



**Elizabeth Machinjiri (Malawi)**  
Founder of Hanna Foundation Inclusive School, Malawi; Albinism Activist

I was born in Malawi, Blantyre. As a child I had experienced no discrimination until I began primary school. Here, I found out that I was different. Other children would call me 'mzungu panda chuma', which means, a white person without money. Due to my low vision, my niece (sister's daughter) would help me obtain the important information taught in class that I missed.

Later on my sister transferred my niece to a different school; at this point I dropped out because I did not have anyone to help me keep up with school work. I was in standard 6 when I dropped out. My mother and my aunt encouraged me to get married, because that was my only hope at a secure future. At 11 years old I got married, my husband was a 15 year old boy from South African. In 1987 when I was 13 years old I had my first daughter, Faith. I ended up raising the child by myself.

At 15 I remarried, still, hoping that without education, marriage would be my way out of poverty. My second husband violated me, sexually and verbally. He would tell me I was not a real European and that I was a ghost. He was always drunk. Me and my husband separated from one another. It is here that I realised that marriage would not feed me or my children so at the age of 18 I decided to go back to school. I paid my own way up to Grade 8. While, my brother covered my schooling for Grades 10 and 11. My brother and I both have albinism. My brother was encouraged by our family to continue with school. However I am a woman so my family believed that marriage was the only thing that would help me in life.

My experiences as a young mother made me resilient and aware that I should not give up. At 24 years old I finished high school and received a job at the MACOHA weaving factory. After beginning my work at MACOHA, I went to MACOHA vocational school and attained a diploma in tailoring. I later applied for a business and management course, which I graduated from in 2 years. When I went back to MACOHA I was promoted to being an office administrator.

I joined the Association of Persons with Albinism (APAM) when I was 26. Today, I have started my own organization called the Disability Rights Movement, aimed at addressing the issues affecting persons with disabilities. I am also the founder and director of the Hanna Foundation Inclusive School, a primary school that caters for children with and without disabilities. We have 103 students currently enrolled at the school.

I have gone through so much bad in my life, but I have also come out of it. It is not very safe to be a person with albinism here (Malawi), but I don't think there is nothing I cannot achieve. Just because you are a woman with albinism it does not mean you cannot achieve anything. The importance of education cannot be stressed enough. On my part, I will always ensure that those around me, those that I can help do not experience what I had to experience and access an education.



**Jane Waithera (Kenya)**  
Co-founder and Programme Director of Positive Exposure Kenya and Climb for Albinism; Albinism Activist

I was born in Kenya into a "normal" African family. As a person with albinism I experienced more than my fair share of challenges. I knew I was different because of the way the society treated me; even from the stares. I knew I was different in a bad way; it's not that kind of difference that is to be celebrated. My mother abandoned me when I was a child, leaving me with my grandmother because of the stigma attached to my condition. In school fellow students would cut me with blades to see if I bled. I struggled with a lot of things especially when it came to reading and writing. I was punished every other day because of my visual impairment which meant that I struggled to see my assignments and class work. When I was about 12 years old I learnt the simple technique of moving closer to the board whenever I had difficulties reading which helped to some extent.

My childhood was filled with discrimination and stigma and I remember my childhood experience more than any other experience I had to go through as a grown up. In the midst of all this cruelty; my grandmother was my pillar of strength. Her unwavering support and love was a force that kept me going. Today, I run two initiatives on albinism. The first is *Positive Exposure* which focuses on education and advocacy through photography and art the narrative on persons with albinism. My second initiative is the *Climb for Albinism*. *Climb for Albinism* works with women across Africa for positive impact. In September, six women with albinism will be climbing Mount Kilimanjaro to demonstrate the strength and resilience of women with albinism. Kilimanjaro is the highest point in Africa; our voices will be heard as no voice from the roof top can be ignored. I firmly believe that the voices of women with albinism have been missing and it is time to begin an gendered discussion on albinism.

Persons with albinism are the most visible group of persons with disabilities, but issues about our rights are not being addressed. We are visibly rendered invisible. The absence of melanin and the visual impairments affecting people with albinism are disabling in and of themselves. I am limited to what I can do indoors. I can apply sunscreen, but the sunscreen does not render me immune against skin cancer. Corrective glasses, help where they can; but my vision will never be 100%.

Mere tolerance is not enough. The world must begin to accept, embrace and celebrate diversity. We must all adopt a vision that challenges us to 'change how we see, and see how we change'.



**Perpetua Senkoro (Tanzania)**  
Advocacy and Human Rights Officer at Under the Same Sun; Albinism Activist

I was born in Mwanza, a region bordering Lake Victoria in Malawi. The name-calling I experienced from people around me, as I walked to school made me start to wonder about my condition. I have never experienced problems with my family, because both my siblings also have albinism though our parents don't. In fact, my mom always made sure that we wore protective clothing and stayed out of the sun, while my dad always bought us books, so we had a habit of reading a lot, which was extremely helpful especially in primary school where our visual impairment was a great challenge.

I hated the fact that I would go into class and find notes or test questions on the blackboard, I couldn't see a thing. Sometimes no one wanted to read for me, some of my classmates teased me each time I tilted my head trying to read what was written on the board. I hated it when I had to pretend to write and when the teacher collected our exercise books for marking mine was empty. I hated Math, because teaching was done on the blackboard where I could not read. I hated my walks to school and back home because I would get teased all the way. I was a loner and I hated school altogether. Primary school to be precise, but weird enough, in mid-term and annual exams (which were printed on paper) I always came first, second or third of my class.

As I grew into my teens, I became more insecure about myself, I remember, each time I made a new friend, I would say to them, "you know I have lots of spots on my skin eey" in a way to see whether they'll still be friends with me or not. However, as I grew older, that gradually went away, and when I began volunteering at Under The Same Sun, an NGO advocating for rights of people with albinism, things changed completely. For the first time I understood what albinism was, and I met people like me who faced what I have but succeeded anyway, I met people like me who encountered terrifying experiences that made me thankful and appreciative of the good that I was blessed with. I graduated university with a law degree and am now an employee of this NGO. I have learnt to accept and love myself. Better yet, I am full of confidence and morale to reach my full potential to achieve greater goals. I'm in no way ashamed of myself, and I no longer feel obliged to justify my flaws to anyone. To make it simple, my albinism no longer hurts my feelings. I am a mom, an LLB graduate and currently managing an albinism awareness project and lobbying the government for policy and legislative reforms. I was blessed with supportive parents, and I was lucky to get supportive friends in university.

I aspire to become an influential international human rights activist able to do even greater in advocating for rights and welfare of people with albinism. I wish women with albinism in Africa learn to love and accept themselves and be confident enough to show their full potential. I wish we get more graduates, leaders and other professionals who are women with albinism. To the young girl with albinism I say, it's ok to have albinism. Don't be ashamed of your condition. You are beautiful and unique. You don't need to fit in! Do not conform yourself to the standards of those who belittle you. Cancer kills, wear sun protective clothing. Don't be a slave of "how will people see me?". Whether you are a student, farmer, street vendor, working in an office somewhere, give it your best, aim higher. You are capable of succeeding.



**Madalo Kajadza (Malawi)**  
Account supervisor, MACOHA Weaving Factory; Board Member, Association of Persons with Albinism; Albinism Activist

I was born in Jinji, a district in Malawi that shares a border with Zambia. My mother was schoolteacher; my father was my best-friend growing up and still is today. My mother tried to educate the other children about albinism and to make sure I was not excluded from activities. I had a great childhood experience and did not experience any stigma. Only after I moved to Balaka at the age of 7 and changed schools, did I experience bullying.

It is psychologically damaging for people to call you terms like 'mzungu' (white person), 'napweri' (pigeon pea that has just been boiled) and raw tomato.

I am currently an account supervisor for MACOHA weaving factory. I am one of the youngest females in the organization. I am also the youngest female member on the board of the Association of Persons with Albinism. I credit my achievements to the great support my family gave me.

I have been called 'millions' by people in the streets and it made me feel like I was not human, I feared for my life. I was called 'millions' because people think our body parts can make them rich. I had to turn down a job that was offered to me. I feared for my life so I could not accept the job as I would have to be based in Machiga district, one of the districts experiencing most of the violence perpetrated against persons with albinism. Recently, a man in the streets grabbed my breasts and I was really upset by the actions. I don't know if it had anything to do with me being a person with albinism, or simply, being a woman.

**About the campaign:**  
**#CelebratingWomenWithAlbinism**

**#CelebratingWomenWithAlbinism is a campaign by the Disability Rights Unit, at the Centre for Human Rights, University of Pretoria.**

**The campaign aims to celebrate the achievements and to highlight the stories and experiences of women with albinism. The campaign was launched in 2018 on International Albinism Awareness Day on 13 June.**



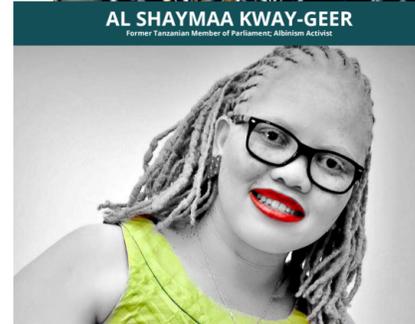
**AL SHAYMAA KWAY-GEER**  
Former Tanzanian Member of Parliament; Albinism Activist



**ELIZABETH MACHINJIRI**  
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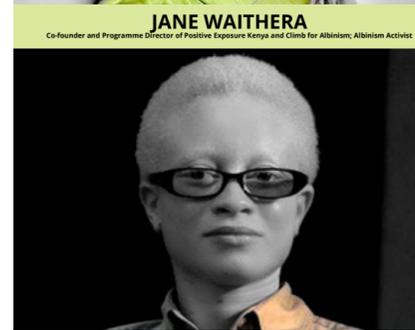
**JANE WAITHERA**  
Co-founder and Programme Director of Positive Exposure Kenya and Climb for Albinism; Albinism Activist



**THANDO HOPA**  
Model; Actress; Lawyer; Albinism Activist



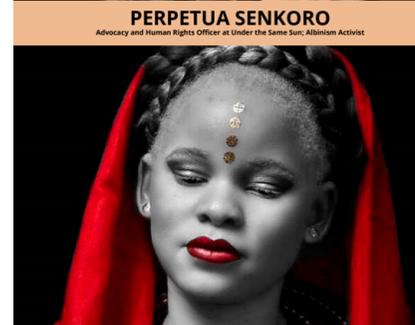
**NOMASONTO MAZIBUKO**  
Commissioner, Commission of Gender and Equality; Founder of Albinism Society of South Africa; Albinism Activist



**PERPETUA SENKORO**  
Advocacy and Human Rights Officer at Under the Same Sun; Albinism Activist



**RUUSA NTINDA**  
Chief Legal Officer, Law Reform and Development Commission of Namibia; Albinism Activist



**MADALO KAJADZA**  
Account supervisor, MACOHA Weaving Factory; Board Member, Association of Persons with Albinism; Albinism Activist



**REFILWE MODISELLE**  
Radio & TV host, Model, Actress and Voice Over Artist; Albinism Activist



**GRACE MASSAH**  
Vice-Principal at Nkhoma School of Nursing and Mid-Wifery; Chairperson of the African Disability Alliance; Programme Manager, Malawi Network of AIDS Service Society Organisation (MANASA); Albinism Activist

**#CelebratingWomenWithAlbinism**

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#### **Nomasonto Mazibuko (South Africa)**

*Commissioner: Commission of Gender and Equality; Founder of Albinism Society of South Africa; Albinism Activist*

I was born in Sophiatown, South Africa as one of ten siblings, five of whom had albinism. Having older siblings with albinism meant that my family and the community I was born into understood my condition and were accepting of me. I salute my parents for standing by us.

Things changed when I left home. I wanted to become a teacher so I had to relocate to KwaZulu Natal to get training. I took the train to Durban, it was a 2-day journey. When I arrived there, no one knew anything about albinism. In the teaching and training programs the children would run away from me, because they had never seen anyone with albinism.

When I qualified to become a teacher, I could not get employment. People did not want to hire me, and at that time it was school boards that hired people, so the people's prejudice about me, as a person with albinism influenced their decision to not hire me.

Eventually, I was employed as a teacher at a school where my sister was the Principal. I taught there for 20 years. When I applied for the Vice Principal position I did not get the position despite my experience, I suspect this was also because of my condition. When my sister and I were fired from the school shortly after I made the choice not to dwell on this. I picked myself up and applied to the University of Witwatersrand to further my studies.

At the University of Witwatersrand I received a scholarship and while I was there I started the organization to educate and provide user friendly information on albinism to the community which is today called the Albinism Society of South Africa. I have achieved much in my professional life since then that I am very proud of. I founded the Pan African Albinism Alliance. I have served as a Social Cohesion Advocate at the Department of Arts & Culture. The President appointed me as a Gender Commissioner. I have travelled extensively advocating for the rights of persons with albinism.

I will never stop working; I will only rest when there's no more killing of persons with albinism in Africa. Being 68 I am also conscious of the issues facing older women with albinism and the need for us to get together and address this.

I am also a phenomenal singer and a mother of four great kids, I am very proud of that. My husband and I were classmates, so we watched each other grow. And when his family met me they were amazed that he chose me. So I had a lot to do to prove myself to them. I took the role of taking care of my husband's siblings. I had to prove to people that I was like other women, that even though I had albinism I was also still a woman. I am a world phenomenon. I am a wonder.

My advice to young girls with albinism is get an education, look after yourself, and make sure you are safe and practice caution.



#### **Grace Massah (Malawi)**

*Vice Principal at Nkhoma School of Nursing and Mid-Wifery; Chairperson of the African Disability Alliance; Programme Manager, Malawi Network of AIDS Service Society Organization (MANASA); Albinism Activist*

I was born in Malawi, Lilongwe district but raised in three regions (Central, Southern and Northern). I am a twin and the 2<sup>nd</sup> born of six children, two of who have albinism. I grew up in a loving, caring and supportive middle class extended family that sheltered me. The fact that my older sister has albinism, meant that my mother understood the condition well by the time I came along.

My primary school life was quite bitter sweet, I went to two primary schools which both exposed me to new people and it was a challenge getting used to them. Although my fellow students called me names in school, wondered if I was normal, if I drank water differently, I never really felt isolated and soon got used to it. My biggest challenge was teachers not knowing how to accommodate me in class. As a person with albinism, I suffer from short-sightedness, which is common with people with albinism, but my teachers always forgot to prepare special materials for me. I also always ended up writing exams alone as they never remembered to prepare the exam in large print for me on time. I could not copy notes from black boards and always had to ask my friends who at times felt that I was slowing them down. As other students got time to play, I spent that time catching up on notes I wasn't able to finish during class time. I commend my parents for always being at the fore front in advocating for my needs as they made sure I had the text books I needed to excel in school. They did their best to try and ensure that my siblings and I were not abused in school.

The biggest challenge as a teenager was not knowing how to handle the social stigma. People continued to call me names and it was very hurtful. I developed the passion to advocate for people with albinism because I did not want them to go through what I had gone through. I was in a market one day and heard a man telling his friends how he can never take me to his bed. What made him think of me that way, to begin with? We have not advocated for our rights enough, I did not say anything to that man in the market and yet I should have. Too little is being done on the ground. People look at you like they have never seen anything like you. When I am in a relationship with someone, people want to know who that person is that can love me, me a woman with albinism. How can anyone love her, she cannot be living the same life that we live, they say.

I am a programme manager at Malawi Network of AIDS Service Society Organisation (MANASA), Vice-Principal at Nkhoma School of Nursing and Mid-Wifery and a Board Chairperson and Board Member for the African Disability Alliance South Africa and the Association of People with Disabilities in Malawi respectively. In the future I hope to attain a PhD in Policy Development, preach the gospel, and see women with albinism enjoying their human rights to the fullest and women in Africa leading in higher profile positions. To young girls living with albinism today, I say achieve more than I have been able to achieve, reach where I was not able to reach. Focus on you intelligence and wisdom and not your outlook. Work hard and be proud of yourself. But always remember to pray and lean on God.



#### **Thando Hopa (South Africa)**

*Model; Actress; Lawyer; Albinism Activist*

I was born in Sebokeng and raised in Lenasia South. Growing up I had two older siblings, extremely supportive parents and a loving grandmother who played a massive role in my upbringing. I had a lovely childhood which was filled with love and a whole lot of singing.

The issues began when I started the first grade. I went to a public school which had a lot of students. It was here where I started to notice that I had a different pigment to everyone else. In high school my insecurities began to manifest, I continuously tried to hide my albinism so that I could be like all the other children to the extent that I walked around in the sun without my cricket hat because people were making fun of me for the hat. My mother was so angry.

Modelling has been the one thing that made me reflect and dig deep into my self-esteem, to question my motives for wanting to alter my appearance. Being on the cover of Marie Claire was an awesome experience. To be on the cover of a reputable magazine and to look the way I looked. I didn't have to colour in my eyebrows, my hair was in its natural afro state. I felt that it showed a positive image for black children growing up with albinism to have someone on the cover that looks like them, I appreciated the fact that I was not required to look like what society perceives to be the perfect cover girl look. Marie Claire helped me express my truth in this respect.

I have had to be creative in navigating my way through the world as a person who is considered to be legally blind. I experience limitations in the industry as well. Acting is my main love, however the roles that come to me are very boxing and limiting in their very nature often having prejudices and supernatural connotations. I am never just presented with a role that requires me to be a doctor or a lawyer like actors and actresses normally receive.

The recent *Pirelli* calendar with P Diddy, Naomi Campbell and Whoopi Goldberg was a huge accomplishment for me. To be featured as the first South African and to look the way I wanted, it was on my terms. I was the only task member asked to write on the calendar, the only other person was the editor of the French *Vogue*. I went in as a model and representative for South Africa, albinism, blackness and womanhood and found my space as a writer. It was serendipitous.

The words we use in our indigenous languages to refer to people with albinism are derogatory and offensive. We should develop our languages to ensure that the correct terminology is used without offending people. It is pertinent that we look into this. Commissioner Nomasonto Mazibuko presented a term recently *'Abantu be fuzo'*, in isiZulu. Without these developments, our right to dignity and equality will continue to be encroached upon.

I would like to get to a point where we feel the fullness of our human agency, where we can navigate the things that we do without having to fight so many barriers. The more fluid I am

in my career and society, the more I know that the work I have done is worthwhile. I am beginning to see it and I will not stop until we are in a place where the new generation does not have to work as hard as I did to break through barriers.

My message for young people living with albinism, especially young girls, is that you are enough, you have everything in you to navigate this world. Everything outside of you is for your growth. Continue to know that you are enough, you are beautiful and capable. Cultivate that sense of worthiness, that is your mantra



#### **Ikponwosa Ero (Nigeria)**

*UN Independent Expert on the enjoyment of human rights by persons with Albinism, Albinism Activist*

I was born in Nigeria and I couldn't walk the streets without being subjected to abuse and cruel remarks and songs for having albinism. I used to question why I had been born in the first place. My mother comforted me by assuring me that God made no mistakes and that I was perfect as I was.

Recalling my youth during a conference in Nairobi, I spoke of how often I was beaten in school, because I told the teachers that I could not see and the teachers thought I was lying. I got through school by getting another student to copy the exam questions from the chalkboard in exchange for the answers. I went on to become a lawyer in Canada and in 2015, the United Nations Expert on Albinism, a post I still hold to date. Albinism is a congenital order affecting up to 15 000 people in sub-Saharan Africa. My priority is to end the brutal attacks on people with albinism by assailants seeking to use their body parts in witchcraft related rituals.

I recently appeared at the Pan African Parliament to outline the issues relating to the shortfalls of legislation in dealing with the trafficking of the body parts of persons with albinism. I have over a decade of experience in the research, policy development and practice of human rights concerning persons with albinism. I have advised persons and organisations around the world on human rights concerning people with albinism and have authored numerous papers and articles on the issue, including with regards to the categorisation of persons with albinism in the international human rights system.

**“My advice to young girls with albinism is get an education, look after yourself, and make sure you are safe and practice caution.”**



#### **Ruusa Ntinda (Namibia)**

*Chief Legal Officer, Law Reform and Development Commission of Namibia; Albinism Activist*

I was born in the small village of Okapyia, in Northern Namibia. I later stayed all over the country for academic purposes. I was born into a large typical African family, where I was mostly raised by my grandmother. My father stepped in when I got older. My father was strict with me; he showed me love, guidance and support and encouraged me to view my albinism as a gift. All this, empowered and equipped me with the tools that I required to be successful today.

I was loved and generally well taken care of, however there were some family members who were not so accommodating. I remember comments that would be made: 'I pray to God, that I don't get a child like you', 'I only assist you so that I am not cursed' as well as 'I don't know why your father bothers with your education, it's a waste of time people like you don't live long. You will soon disappear. I mean I have never seen a funeral for people like you.'

In school I was badly misunderstood by both students and teachers. I was visually impaired because of my condition. Some ignored me, while others would say that I am an abomination, others would spit on the ground when I addressed them and many questioned why I needed an education. As a defence mechanism I became rebellious and troublesome. Some teachers were okay, but the kids were quite cruel. Some students would refuse to sit next to me in class while, others would cut me and beat me to see how my blood and tears looked. This mostly happened in primary school. In high school I would defend myself so it did not happen.

As a teenager most of her time was spent selling goods on the side of the road. Any other time was reserved for school, my extra mural activities as well as helping out at the school and the public library.

The misconceptions, myths and cultural attitudes towards albinism result in the persecution of people with albinism. This has also has a bearing on how people with albinism are viewed in employment spaces, our abilities are questioned based on our skin and our sight. As such, there is constant need that builds inside us, for us to prove ourselves as just as capable as the next person.

I am extremely proud of my academic achievements; they have empowered me to achieve many other goals. I made sure that I become somebody through my sweat and tears. I took charge of my life and wrote my own destiny. I would say, I wrote the book I wanted to read or see on the shelf about my life. My vision for women with albinism on this continent is that we are more empowered and confident. You can achieve anything you set your mind to as long as you are empowered and confident. I encourage women with albinism to use the negativity that they are going through as a stepping stone for a brighter future. Use these experiences to write the story that you want to see tomorrow. Continue to stand out!



#### **Al-Shymaa Kway-Geer (Tanzania)**

*Former Tanzanian Member of Parliament; Albinism Activist*

I was born in the coastal region of Tanzania in a place called Tanga but raised in many regions as my father moved a lot due to his various job opportunities. My childhood home was loving and I received extra care and attention due to my condition. We are nine children, five boys and three girls and only three of us have albinism. I never experienced any violence or discrimination in my family at all. I was deeply loved and cared for.

As a young girl going to primary school, I found it very difficult as I encountered so many challenges in class. I was never comfortable in school as people spat on me and constantly pinched me because they noticed that my skin would always turn red when they did and they found this funny.

As a teenager I was afraid of relationships, I always thought boys wanted to use me and to avoid all that I kept to myself and was mostly with family. But as a result of this, I never had to deal with peer pressure which was a good thing.

As a woman with albinism, I don't feel like having albinism itself has limited me, I have done my work like any other person. I have been a leader, I have been accepted in my line of work and so have done my work like anyone else would be expected to. Women with albinism can achieve great things if equal opportunities are provided.

My proudest achievements have been in my professional life. As a member of parliament I have served on the women's caucus as a treasurer and signatory. I was appointed by the president to the Tanzanian Constitution Review Commission. I was a committee member on the Committee of the Natural resources and environment. Because of my work, I have been invited to contribute to important forums such as the UN Durban Review Conference that took place in Geneva where I spoke on behalf of the Late Nelson Mandela, Former President of South Africa.

The challenges I have encountered have been people talking about me on the streets, while carrying out my work in the villages there has always been fear of being alone and I have always made sure I am with a partner as it is not safe. But as person with albinism I do not want us to focus on the challenges anymore but change the subject of albinism. I want to focus on the future, a better life and education.

In the future I hope that awareness continues because I want to continue spreading awareness and advocating for inclusion of persons with albinism in society.

Young girl with albinism, focus on your health first and then your education second. Do not give up because of the discrimination.