

Albinism In Generations



Photographed by Adebayo Okeowo



About the Campaign

Albinism is a condition that is genetically inherited which results in the lack of melanin in a person's hair, skin and eyes. Albinism is non-contagious and transcends gender and race.

Unfortunately, in some countries in Africa, the highly misunderstood nature of this condition has resulted in diverse forms of violations against persons with albinism including discrimination, ritual killings, infanticide, lack of access to quality healthcare and education, amongst several others.

Addressing these misconceptions is what inspired the Albinism in Generations campaign, which aims to visually tell the stories of persons with albinism in a bid to dispel the myths and foster inclusion in society. Through these photographs, you will discover the personal stories of five individuals and their journeys towards overcoming the challenges, neglect and discrimination encountered as a result of their albinism.

Copies of this photo book will be placed in strategic public spaces like schools, hospitals, malls and restaurants in order to facilitate conversations around how, as a society, we can better respect and protect the rights of persons with albinism.

Special thanks to Open Society Initiative for Southern Africa and the I Am Movement for partnering with us on this campaign. If you wish to collaborate with us, please feel free to get in touch.

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Andrew Keane



Ingrid Bame, 28 Years Old.

Ingrid, 28 years old, is from the small gold mining town of Carletonville.

She currently resides in Johannesburg and works for one of the top IT Companies in the country as the Project and Client Manager. Ingrid is the eldest of 2 siblings who both have albinism.



Words from Ingrid

I love having albinism. I love standing out. I love walking into a room and grabbing the attention of everyone. But despite that, there is more to me than my skin. The beauty of my inner self transcends the fact that my skin lacks melanin. So my individuality is what makes me unique and not necessarily the fact that I have albinism.

I desire to see that day when we all can live in a unified space in which persons with albinism will not be afraid of being attacked or discriminated against. I hope that, a few generations from now, persons with albinism will not just be told that they belong, but will feel that we belong.





A young man with albinism, Sabelo Mpanza, is shown from the chest up, holding a large, fluffy seed head. He is wearing a light blue shirt. The background is a field of tall, golden-brown grass with green blades, slightly out of focus. The lighting is warm, suggesting late afternoon or early morning.

Sabelo Mpanza, 19 Years Old

Sabelo, 19 years old, from Swaneville in the West Rand of Johannesburg is the only child with albinism amongst his 5 siblings.

He is currently studying towards a qualification in Sound Engineering.







Words from Sabelo

My biggest challenge as a person with albinism is with my eyesight. It is really bad. I cannot open my eyes while under the sun unless I wear sunglasses or a cap. Also because of my poor eyesight, I have concluded that I cannot specialize in certain areas of Engineering that require visual signals. But I am coming to embrace it all and not see them as weaknesses but rather as things that make me different. Even when it comes to driving, I have been skeptical about it for the longest time, but now I am building the courage to learn how to drive.



The most extreme case of discrimination I have faced has been name-calling and I suffered temporary depression because of it. But all that is still nothing compared to those who get attacked just because they have albinism. I can't imagine what they are going through. I have never had to worry about going out and not coming back home. So it makes me angry when I think about the kind of things people do to others like me. Those that carry out such cruel attacks should stop being ignorant. The only difference between us is the lack of melanin.

Hannah Tshuma, 9 Years Old

Hannah, a young girl aged 9 is the first born of 2 siblings from Johannesburg.

Her younger brother is 4 years old. Hannah currently attends a mainstream school in Bedfordview where she is in Grade 4. She is the only person with albinism in her family.





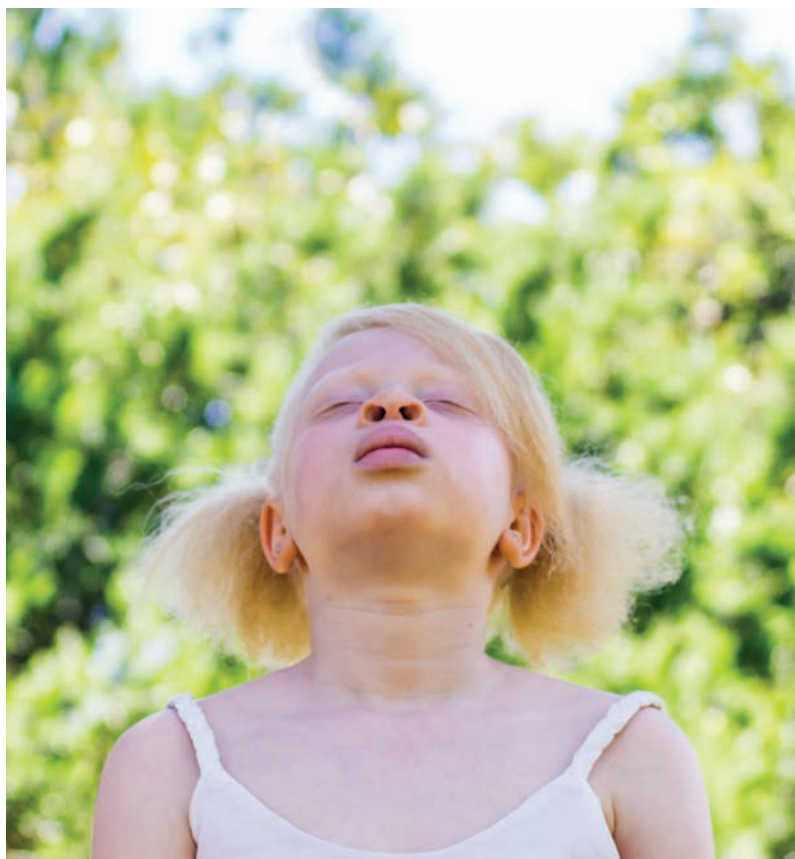
Words from Hannah

I feel great about being a person with albinism. I am beautiful and I feel great because of my skin colour even though I have to be extra responsible about it. I have also got very nice, soft and fluffy hair and I love that!

I have been teased and bullied because of my albinism but I fight back by telling those who call me names that I am human just like them.

I will want to see people treat us kindly and not calling us names or doing terrible things to us like killing us.

And for other kids like me who have albinism, I would like everyone to live a happy life and I encourage them not to be afraid to be themselves.









Kenneth Apane, 43 years old

Kenneth, 43 years old, from Mamelodi is a respected and popular taxi owner in in Pretoria.

Kenneth is married and is the father of 3 children, none of whom have albinism.



Words from Kenneth

When I was much younger, I used to get teased by people in my community. I was called all sorts of names. Even as I grew older, dating was an issue because some girls thought I was inferior to other boys.

I initially wanted to be a traffic officer but I faced discrimination and had to abandon that dream.

Then when I decided to start driving a taxi, some people refused to board because of their superstitious beliefs. But with persistence, I eventually became a man of the people. I wish people will not see albinism as a curse. I hope society will treat all persons with albinism with utmost dignity.



A woman wearing a vibrant red shawl is partially visible on the right side of the frame. The background is a soft, out-of-focus green, suggesting a natural setting with foliage. The lighting is natural and soft, creating a gentle bokeh effect.

Moleboge Lekwane, 37 Years Old

Moleboge, 37 years old, lives in Midrand, Gauteng and is a mother to a 3-year-old son who does not have albinism.

She is a Lawyer by profession and works for South African Freight and Rail company Transnet.



Words from Moleboge

Growing up along with two other siblings with albinism gave me a sense of normalcy. Our parents did not have albinism but my other siblings did and so we ended up being each other's places of solace whenever that was needed.

Back when growing up, it was my parents who had questions about how their three children had albinism whereas they did not. Now that I am mom to a son without albinism, I can only imagine the questions he will start to have as he grows older seeing

the difference between us. I suspect the discrimination persons with albinism face might drive him to be an activist on my behalf.

The killings of persons with albinism breaks my heart and I don't want to live, constantly looking behind my back, to see if someone is out to get me. I hope people will be better educated and there will be a demystification of the perception that our uniqueness is something to kill us for.





About the Photographer



Adebayo Okeowo is a human rights lawyer with vast experience working for African and international organizations. He is also an award winning photographer who has extensively used images and videos to bring attention to human rights issues and social justice problems. He has had his work featured in publications as well as exhibited in Italy, Mauritius, South Africa, Ghana and The Gambia. He also gave a TED talk in 2017 on the TEDx Pretoria stage titled: Visually Disrupting Injustice

Adebayo continues to create riveting visuals because he believes they are capable of challenging stereotypes and changing the status quo. He holds an LL.M from the University of Pretoria and is also an alumnus of the International Institute of Human Rights, Strasbourg, France.





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Implementing Partners

This project is a collaborative effort between the Advocacy Unit and Disability Rights Unit of the Centre for Human Rights, in partnership with the I Am Movement, and with the generous support of Open Society Initiative for Southern Africa (OSISA).

The Centre for Human Rights is a leading organisation working on human rights education and advocacy across the African continent. Founded in 1986 as part of domestic efforts in South Africa against the apartheid system of the time, the Centre continues to contribute in numerous ways to the advancement of human rights and democracy and the strengthening of institutions all over Africa and beyond.

The Open Society Initiative for Southern Africa (OSISA) is part of the global network of Open Society Foundations (OSF) and operates in eleven Southern African countries. OSISA promotes open society values by working towards building vibrant and tolerant democracies across the region, through its various thematic and country programmes.

The "I AM" Movement is a social platform that celebrates the lives of persons living with albinism and actively ropes in the broader society in order to increase the knowledge of albinism and break down myths. This is achieved through storytelling, visual arts and public debates.





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