



LISTEN TO MY HEART

A PASSION FOR PATIENT ADVOCACY

Flavia's Story

Flavia is a mother, wife and a nurse who has RHD. She is also a tireless advocate for People Living with RHD, networking and speaking on behalf of both health workers and PLWRHD to the global health community.



Globally, RHD is the most common cause of acquired heart disease in children and young adults, claiming over 300 000 lives annually and affecting 33 million people. Many RHD patients first present with advanced disease after a long symptom-free period. Women suffering from RHD often present during pregnancy being a stressful time for the heart.

Flavia is a mother, wife, and nurse who has RHD. Growing up near Kampala she remembers being very sick with fever and sore throat as a child. But she was never diagnosed with acute rheumatic fever. She also remembers, while in university, when her heart was beating fast and she had little energy. She went to the hospital and was given blood pressure medication. She felt better after two months so she stopped taking it.

After graduating university, Flavia got married and started her family. Just after her first baby was born, she was diagnosed with RHD when the fast heart beats and lack of energy returned. This time she was coughing blood and short of breath.

Her second pregnancy was successful but worrisome as Flavia now knew she had RHD. She had been told it was too risky to fall pregnant again. Flavia's second baby boy is now a healthy toddler but delivery was difficult and he was seriously underweight. Flavia now works as a nurse, raises her family, and is a member of the

RHD Patient Support Group at the Mulago Hospital. She was recognised by her colleagues as a passionate advocate, so she was chosen to represent PLWRHD at the first RHD Action patient event in Cape Town in 2016. Participating in this meeting was a turning point in her life; she met many people who were living successfully with their disease.

Flavia's talent for advocacy was also noticed by the global RHD community. In May 2017, she was invited to speak at the 70th World Health Assembly in Geneva to support the new RHD Resolution.

Shortly before the Geneva trip, Flavia underwent valvuloplasty at Uganda Heart Institute. A small balloon was inserted into her heart through a vein

in her leg to open a damaged valve. She says it has greatly increased her quality of life reporting that she can work harder, and even run with no challenges. She is playing with her sons and enrolled in a master's nursing programme.

In July 2017, Flavia was invited to a third global conference in Barcelona, Spain for the World Congress of Paediatric Cardiology and Cardiac Surgery. She shared her story as a PLWRHD and health worker in a developing country. Again, she formed new and important relationships with other patient advocacy groups.

Flavia continues her work as a PLWRHD advocate in both her local and global communities. She is now a social media expert, maintaining her new relationships on Twitter, Facebook and What's App.

'I did not know how long my life would be so I was not thinking about the future until I met a lot of people who were successfully living with RHD at a patient event.'

