareness, especially teachers Parents and caregivers, let's support those living with epilepsy to socialize. People living with epilepsy you can do it, you can live a normal life without seizures if you learn to accept yourselves, avoid triggers, and adhere to medicines. *EPILEPSY has taught me to be a fighter and the scars always remind me how many times epilepsy has tried to bring me down but I always emerge a winner.*





## Nurses running for epilepsy

It is an honor to share with you our recent experience in Rwanda, participating in the Kigali International Peace Marathon on September 6, 2024. In fact, it was more than a race, but one important step to make people aware of the fact that epilepsy is a life-threatening condition affecting millions of people worldwide.

Epilepsy is a serious and life-threatening condition affecting people from all parts of the globe; though the good news is that it can be managed with proper treatment and care.

We proudly represented ILAE and EAA in advancing accessible nurse training programs and universal free medications through the various initiatives of RBC-Rwanda. Epilepsy Alliance Africa Stripe Week Ubuntu Program advances both medical and social inclusiveness for people with epilepsy.

That day, in running for peace here in Kigali, every step we ran was a pledge to stand in solidarity with the patients on antiepileptic drugs. Every step that we have taken is not only our resolve but that of millions suffering from epilepsy: 50 million people worldwide, 10 million in Africa, 600,000 in Rwanda.

It is very critical to note that epilepsy is not contagious. As we run and share our message that day, we hoped to bring down this stigma and create a more accepting world where no person's life is limited by epilepsy.

Thank you, Rwanda, for the support in making this event a nice expression of solidarity and hope. Together, we can make a difference!

Servilien  
Rwanda

# SERVILIEN NDERERIMANA



Story  
Tatu  
(3)





## My family has been helpful

My name is Rosemary Wacera Njuguna. I am 33 yrs and a single mother of 2 daughters I have lived with epilepsy since 2010. It was hard for me to express my feelings to my friend and family. The painful time is when I was living alone and my sisters were away so there no one to help at that time,. But through our the years my family have been so helpful when I get attack.

Now my seizures frequency have gone down due to the antiepileptic medicines I'm using and I have learned to control and manage well my seizures. I was divorced by my husband of 4 years because of my epilepsy condition. And now I'm taking care for my two beautiful girls as a single mother despite my condition.

I usually face challenges when I get seizure attack and I'm living with the kids alone or sometimes I'm in my usual hustle business.

*I take great risk though but life must continue.*

# ROSEMARY WACERA NJUGUNA



Story  
Nne  
(4)





## Epilepsy doesn't define me: Trish's story of resilience and purpose

**TRISH ESTHER  
ZVIKOMBORERO  
SHUMBA**

From the day I was born on January 12, 1989, life presented me with challenges—some visible, like my smaller right hand, and others invisible, like the battle raging in my brain. But this story isn't about the challenges—it's about what I've done with them. It's about resilience, purpose, and the power of embracing who you are, no matter the obstacles.

Growing up, I always knew I was different. I struggled with movement on my right side—simple things like walking, holding objects, and even seeing clearly were harder for me than for most kids. But that was only part of the picture. From a young age, I also experienced seizures, episodes that would come out of nowhere and take control of my body. At four years old, I had my first seizure while playing at preschool. One minute I was on a swing, the next, everything went black. I woke up confused, surrounded by teachers, with no idea what had just happened. That was the beginning of my journey with epilepsy, a condition that would follow me through childhood, teenage years, and adulthood. As a child, I didn't fully understand what epilepsy was, but I quickly realized it made me different from everyone else. And for a long time, that difference felt like a burden.

At school, kids bullied me for the way I walked, the way I talked, and the fact that I sometimes had seizures in front of them. I became an easy target for cruelty. I remember how they would imitate my movements, throw my backpack around, and call me names like “deformed” or “broken.” But even as a child, I found a way to fight back. I developed an inner voice that became my shield. I would say to myself, “You are worth it, Trish. You are.” Read full story: <https://epilepsyalliance.africasocialwork.net/trish-shumbas-story-of-resilience-and-purpose/>



Story  
Tano  
(5)



# TOPE-OJO OREOLUWA



Story  
Sita  
(6)



## **We are warriors, we fight everyday and we are strong**

My name is Tope-Ojo Oreoluwa, I am 22 years old from Ondo State, Nigeria. I am a content writer and a student. I have been living with epilepsy since I was 2 but I officially got diagnosed when I was 11 years old.

As a teenager living with epilepsy, I always felt left out of everything. My teachers would not allow me participate in activities I desired to do, I was fragile to them and I constantly felt like the sick one.

Entering the real world as an adult felt like a nightmare. I hated people seeing me having episodes, I always felt alone but my parents and siblings always encouraged me. I started fighting a battle I didn't have strategy for. The episodes became worse as I entered the university. I just kept having seizures, then anxiety crept in and I started exempting myself from doing any activities even to the extent of going out to buy things.

Everything changed when I was introduced to a doctor who placed me on a better medication [keppra].it's been 4 years since I last had a seizure and that doesn't stop me from taking my medication religiously.

I still deal with fear and anxiety. Epilepsy in Africa is not really discussed about and there are certain stigma attached to it even in this day and age, especially for someone like me who lives in Nigeria.

One thing I am sure of is that we are warriors, we fight everyday and we are strong. We fall and we get right up, it doesn't define us. Healing takes courage and part of the healing process is sharing with who cares and are ready to listen. Awareness is one of the first steps in this process. LET'S SPREAD THE WORD.





# DAVID MIHIGO AND LYDIA MASSI



Story  
Saba  
(7)

## A special warrior

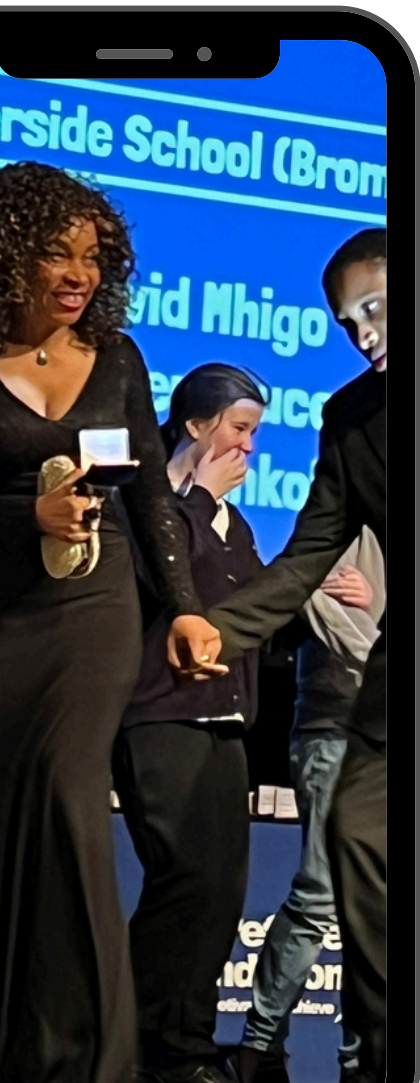
David Mihigo is a student at a special needs school based in Bromley, London. He was affected by meningitis at young age which destroyed his brain as a result of severe brain damage.

Today he is affected by epilepsy, autism and cerebrospinal injury with no ability to speak, even his mobility were significantly affected.

Thanks God, due to policies of children with special needs in UK, David is well restored now. He is in high school, graduated and established his foundation in Africa able to assist children with special needs regards health insurance, awareness - providing hope for their future. The Trust covers health insurance of 200 hundred families in Rwanda, donated Arsenal football team kits to a special needs school in Kigali supported by CBM during previous Stripe Week and supported EEG interpretation training and now on stripe week 2024 he delivered an awareness bonus grant for care givers. Lydia Massi is a qualified lawyer and social worker. Lydia's hard work is making an impact because she is providing for other families affected by severe brain disease. This work is recognised.

EAA congratulates Lydia for fighting for his special warrior David and other womens crossing the same challenge in Africa.

The charity of David and Lydia is called Hope for All Trust UK.



# MENNANA ELQASSRI



Story  
Nane  
(8)

## A great women who is empowering caregivers

Meet Mennana Elqassri Northen Morocco.

She is an independent care giver who does awareness, advocacy and support parents to go to the right clinic. She organises reviews of local patients, repeat prescription by supporting Telehealth. She participates in MENA brain week.

She is also an expert on culinary programs hospitality as a chef, with multiple skills, certified designer of clothes, local provider of school uniforms and founder of associations of patients!

The Epilepsy Stripe Week marks the greatness of care givers as her who empower patients and carers.

*In the photo, Mennana Elqassri is giving a gift of a girl's dress to Chantal Kanyabutembo from the EAA. Chantal and Mennana talked about Mennana using her skills to support Ester Aid Rwanda Teaching Vocational Training in Rwanda.*



# A Journey of Giving, Receiving and Valuing Care



# Epilepsy Stripes Week

*3rd Week of September each year*

## **What is Stripes Week?**

Stripes Week is an annual event promoted by the Epilepsy Alliance Africa (EAA). It is celebrated globally during the 3rd week of September each year. During Stripes Week, we mobilise people for epilepsy awareness throughout the world.

## **What is the easiest action to do?**

Wear or use zebra colours. Anything with stripes or zebra colours. A hat, scarf, headcover, shirt, dress, blouse, trousers, bag, belt, t-shirt and tie or cushion or hair.

## **Why this event?**

To accelerate epilepsy awareness and policies.

**Epilepsy Alliance**  
*africa*



# *Epilepsy Stripes Week*

*23-27 September*

**2024**

*Empowering Caregivers*

*A Journey of Giving, Receiving and*

*Valuing Care*

**Epilepsy Alliance**

*africa*

