

AL SHAYMAA J. KWEGYIR's VOICE

"First of all allow me to use this opportunity to express my sincere thanks to the organizers of this conference for their resolve to invite me to give a talk on my personal experiences regarding Albinism in Tanzania. But, before I continue may I call upon you to stand up for one minute to remember those innocent Albinos who have lost their lives through brutal killings worldwide.

As some of you may already know, Albinism is "disability" just like any other form of disability. It is a genetically inherited condition which is said to be caused by lack or inadequacy of a substance called melanin. According to scientists, this genetic disorder is passed on by both parents to their off springs resulting in significant reduction in or absence of pigmentation in the hair, skin, and eyes at birth. As you can see me, eyes of Albinos look blue that can sometimes take on tones of purple or red in bright lighting. Small blood vessels can sometimes be seen through the transparent colorless iris of our eyes.

It is very unfortunate that in Tanzania, due to serious lack of knowledge as to why their "white skinned" off springs came about, African mothers and fathers became more and more fearful and suspicious and began to separate (in some tribes they are killed immediately after birth) "white skinned" off springs away from the "black skinned" population.

For several reasons or superstitious beliefs, in Tanzania stigmatization is common. Albinos are ostracized by their own families—especially in families where the difference in skin color is more distinct. This is a massive challenge, for which the international community must stand up and say, "NO".

Some attempts have been done in Tanzania to address some of the challenges confronting Albinos. Examples include my appointment as a Member of Parliament, formation of several pressure groups/NGOs; country wide campaigns etc. However, Albinos in Tanzania are still getting a hard time to survive. The challenges include:

- Social challenges – In addition to on going killings, stigmatization is rampant, the actual number of Albinos in Tanzania is not even known. The majority lack access to education and very few manage to go beyond primary school level
- Political – they are less represented in the Parliament, Local governments and other important decision making institutions

- Biological – living in the Tropical zone exposes them to strong sunlight and hence are susceptible to skin cancer
- Economic – because they lack education, the chance of getting well paid jobs is very slim and hence the incidence of poverty among Albinos is alarming
- Technological – because they are poor they are unable to access medicines they would reduce susceptibility to skin cancer

Allow me now to give you my own experience as an Albino living in Tanzania:

At birth, out of nine siblings, we were three albinos in our family. I am the eldest among those three. My brother and younger sister are also albinos. Our parents loved us, there was no stigmatization within our family. I was surprised why my skin was white while my brothers and sisters were black. I asked my mother why it was so. She told me it was God's wish. As I grew up, I realized I was being discriminated by children whom I played with by verbal abuses. Some said I was not a human being, that I was a ghost. A crowd of people called names in my back. I cried when returning home to my parents. They comforted me by saying "we love you, don't care about them".

That was the time when I started to feel the pinch. As I grew up I experienced the stigmatization to people with albinism. Many of them are single parents. Father chases mother with her baby, as a result no education for the child.

All these problems are just because of our colour. At the workplace I had so many friends, but verbal abuses continued. Many of them were gossiping when I was on duty, but at that time I didn't care. What I kept in mind was that I have to work hard and continue with my style of life, charming to everybody and respect all.

Now as a Member of Parliament I am proud of my President Jakaya Mrisho Kikwete who appointed me. He didn't care about my colour, he cared about my ability. I salute him. My appointment has raised awareness in my country, Tanzania, and all over the world, regarding the challenges that albinos face. I have formed a foundation – Good Hope Star Foundation – with a view to advocate for the rights and intertests of albinos, people with disability and other marginalized groups. Albinos if empowered can by themselves contribute to national economic development, create employment opportunities and generate income through various activities.

I believe you are better placed not only to raise awareness of the challenges faced by Albinos in developing countries, but also to support (financially, technically and morally) pressure groups such as the Tanzania Good Hope Star Foundation which is working very hard to end the killings and all other forms of discrimination."