



LISTEN TO MY HEART

A PASSION FOR PATIENT ADVOCACY

Christine's Story

Christine, 25 years old, has recently finished her Bachelor's degree in Industrial and Organisational Psychology at Makerere University in Kampala, Uganda's sprawling capital city. It's been a long journey from 2002 when she was first diagnosed with RHD.

RHD is a preventable and treatable form of heart disease that affects 33 million people around the world, particularly children and young people living in resource-limited settings characterised by overcrowding. It typically begins in childhood as strep throat, and if left untreated can progress to serious heart damage.

Christine is an active member and vice chairperson of the Rheumatic Heart Disease (RHD) Support Group at Uganda Heart Institute. This group offers peer support for medication adherence and advocates for the empowerment of People Living with RHD (PLWRHD). The group also provides community outreach for PLWRHD, to bring "lost patients" back to care.

Christine's passion comes from her personal experience as a PLWRHD and her desire to help others whose experiences may not have been as positive as her own.

Christine had always been a small and weak child. When her parents took her to local clinics, the diagnosis was always "malaria." Frustrated, her parents also took her to the local church for prayers and to traditional healers for herbal treatments. Finally, an x-ray revealed a heart problem.

Christine started medication that made her feel better, however her parents were told she needed heart surgery in India - an expense her parents could never afford. When Christine was

13 years old, Rotary International's Gift of Life provided funds for Christine's surgery in India. Her parents saved and raised money for transport using local television and radio appeals.

In September, 2005, Christine left her rural village in Western Uganda for the long voyage to Amrita Hospital in Kerala, India for a procedure to repair her damaged heart valves. A boy from another village also made that trip to India for heart surgery. A little older than Christine, and much sicker, his mother was chosen to accompany both children to India. Anxious and worried, Christine's family remained at home. After three weeks, the children were well enough to travel home. Christine has never seen that boy again but he has never left her thoughts.

Now Christine is a young woman with aspirations for a family and career. She

is healthy because of good lifestyle choices, taking her medications and keeping follow-up appointments. She has mechanical valves that produce a soft click-click sound, and takes antibiotics to prevent a relapse of the streptococcus infection that originally damaged her heart

Christine knows that early diagnosis and treatment prevent long-term complications of RHD. She is also very aware of the knowledge gap about the causes and proper treatment of the sore throat and rheumatic fever in her communities. Christine has been touched by the kindness and generosity of others along her journey back to health. She has personally faced the challenges that PLWRHD encounter and now dedicates her time and energy to help others manage their disease to live a full and healthy life.

'I think we can fight RHD to live a healthy and happy life despite the challenges we sometimes meet.'



Christine has shared her story in the hope that it will raise the profile of rheumatic heart disease. There is much to do to increase awareness of RHD at the local, regional and global levels. To find out more, please go to www.rhdaction.org.