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## Tanzanians with albinism embrace a life beyond stigma and superstition



▲ Graphic artist Camille Wulala and her collaborator Julia Jomaa sit alongside residents of Ukerewe on a brightly coloured water tower. All photographs by Harry Freeland/Standing Voice

In a country where myths about albinism can have deadly consequences, an organisation set up to battle discrimination is having a profound impact

Paschal Merumba has suffered prejudice from the day he was born.

His mother refused to breastfeed her “cursed” baby, the second child in the family born with albinism; the first had already died of neglect. Merumba was thought to have contaminated the community. He was made to eat apart and sleep on the floor.

In 2013, Merumba was attacked by men who tried to kill him. “I was out one evening looking for something to eat when I was ambushed by a group of men,” he recalls. “They tied my arms and legs, hooked a rope round my neck, and began pulling me into the bush. They wanted to cut my head off to perform witchcraft.”

He was saved when a neighbour ran screaming towards the group with a torch.

The health implications of albinism - visual impairment and the risk of skin cancer - are well known. For some, though, social stigma is the biggest danger.

“My life was spent in darkness,” says Merumba. “At my lowest point, I drank battery fluid in an effort to end my own life. When it failed, I said to myself: maybe it’s not God’s wish that I leave this world. Not yet.”

Now 54, his life changed after a meeting with Alex Magaga, who had worked on a BBC documentary, [In the Shadow of the Sun](#), which tells the story of two Tanzanians with albinism. Its success led director Harry Freeland to set up [Standing Voice](#), an organisation based on Ukerewe, an island in Lake Victoria, that defends the rights of people with albinism. Magaga is now its operations manager and Merumba the site gardener.

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