Kenyans with Albinism and Racial Discrimination

- This report is respectfully submitted by the NGO, Under The Same Sun, to the Committee on the Elimination of Racial Discrimination regarding concluding observations on Kenya.

- Under The Same Sun (UTSS) is a civil society organization committed to ending the often-deadly discrimination against people with albinism. UTSS promotes, via advocacy and education, the wellbeing of persons with albinism who are misunderstood, marginalized, and even attacked and killed because of their genetic condition. While UTSS acts globally, much of our focus has been on the crisis faced by people with albinism in Tanzania.

Executive Summary

- Albinism continues to carry a deep stigma in Kenya. In March 2017, Senator Mike Sonka publicly insulted former Gatanga MP Peter Kenneth by calling him “albino” in a Citizen TV interview. Neither man has the condition, although the insult targeted Kenneth’s lighter skin tone. Sensitive to the upcoming August election, Sonka later apologized.

- A small, vulnerable population within Kenya regularly experiences discrimination and violence based on the colour of their skin. Often friends, relatives, community members or people in positions of power / officialdom collude in or are the authors of this violence and discrimination. This makes it hard to trust people, and persons with albinism can become alienated from community, social, cultural and economic life. They come from all races, but are stigmatized for their lack of pigment in the skin, hair and eyes. Myths and superstitions abound.

- Across the region, people with albinism are ritually hunted, attacked and murdered. Their arms and legs, bones and blood, fingers and toes are commodities. Limbs and digits are hacked off to feed an illegal trade in the body parts of persons with albinism, which are sold in the form of bogus potions or charms.

- Discrimination also arises from false beliefs and mystification of albinism’s striking appearance. Negative cultural attitudes and practices can be found around the world. From Africa to Asia to North America, albinism conjures a mystical spectre in the social imagination – a “blank slate” upon which cultural and religious fears and fallacies are inscribed. Aside from ritual beliefs, societies commonly define this group as “Others” or outsiders. People with albinism are easily recognized and targeted for persecution.

- Albinism occurs throughout the world and within every race, but albinism does not constitute a distinct race or ethnicity itself. Yet, people with albinism
experience discrimination related to skin colour. Many systems of privilege and prejudice are founded on the degree of lightness or darkness of a person’s skin colour and have been variously described as ‘colourism’, ‘shadism’, ‘skin tone bias’, ‘pigmentocracy’ or ‘colour complex’. These dynamics are recognized in history, sociology and international law.

- Ridicule, stigma and social exclusion are common. People with albinism in Kenya’s schools and on the streets are incessantly teased and bullied. Classmates as well as teachers and others in authority hurl insults. It leads to demoralization and psychosocial issues.

- These names are often deeply derogatory and dehumanizing. These include, “zeru zeru” - a mystical or ghostlike being or “mzungu’ a name used to refer to Caucasians.”

What is Albinism?

- Albinism is a rare, non-contagious, genetically inherited condition characterized by a lack of pigmentation in the hair, skin and eyes. It occurs regardless of ethnicity or gender. Both parents must carry the gene for it to be passed on, even if neither have albinism themselves.

- The majority of people with albinism are “legally blind” and very sensitive to light. Eyeglasses can only partially correct this problem. While most can read large print and don’t require Braille, they cannot see a blackboard in a regular classroom setup. This limited vision when unaccommodated often results in disability. In most cases, structural barriers prevent participation in society on an equal basis with others.

- Albinism occurs across Africa at a rate of between one in 5,000 and one in 15,000 with certain tribes exhibiting higher frequencies averaging 1 in 1,500. UTSS believes this range is a conservative estimate, since data is inconsistent in quantity and quality across the continent.

- With no melanin or pigment for protection, skin burns immediately in the sun. Most Africans with albinism have severely sun-damaged skin, acquiring dramatic, visible skin damage at an early age. Fatal skin cancer will claim the vast majority before they reach 30 to 40 years of age. There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable.
Applicable Human Rights Law

- People with albinism face stigma and discrimination arising from their pale colour and disability. An intersectional approach is the best lens to understand the multiple dimensions from which a person with albinism experiences social and political responses to their condition.

- In its concluding observations on the combined fourth to eighth periodic reports of South Africa, the Committee monitoring CERD compliance\textsuperscript{10} made recommendations on the situation of persons with albinism which are equally true in the Kenyan context:
  
  o "The Committee is concerned about the discrimination and stigmatization faced by persons with albinism, on the basis of colour. It is also alarmed by reports of cases of abduction, killing and dismembering of persons with albinism, including women and children, as their body parts are allegedly used for witchcraft purposes." (para 20)
  
  o "The Committee recommends that the State party take effective measures to protect persons with albinism from violence, abductions, discrimination and stigmatization, including through the action plans and other measures taken to implement the Durban Declaration and Programme of Action." (para 21)\textsuperscript{11}

- The Durban Declaration and Programme of Action considers "colourism" as "racism and related intolerance." The Declaration also speaks to "xenophobia and related intolerance" which covers discrimination faced by people with albinism.\textsuperscript{12}

- Discrimination based on the pale skin colour associated with albinism is covered by the Convention on the Elimination of All Forms of Racial Discrimination under Article 1, section 1: "In this Convention, the term "racial discrimination" shall mean any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin...\textsuperscript{13}" (emphasis added).

- At the 2014 Expert Meeting on Persons with Albinism: Violence, Discrimination and Way Forward former CERD member, Mr. Patrick Thornberry, talked about the relationship between albinism and the work of CERD:
  
  o "...bringing discrimination against persons with albinism within the concept of racial discrimination might appear counter-intuitive because albinism is not confined to particular ‘races’ or ethnic groups. On the other hand... in the Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the governing concept was not ‘race’ but ‘racial discrimination’, which may be based on any of five ‘grounds’: race, colour, descent, national origin, and ethnic origin."\textsuperscript{14}
The Constitution of Kenya prohibits discrimination on the grounds of colour and disability, which speak to albinism: S 27(4) “The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth”¹⁵ (emphasis added).

In her report to the HRC, the Independent Expert on the Enjoyment Of Human Rights by Persons with Albinism notes the same thing. According to Ikponwosa Ero:

- “Discrimination, stigma and bullying of persons with albinism owing to their appearance have been reported in all regions of the world, to varying degrees. Such discrimination has been described as discrimination based on skin tone or shade, including within the same ethnic group. While discrimination based on skin colour is an everyday reality for most persons with albinism, discourse on discrimination based on colour has rarely been applied to albinism. This is for various reasons such as the lack of visibility of albinism, until very recently, the lack of understanding of what persons with albinism experience and lastly, but perhaps most significantly, strong historical ties of racial discrimination discourse to race or ethnicity. Yet, there is potential to address albinism under the International Convention on the Elimination of All Forms of Racial Discrimination, as the governing concept is not “race” but “racial discrimination”, which may be based on any of five “grounds”: race, colour, descent, national origin and ethnic origin.”¹⁶

High Profile Individuals

- Kenyan Genge musician Nonini uses Narobi hip-hop beats in “Colour Kwa Face” to rap about discrimination against people with albinism: “Why do u keep discriminating me? / Am I not a human being? / Why do u make me feel inferior? / You don’t have respect for me. / Why do keep killing us... / Why...? Why...?”¹⁷

- A few individuals with albinism have achieved high profile status in Kenya. Isaac Mwaura is the first Kenyan Member of Parliament with albinism. Two county assembly representatives also have the condition. Madam Justice Mumbi Ngugi is a high court judge with albinism.

- In October 2016, Mwaura organized a beauty pageant for people with albinism to fight stigma.

- The fact that such individuals have attained higher profile status in Kenyan society is positive. However, Madam Justice Ngugi has been the subject of insults, including from a politician. In March 2017, Senator Mike Sonka publically insulted another politician by calling him “albino” – though neither have the condition.¹⁸
Attacks and Killings

• Across East Africa many believe that the body parts of people with albinism can bring good luck. There have been thirteen reported attacks in Kenya, including five killings and eight survivors.\(^{19}\)

• Attacks and murders of Kenyans with albinism are part of a wider, cross-border black market in the region, where demand increases during election campaigns. There have been 519 reported attacks across 28 countries, including 190 documented murders of people with albinism and 329 cases of missing persons, assault, mutilation, rape, attempted abductions, grave violations and other acts of violence.\(^{20}\) These numbers are likely very low, as there are almost no monitoring mechanisms, family members are sometimes involved and secrecy usually surrounds witchcraft practice and ritual killings - the sociocultural context of most of these attacks and violations.

• Jayne Waithera, a Kenyan activist with albinism and co-founder of NGO Positive Exposure said “You don’t feel safe at all, you feel like a foreigner, I mean I’m a Kenyan citizen, but I don’t feel entitled to be a Kenyan, I feel like my life is at stake, as in I don’t know how many more days I got to live. We die out of skin cancer but now I would rather die out of skin cancer rather than die in the hands of a witch doctor, you know?”

• Waithera adds: “when you go to these urban areas, like Nairobi, Kisumu, Mombasa, it’s so scary. See, these people have access to information and they know exactly what is happening in Tanzania [where demand for body parts is concentrated]. See, they sell us for a lot of money, around $25,000 to $75,000 [USD], that’s a lot of money. You walk on the street and somebody just points at you: "that's money!" I mean, "that's walking banknotes!" \(^{21}\)

• Women with albinism are often targets of sexual violence. According to OHCHR (2013), common myths associated with albinism include that “sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS.”\(^{22}\) Survivors of sexual violence can experience increased health complications such as Post Traumatic Stress Disorder (PTSD), pregnancy and Sexually Transmitted Infections (STIs).

• On September 20, 2015, a 56-year-old man with albinism by the name of Enock Jamenya died of injuries from a brutal machete attack. Ten days earlier Enock was attacked by three men armed with pangas at his home in Gavudunyi village, Hamisi Subcounty, Vihiga county, Kenya. Attackers hacked his left ear, arm, neck and fingers. Jamenya’s body parts were sought for sale in Tanzania.

• On March 15, 2013, a seven-year-old boy with albinism in Embu, Kenya, escaped relatives attempting to sell him for ritual purposes. He was kidnapped by his uncle and other relatives to meet up with buyers. Kidnappers threw the boy out of the window of a moving vehicle when he screamed.\(^{23}\)

• On April 18, 2012 a three-year-old with albinism was abducted, drugged and
transported illegally by three men through the Nairobi airport in transit from Tanzania to Ouagadougou in Burkina Faso.  

- On Sunday, March 4th, 2012 Mrs. Mzungu took her daughter Joyce to church. After the service, Mrs. Mzungu couldn’t find Joyce. She approached the pastor to enquire on the whereabouts of Joyce. He said to be patient and pray. Eventually, she went looking for Joyce but to no avail. The next day, the Pastor called stating he had Joyce. But he left the area and Joyce has not been found.  

- On December 24, 2010 a mother killed her three-week-old baby boy with albinism. The father had threatened divorce, claiming the baby was not his, but rather was a ghost.  

- In September 2010, police made arrests of individuals involved in a syndicate selling human body parts across borders in East Africa. This network included mortuary attendants and funeral home workers. Police arrested two attempting to smuggle male genitalia across a Kenyan border.  

- On August 2, 2010, a 4-month-old baby girl with albinism by the name of Esther Moraa was killed by her mother, Sara Kemunto Nyabuto, age 23, at Bokimweri sub location in Nyamache district, Kenya. The father was threatening divorce and had convinced her to kill the baby since she was born with albinism, hence a bad omen and a disgrace to the family. The mother has been sentenced to serve one year in jail by a Gucha court. Ogembo Resident Magistrate Richard Koech said, “the accused killed her child for being an albino.”  

- In August 2010, Nathan Mutei attempted to sell his friend, Robinson Mkwama, a Kenyan with albinism for Tanzanian Sh400 million (KSh22m). Mutei smuggled Mkwama to Mwanza, Tanzania via Kitale in Kenya’s Rift Valley Province. Mutei was searching for customers in the mining sector who believe the body parts of people with albinism bring luck in prospecting. Tanzania is the largest market for such body parts in East Africa. The plot was overheard and reported to police. Mutei was sentenced to 17 years in prison.  

- In January of 2008, Margaret was abducted by three men. Her body was found the following morning with her legs, genitals, breasts and hands removed.

Recommendations

Justice for Victims

- All cases of attacks and rights violations against people with albinism must be investigated and prosecuted properly and immediately. The vulnerability and marginalization of persons with albinism should be considered an aggravating factor. Publicize convictions and sentences in all cases wherever possible to increase the deterrent effect.

Victim rehabilitation
• In line with the UN support for victims of torture\textsuperscript{31}, provide immediate and accessible remedies to victims and their families including:

  o Psychosocial support to all victims and their family members should be available and accessible at the community level

  o Socio-economic support should be provided to victims and their families to support the rebuilding of their lives.

  o Legal support including legal aid to victims of families to attain legal remedies

  o Medical support if and where a victim and their family sustained injuries

**Raise awareness**

• UTSS congratulates the government for all its efforts so far in raising awareness but as the recent public ridicule of albinism shows, there remains work to be done. Therefore the government should:

• Continue to work with albinism civil society groups to demystify albinism and normalize the appearance of persons with albinism through replication of images of persons with albinism in the public sphere. This can be accomplished by appointing more persons with albinism to public roles, denouncing verbal abuse around albinism and building on the success of previous awareness programs such as Mr. & Mrs. Albinism Kenya and awareness-raising campaigns conducted over recent years, around International Albinism Awareness Day on June 13.\textsuperscript{32}

• TV and radio spots, seminars, “in-person” encounters and public health campaigns should be produced and strengthened to raise awareness about the condition and its stigma and to humanize and normalize albinism. Family members, legal guardians, caregivers, youth, schools, labour organizations, communities, community leaders, the media and other civil society organizations should be targeted with de-mythologizing messages about human dignity and respect, focusing on simple genetic & medical explanations, offering easy ways to live with and care for the condition.

**Fine-tune healthcare**

• The Ministry of Health, (and not just the council on disabilities) should properly facilitate programs to enhance health for people with albinism and prevent early death due to skin cancer. These include:

  o In 2015, the government announced a program for the purchase and distribution of sunscreen for people with albinism via the National Council of People with Disabilities (NCPWD) and Kenya Medical Supplies Authority (KEMSA). Authorities must ensure this program is effective and that people with albinism are receiving sunscreen in various parts of the country.
For that program to be effective, medical personnel must be trained on how to use sun protective creams so that they in turn can demonstrate this to persons with albinism.

All locations where dermatological and ophthalmological services including sunscreen and eyewear are available should be well publicized, including those in rural areas.

Dermatological and ophthalmological products and devices must be made available and accessible at little or no cost as a matter of the right to the highest standard of attainable health (ICESCR) and reasonable accommodation (CRPD).

The government should support initiatives for producing sun protection cream locally so that the problem of expired sunscreen that is procured will not be a barrier to providing adequate healthcare and dermatological support.

Invest in education

The government should invest in education for children with albinism as this population tends to have less access to education and employment and therefore disproportionally experiences entrenched poverty. Getting a job indoors is key to lowering premature deaths due to skin cancer.

In particular, spaces within safe, supportive, nurturing environments should be made available. Albinism civil society organizations should be consulted to identify children for this initiative.

The government should consider as a model the UTSS Education Program, which funds education for 300 Tanzanian children with albinism, from kindergarten to graduate studies. This number represents only a small fraction of children with albinism in need of such opportunities. UTSS covers personal expenses, school supplies, uniforms, medical services (regular dermatology and optometry examinations) as well as sun protective clothing, sunscreen lotion and low vision devices.

UTSS monitors the schools to ensure the environment is free of abuse and that students’ health, education and social well-being is being looked after. UTSS follows up to ensure staff, administrators, teachers and other children have a good understanding of albinism.

Train educators

The government in consultation with albinism civil society organizations should develop appropriate training for educators (teachers, administrators, staff, etc.) specifically suited to responding to the bullying and discrimination against students with albinism, which often leads to school dropout.
• Training should also make educators aware of the particular low-vision needs of children with albinism. Being legally blind is a physical disability and entitles one to reasonable accommodation at school. Large print, glasses, magnifying glasses, monoculars and specialized computer equipment are helpful to most children with albinism. The child should be consulted on the best vantage point in a classroom from which to see i.e.: proximity to the blackboard; from the right, left or centre, and; out of bright, direct light. Blackboard notes, exams, assignments, etc. should be made available in appropriate print sizes. Extra time should be provided for written exams – an additional 50% is suggested. Providing a level academic playing field for children with albinism can help mitigate discrimination.

• Training should also make educators aware of the specific sun protection needs of children with albinism, such as: using sunscreen lotion with Sun Protection Factor (SPF) of 30 or more; ensuring kids are wearing wide-brimmed hats and sun-protective clothing e.g. breathable long-sleeved shirts with high collars, long trousers, and long skirts, and; sun-avoidance in shade or in-doors. Implementing these measures should be done in such a way as not to compound marginalization.

• In some circumstances, the family will enable or even be the source of discrimination, aggression and violence. Children model adult behaviours, which are transmitted and reproduced via myths, insults, and cultural stereotypes. Educators and other non-family members should be empowered to protect children with albinism from discrimination.

Employ Persons With Albinism

• The constitutionally protected affirmative action initiative on hiring persons with disabilities has been extended to include people with albinism. But it needs to be fully implemented.

Collect data

• The current – often published number – of persons with albinism in Kenya as being 3,000 is unreliable given that its source appears to be the registry of those who access sunscreen from government / the national council on disabilities. Since sunscreen remains inaccessible to many and some remain unaware of the program, there is need to verify this data to support future planning on the issue.

• Therefore, the criterion of albinism needs to be included in the next census. This could be as a type of disability so that persons with albinism are not forced to only check off “vision impairment” or “other” as a category.

• For now, prior to a census, ministries and quasi-government bodies such as schools, hospitals and social services agencies can amass data for consolidation at the national council on disabilities, to reflect the true count of persons with albinism in Kenya.
The government should investigate, collect and publish data about violence and discrimination against Kenyans with albinism. Better data is needed on attacks, murders, employment, health and other indicators of well-being. Statistics on attacks and murders provided in this report are well-documented but represent individual cases that underrepresent the true scale of the issue. The scale and character of discrimination faced by Kenyans is not well understood. Change need not wait for data, but ultimately, evidence-based policy requires it.

Such data should be made available to the civil society and the public. However, it needs to be anonymized in such a way to not to reveal the actual location or personal information about any individual. UTSS is available to consult on the specifics of data collection and sharing.

Challenge negative stereotypes

The government and civil society organizations should challenge negative stereotypes about albinism in popular culture and film, which reinforce discrimination and fuel attacks.

Member States and albinism civil society organizations should encourage academics, journalists, film producers, film funders, film directors, online content creators and popular culture curators to abandon pernicious negative portrayals of people with albinism in favour of portrayals as neutral or positive characters, in roles unrelated to the condition.

Ensure Justice

Government should increase efforts to prevent crimes affecting persons with albinism, strengthen the legal response to such crimes and bring perpetrators to justice through prompt and impartial investigations.

The legal system must guarantee victims’ right to justice and redress as well as providing medical, psychosocial and legal support to victims of attacks.

Conclusions

Kenya promised to “leave no one behind” as part of a pledge to carry out the UN sustainable goals, Agenda 2030. The government committed to “start with the furthest behind first.”

Persons with albinism are among the furthest behind, having been left out of discourses on colour, disability, gender, and other intersecting identities that are part of life with albinism.

Under the Same Sun commends the government of Kenya on taking many positive steps. But significant challenges remain for Kenyans with albinism. These can be overcome by implementing the above recommendations.
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1 Ghafla.com “Mike Sonko’s albinism insult made on Citizen TV rubs Isaac Mwaura the wrong way ... This is the ultimatum he issued” March 21, 2017 http://www.ghafla.com/2017/03/21/mike-sonkos-albinism-insult-made-citizen-tv-rubs-isaac-mwaura-wrong-way-ultimatum-issued/ Accessed April 2, 2017


8 From the Convention on the Rights of Persons with Disabilities, Article 1, paragraph “e”


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26 Source: Citizen Television, Kenya
29 Vicky Ntetema, “PWA Robinson Mkwama sold alive by friend who is arrested by police” UTSS report. See also Gerald Lumanyika “Kenyan held over attempt to sell albino friend ” Daily Nation, August 17, 2010 http://www.nation.co.ke/News/-/1056/978228/-/wbclaa/-/index.html Accessed April 2, 2017
30 Agent of Under The Same Sun in Kenya who visited and interviewed survivors of the victim (July, 2013).
32 A/HRC/26/L.7 International Albinism Awareness Day

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