

International Golden Light Award Winner 2023

Fides Uiso

TANZANIA



My name is Fides Uiso, and I am the mother of a 6-year-old child who has severe epilepsy. In light of the stigma and discrimination I faced due to my child, I decided to act as a beacon of hope for all those suffering in silence by becoming an epilepsy activist and human rights defender. As a result, we registered the Tanzania Epilepsy Organisation as a non-profit to fight against the negative attitude toward people with epilepsy.

I decided to advocate for epilepsy patients' rights by asking the Government to change all discriminatory laws related to people with epilepsy in order to change the negative attitude toward epilepsy patients.

I am the first person with the organization in Tanzania to file a lawsuit. Section 39(a)(ii) of the Law of Marriage Act [Cap 29 R.E. 2019]. In accordance with the section, a spouse may petition for annulment of marriage if the other spouse suffers from epilepsy or recurrent attacks of epilepsy. In order to reduce stigma, we must eliminate all discrimination and laws that violate the dignity of people with epilepsy.

Nearly 100,000 children in Tanzania live with epilepsy, and at least half of them are out of school (Quereshi et al., 2017). Stigma and discrimination associated with epilepsy, as well as concerns that schools are not equipped to support children with these health concerns, discourage parents from enrolling their children in school. Teachers are generally unaware of epilepsy, its treatment, and seizure first aid. Teachers are also not trained on how to create

an inclusive learning environment that supports all students, including students with epilepsy and other health concerns.

I created a project called *Kifafa sio Laana wala Uchawi kinatibika* (Epilepsy is not a curse, it can be treated) to improve the inclusion of children with epilepsy in primary schools in Tanzania through teacher training and capacity building. I launched another program for Youth with Epilepsy called *I AM A STAR* as I believe every person is born as a Star so By mentoring and empowering youth with epilepsy (Champions), we help them to serve as role models, inspire others, and reduce the stigma associated with epilepsy. Here we have youths with epilepsy who are great athletes, doctors, environmental activists, and IT specialists. Epilepsy awareness is usually done together, and we train them on how to control their triggers.

I launched the Mothers On A Mission Forum (MOM FORUM) in 2022 for mothers with children with developmental disabilities, since I realized that most children with developmental disabilities suffer from epilepsy. Unfortunately, most parents, especially mothers, are divorced after they have children with disabilities, so the Forum aims to provide them with mental and wellbeing training so that they can be empowered.

This year, I decided to organize a one-day workshop to build the capacity of human rights defenders with disabilities in Dar Es Salaam. The workshop covered epilepsy, protection mechanisms, mental health and wellbeing, and creating a father engagement group.

In addition, I was selected among 100 awardees in 2023 selected from around the world by Rehabilitation International under RI's Committee for the Centennial Award for Significant Contributions to Persons with Disabilities. The awardees are individuals and organizations that have made outstanding contributions to or had a profound impact on the equal participation and inclusive development of persons with disabilities.

In May 2023, I was invited to attend a meeting on implementing the intersectoral global action plan on epilepsy and other neurological disorders, with the aim of strengthening public awareness. In the meeting, which was organized by the WHO and Ministry of Health, I was invited to discuss my experiences regarding stigma and access to treatment for neurological disorders in Tanzania. I also proposed some steps to mitigate this issue.