

## Wangode David struggles to show the way for other albinos

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When Wangode David's small, white body emerged from his black mother's womb, his father said he was a curse from God, a Western devil, and a humiliation.



Wangode David

He told his wife to kill Wangode, but his mother held the tiny albino baby close in the dark of the Ugandan night and refused. Wangode's father was too afraid to touch albino skin himself, so the infant lived to tell the tale.

"He did not dare touch me. He was too scared of the colour," said Wangode, now 40, a Ugandan adult albino. "The same thing that doomed me also saved me."

That's only one of the paradoxes of an albino's life in Africa. Endowed with black features but white pigment, albinos are not black or white. Treated like lepers, they exist between worlds, struggling with the stigma of appearing like a rich mzungu Westerner but, because of widespread discrimination and stigma, being much poorer.

"We are not mzungus, but we are not Africans," says Wangode, who lives in Uganda. "We are a bat, we are not a bird, we are not an animal."

Albinism is an inherited genetic condition characterized by the lack of the pigment melanin in skin, eyes, and hair. Without melanin, an albino has very pale skin, vision problems, and an increased risk of skin cancer, especially dangerous under hot, sub-Saharan African skies, but it's certainly not dangerous to others.

Try telling that to most Africans, said Wangode. Many albinos are killed at birth, and the ones that survive are treated like outcasts, shunned by society and denied jobs. Pregnant women believe they can catch a curse if they look at albinos, and families often hide albino children when visitors come to call.

#### **Not much help**

While information is scarce about Uganda, the Zimbabwe Albino Association says life expectancy for albinos is 43 years, compared to 57 years for darker Zimbabweans. Making up about one in every 4,000 people, only 29 per cent of albinos live to reach the age of 60.

"Very few African governments have policies to help albinos," said Theresa Ibisi, of the Albino Foundation in Nigeria.

One of the association's pressing issues is to excuse albino children from sports in the sun, and reduce import duties to make sunscreen more affordable. But the most important thing is education to stop the stigma, she said.

Wangode's father would not even touch his mother after she washed him. Children and teachers feared him at school, and after he graduated he took jobs his mother could get him, always hidden in the back, working in the early morning and late evening to avoid the heat.

He was barely shocked when his mother revealed that Wangode's birth was the trigger for her divorce.

"There is too much discrimination," he said. "The deaf, they have schools, the blind, the cripples, but not us. It is very lonely."

After hearing of albino organizations that sprung up in Zimbabwe, Malawi, and this year in Nigeria, Wangode decided to start one in Uganda. While those were often funded by wealthy, self-made albinos,

none were offered in Uganda, a small East African country with some 30 million people.

So Wangode drafted an albino manifesto himself, which asked that the government to grant loans to jobless albinos to start income-generating projects. That money would be used to find and educate albinos, fight stigma, and buy long-sleeved shirts, large-brimmed hats, and zinc oxide sunscreen. One bottle goes for half a month's wage in Uganda.

#### **A move to the capital**

He moved to Uganda's capital city, Kampala, with his wife and started a shop. But travelling to register albinos was too dangerous in the hot sun, and too expensive for a shopkeeper, so last year he wrote to the Ugandan government for help.

Florence Sekabira, then-Ugandan minister of state for Elderly and Disability Affairs wrote back, saying, "I concur with the position that albinos are a category of disabled persons on account of their skin deficiency."

But in the same package of letters, the ministry told Wangode that there was no money available for albinos: the government only supplies money to associations, not individuals.

Now, Wangode faces a catch-22: he needs money to travel and to organize albinos into an association, but without an association, the government won't give him any.

And last fall, he lost even the ability to lobby. Skin cancer struck on the back of his head, and he had to abandon his shop in Uganda's capital, Kampala, to recover with his mother and wife in his rural village.

Wangode knew he might face death with cancer, so with the money he had he bought a small parcel of land where his children and wife would live after he passed away. He is still trying to register albinos with a pen and a small pad of paper, but his poor vision and inability to travel outside makes that very difficult.

"Now, I'm trying to reach out to the sympathetic NGOs and the international community for help," he said to me. Even that isn't going far. Long-distance charges are prohibitive for most Africans, and he can't see the small print on a computer screen when he uses e-mail at the internet cafe in town.

"My dream is that if we make an association, we shall have a common voice," says Wangode. "In Kampala, I was defeated, but I can still have that dream."



#### ABOUT THIS AUTHOR

##### BIOGRAPHY



After reporting in Vancouver for the Province newspaper, the Globe and Mail, and freelancing for TIME Magazine, Jonathan Woodward set off to Uganda to write about Africa while building filters for people without clean drinking water. He has a degree in Mathematics from the University of British Columbia and was awarded the Press Freedom Award by the Canadian Journalists for Free Expression.

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