



Protecting Children with Albinism from Bullying

- This report is respectfully submitted by Under The Same Sun to Marta Santos Pais, Special Representative of the Secretary General on Violence against Children.
- 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

- Around the world, children with albinism¹ are particularly vulnerable to bullying. With very pale skin, hair and eyes as well as low vision, these children are almost universally insulted, mocked, harassed and intimidated. They are isolated by stigma, myth and cultural prejudice. In some places, they are physically assaulted and killed.
- In East Africa, this bullying is a catalyst for violence. Across 25 countries there have been 417 reported attacks since 2000. This includes 159 documented murders of people with albinism and 258 cases of missing persons, assault, mutilation, rape, attempted abductions, grave violations, and other acts of violence.² Most victims are children and the violence is under-reported. Myths persist that body parts of persons with albinism bring fortune and good health. A corpse can be worth up to US\$75,000 on the black market. Family members are often complicit. Several attacks occurred over the weeks this report was drafted.
- This type of violence doesn't happen in a vacuum. Bullying enforces an atmosphere where victims are dehumanized, discrimination is normalized, and violence is socially sanctioned.
- Bullying also causes non-physical injuries. Bullied children with albinism lose self-confidence, drop out of school and isolate themselves from classmates, family and community. Alone, they are even more vulnerable.
- This is not just an issue in Africa. Bullying of children with albinism is a near-global phenomenon. In Europe and North America, bullies are empowered and inspired by negative portrayals of people with albinism in popular culture. The 'evil albino' remains a common character in Hollywood. The lives of people with albinism are marked by such cultural prejudices.

But bullying can be disrupted. *UTSS recommends:*

1. Investing in education for vulnerable children with albinism
2. Raising public awareness about albinism



3. Increasing the capacity of teachers, relatives and community members to respond to bullying of children with albinism
 4. Investigating incidences of bullying and collecting data
 5. Engaging cultural producers to challenge negative portrayals of people with albinism in film, TV and online.
- With the right educational environment, children with albinism can themselves become powerful advocates against bullying. They can be future role models within their respective societies; strong voices against bullying and discrimination. Doctors and members of parliament with albinism will replace movie villains in the social imagination. Their success will be the most powerful force for social change.

Children With Albinism as Targets of Bullying

- Most children with albinism don't look like their friends, family, classmates and peers. They suffer discrimination, isolation, stigma and in some places, ritual attacks and killings.³ Pale skin and hair; low-vision and squinting; sun avoidance and skin damage - all mark the child as different.
- 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.⁴
- Almost everyone with albinism is visually impaired. The majority 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. This limited vision often meets the criteria of a disability. In most cases, structural barriers prevent their participation in society on an equal basis with others.⁵
- In North America and Europe, around 1 in 17,000 to 20,000 people have albinism. It is much more prevalent in Africa, where estimates can be as high as 1 in 1,400.⁶
- A 2012 UTSS report stated: "In countries where the population has dark-coloured skin, hair and eyes, PWA [persons with albinism] stand out easily making them easy targets of taunts, discrimination and dangerous myths."⁷ From babyhood, these children are exposed to mockery, laughter, and name-calling. They face harassment, exclusion and intimidation.
- With no melanin or pigment for protection, skin burns immediately in the sun. Most African children 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.⁸ There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable in most African countries.



- Being very light sensitive, children with albinism often squint. Some keep their eyes almost entirely shut. Objects have to be held at close range to be clearly seen. Such behaviour is the subject of mockery and marginalization around the world.

The Bully's Toolbox

- Bullying can present as a single incident, or an enfolding pattern, where a child feels she is drowning in insults, mockery, laughter, harassment, stereotyping, cyberbullying, threats and even assault. The child can feel invisible, withdraw and become isolated.

Insults

- Words hurt. In 2014, UTSS gathered 182 different insulting names for a person with albinism. From dozens of languages, here are a few examples translated into English: *devil, ghost, white dog, soap, one to be eliminated, freak, Casper the Ghost, phantom, fake, enemy of the sun, one who never dies, snowflake, one who is conceived during the mothers menstrual period, commanded by thunder, white person, googly-eyes, apartheid supporter, colonizer, money, millions of dollars, pig, boiled Pidgeon, meat, white goat from the bush, abominable creature, white monkey, white duck, white monster, transparent evil creature, child of the moon, ape* and many more.⁹
- The Albino Network Association (Nigeria) reported: "There is stigmatization in Nigeria with PWA's [Persons With Albinism] subject to random abuses, verbal insults and public ridicule without provocation or any justification. PWA's are cast as persons or portrayed as a social outcast whom anybody is free to insult and ridicule at will. Songs are composed by children not in praise of albinism but in ridicule, derogation and insult."

Laughter and Mockery

- While a single bully delivers the insult, bystanders may laugh along, amplifying the effect. The bully is empowered and the bullied child feels surrounded, outnumbered, and like she has no allies. Alternately, bullies may laugh at the pale appearance or low-vision behaviour of a child without adding a verbal insult.
- In some countries, passers-by may see a child with albinism and spit to ward off a perceived menace, or cross the street to avoid the child.
- Classmates, other children and adults can ridicule pale skin, squinting, the need to bring objects close to the eyes, and the lesions or wounds of sun damage. Gestures, stares, glares, facial expressions and other non-verbal mockery might not always be seen by a child with albinism. The child may simply assume a constant, background level of mockery trails her through life.

Stereotyping

- In East Africa, superstitions persist that people with albinism are ghosts who never die or cursed beings with mystical powers.¹⁰ Killings may have accelerated due to such myths

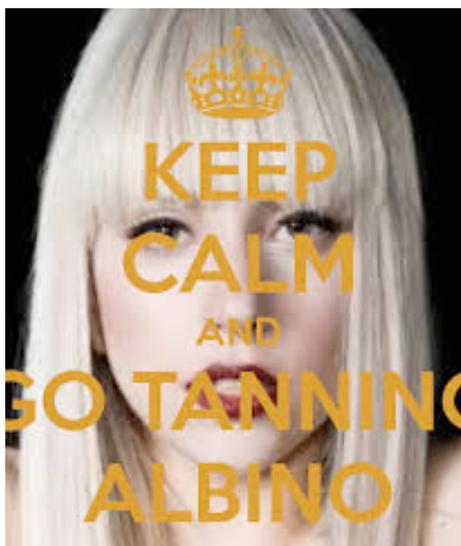


being perpetuated in Nollywood cinema.¹¹ Negative stereotypes of people with albinism are also common in Hollywood film. Disability writer Andrew Liebs says of Hollywood cinema: “albinism is frequently used to ratchet fear and the desire for revenge by turning a villain... into a pallid purveyor of doom: an outsider.”¹²

- For example, in the film *The Da Vinci Code*, the antagonist is an “evil albino” assassin. *The Matrix Reloaded* has evil twin henchmen with albinism. *The Time Machine* (2002) features a pale, white-haired “Morlock” commanding subterranean monsters who hunt pastoral surface dwellers. Hundreds of films reinforce such stereotypes.
- According to Garth Mullins, a Canadian with albinism: “Beginning in early childhood I was frequently subjected to teasing, name calling and sometimes bullying by other children because of my albinism, most commonly by calling me “hey albino”, “freak” , “whitey”, “Casper” and “hey albino freak”. Even as an adult, I attract the attention and derision of other adults on a semi-regular basis.”¹³
- The evil albino trope has a long history. In the United States, children with albinism were performers in circus side shows, some of which persisted up to the 1970s. Such stereotypes are the building blocks of bullying. According to sociologists Link and Phelan, stigmas are created when routinely used labels (such as ‘albino’) are coupled with negative stereotyping.¹⁴
- These negative stereotypes are observed and reproduced by bullies. This treatment can deeply mark children with albinism into adulthood.

Cyberbullying

- Derogatory online memes and images involving people with albinism, animated characters, apes, owls, cats, rabbits, polar bears, and animals of all kinds are common. “Albino” is frequently used as an insult on social media. Patterns of bullying from the classroom or playground follow children into the virtual world.





- In a recent high profile spat between hip hop artists, Snoop Dogg used the image of a woman with albinism in a meme to insult Iggy Azalea¹⁵ (see above left). It was “liked” on Instagram 64,000 times within the first 48 hours. Other common memes comment on tanning (see above right).

Threats

- The words of bullies can have more dire undertones. Jayne Waithera is a Kenyan with albinism. She says in places like Nairobi, Kisumu or Mombasa: “it’s so scary... You walk on the street and somebody just points at you: ‘that’s money!’ I mean, ‘that’s walking banknotes!’”¹⁶ These are insults, but also threats, revealing the slippery slope from name-calling to violence.
- Amadou Tidiane Diallo survived an attack in Guinea. He remembers hearing some men say: “this is the meat we were looking for,” then he woke up in the hospital.
- Another time, Diallo narrowly escaped an attempted abduction. He then tried to report it to police: “They did not consider my complaint nor take me in a serious way, worse they were laughing, saying: ‘You are a poor albino, you don’t need to come and disturb us, we don’t have anything to do with people like you. We are here to take charge of people who are normal; you are not a human being.’”¹⁷

Assaults

- Insults, laughter and threats can lead to non-deadly assaults. Jayne Waithera recalls her childhood at school: “The kids were so mean. I remember I would go home with my skin all red ‘cause more than a thousand kids coming and pinching you to see your skin go white then red, it was just too painful to go through this.”¹⁸

The Vicious Cycle of Bullying

- The bullying of children with albinism sets up a vicious cycle of lowered self-confidence, school dropout, pronounced marginalization and emotional problems. This can negatively affect a child’s ability to realize their full potential.

Loss of self-esteem

- Albinism makes children more vulnerable. As a result, harassment, insults, laughter and name-calling can lower self-esteem.
- Kelsey Thompson, a clinical councillor who has albinism, is active in the National Organization of Albinism and Hypopigmentation (NOAH). She leads seminars called: “Stares, Smirks and Shout-outs.” These sessions address “how to deal with negative experiences in public and how to maintain self-esteem and dignity in difficult situations - from the blatantly rude person who yells “Hey, albino!” to the hilariously annoying inquisitor who asks, “Where did you get such white hair?””¹⁹



- According to a Canadian public radio documentary made by a person with albinism: “We’ve all been ogled and gawked at all our lives; told to get a tan, called ‘Casper’ and many other things. Most respond with humour, but it has definitely affected people’s self-confidence, especially the younger ones. It’s all in the body language: stooped from always having to look at things up close, but also from carrying the weight of the stigma.”²⁰
- Mamidou Coulibaly, founder and chairperson of Bien-Être des Albinos de Côte d'Ivoire explained to UTSS that most reported cases of school dropout are attributable to mockery, laughter and insults endured by children with albinism at school. Many students with albinism have to go right up to the chalkboard, since they cannot see it. Then they return to their seat in the classroom. The procedure is repeated countless times, back and forth to the board, with laughter and insults supplied by class bullies. Some declared they could no longer bear that long walk.

School Dropout

- This lack of self-esteem can lead to school dropout among children with albinism. A young Egyptian with albinism told UTSS that he quit school because of harassment, insults, mockery and physical abuse. In 2011 he successfully sought asylum in a western country. His lawyer wrote to UTSS: “He was seriously maltreated at multiple levels including such things as deliberate cigarette burns from supposed educators.... The hostility toward him was serious at best because of his Albinism.”
- School dropout is also compounded by lack of teacher training and appropriate equipment for low vision students and reasonable accommodation (large print, magnifying glasses, extra time for exams, proximity to the blackboard, etc.) Without these things, children with albinism tend to drop out in Kenya.²¹
- As children with albinism, some UTSS staff were told by teachers: “you’ll never succeed at school and in life in general” and “education is useless for you.” One staffer said “Teachers and educators saw children with albinism as a burden and were unaware of the needs of low-vision students.”
- Many children with albinism do not attend school in Africa. Low vision makes school challenging and families may spend scarce resources on their fully-sighted children. Many families also neglect the education of children with albinism as they see their child as a source of shame.²²
- A joint report from four albinism NGOs on the Universal Periodic Review of Kenya stated: “Even when families take their child(ren) with albinism to school, they are sometimes turned away due to the myths and misconceptions held by the school. For example, the vision impairment of PWA has led to the assumption that they are all blind. This has frequently resulted in children with albinism being forced to enroll in special schools for the blind and forced to learn braille which in turn affects their employability.”²³



Pronounced marginalization

- Parents may pressure their children to stay away from children with albinism, not wanting them to play together.
- The stigma of albinism can extend to family members who don't have the condition. In Vancouver, Canada, one set of parents warned their son: "don't play with your classmate. Her mother is a witch." The mother to whom these parents referred had albinism.²⁴
- Without adequate assistance and support, constant bullying leads children with albinism to give up. Without education or qualification, these children face a bleak future of underemployment and unemployment, a lack of integration into society, further marginalization, and more bullying.

Violence

- According to OHCHR (2013), common myths associated with violence against people with albinism include: "that sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS; that the sacrifice of persons with albinism can appease "the god of the mountain" when a volcano starts to erupt; or that pulling out the hair of a person with albinism brings good luck. It has been reported that miners use the bones of persons with albinism as amulets or bury them where they are drilling for gold."²⁵ The proliferation of these myths feeds violence and bullying behaviour.
- Around the world, children with disabilities face more violence, including sexual abuse, than children without disabilities. African children with albinism are particularly vulnerable and bullying creates the conditions under which violence is tolerated.

The Bully at Home

- The UN General Assembly resolution on protecting children from bullying recognizes that "the family has the primary responsibility for the nurturing and protection of children."²⁶ But African children with albinism cannot always rely on siblings or parents to shield them from bullies. These children are frequently alienated or estranged from their families. Often, families are complicit in the attacks.
- Adam Robert, a Tanzanian boy with albinism, survived a machete attack when he was 12. Three of his fingers were hacked off of one hand. Adam suffered deep cuts to his other arm. But he fought off his attackers and lived. His father, stepmother, older brother, and another relative were involved in the attack.
- According to Albinos Sans Frontières (Burundi) "most albino children lead a life of poverty because they are often abandoned by their parents and often are rejected by their fathers."²⁷



- Since 2007, hundreds of children with albinism fled their homes and families in Tanzania in the wake of attacks against them. Many have taken refuge in overcrowded Temporary Holding Shelters.²⁸ In the lead-up to the October 2015 Tanzanian general election, many more have gone into hiding. New candidates and seasoned incumbents alike drive up demand for body parts during campaigns, in the belief that they will bring good luck at the polls.²⁹
- The Albinism Foundation of East Africa (Kenya) stated in 2013 that they work with “hundreds of women Parents of Children with Albinism that have suffered domestic violence because they gave birth to children with albinism. This has been from their husbands and extended family and communities they live in. Apart from physical violence they suffer psychological and mental torture from insults and isolation.”³⁰ The bullying and stigma can extend to mothers of children with albinism, who themselves do not have the condition.
- Bullies are strangers, neighbours, other children, adults, teachers, family members or all of the above. Bullies rely on false beliefs and myths that people with albinism are cursed, evil, magic or ghosts that never die. Infanticide of babies born with albinism has been reported. In some places, the auspicious absence of anyone with albinism may point to the prevalence of infanticide, but there is limited data.

Recommendations

Recommendation #1: Invest in education

- Member States, particularly where attacks on persons with albinism have been recorded, should invest in education for children with albinism. In particular, spaces within safe, supportive, nurturing environments should be made available for those most at risk. Member States should consult local albinism civil society organizations to identify children for this initiative.
- Member States 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 educational opportunities provide safety from threatening family members. 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.

Recommendation #2: Train educators



- Member States in consultation with local albinism civil society organizations should develop appropriate anti-bullying training for educators (teachers, administrators, staff, etc.) specifically suited to responding to the bullying of children with albinism.
- 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 bullying.
- Training should also make educators aware of the specific sun protection needs of children with albinism, including training in: the use of 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 bullying, aggression and violence. Bullying is learned. 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 bullying.

Recommendation #3: Collect data

- Member States should investigate, collect and publish data about the bullying of children with albinism. General Assembly resolution A/HRC/69/158 on protecting children from bullying also recognized “the importance of generating appropriate statistical information on bullying.”³¹ To that end, better data is needed on the bullying of children with albinism. Statistics on attacks and murders are recent and still improving. The lives of most children with albinism do not end in attacks. However, they are haunted by bullies and the data are poor.

Recommendation #4: Raise awareness

- Member States should work with albinism civil society groups to build on the success of awareness-raising campaigns conducted over the past three years, such as the public service announcements on TV which aired across East Africa in the lead up to June 13, 2015, the first International Albinism Awareness Day.³²



- Anti-bullying / albinism awareness TV and radio spots, seminars, “in-person” encounters and public health campaigns should be produced 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.
- Member States in the 25 African countries affected by attacks and killings of people could utilize public education mechanisms such as those rolled out in HIV/aids & malaria campaigns. The media busses, technology, equipment and skill for country wide awareness raising campaigns already exist.

Recommendation #5: Empower youth

- Member States should work with albinism civil society organizations to hold anti-bullying workshops for youth with albinism along the lines of the “Stares, Smirks and Shout-outs” seminars put on by the US National Organization of Albinism and Hypopigmentation.

Recommendation #6: Challenge negative stereotypes

- Member States and civil society organizations should challenge negative stereotypes about albinism in popular culture and film, which reinforce discrimination and empower bullies.
- 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.

Conclusion

- In 2011, the Special Representative of the Secretary General of Violence Against Children said: “the life of children with disabilities is surrounded by stigma, discrimination, cultural prejudices, ill-perceptions and shocking invisibility. Unfortunately, it is also dramatically marked by heightened risks of violence, neglect, injury and exploitation.”³³ This is especially true of children with albinism.
- The most extreme bullying happens in East Africa, where attackers hacked off 15 year old Kulwa Lusana’s arm. They tried to remove Mawazo Simon’s face when he was five. Meriki Astoliko, age four, was mutilated, hair shaved. Doto Mbiti was only 14 months old when he was killed. Adam Roberts had three fingers hacked off and his other arm badly



wounded at age 12. The body of a five year old was found in Zambia with hair missing. Chantal Ngendakumana, 19, was killed. Her arms and legs were hacked off. A 16 year old was raped in Namibia. But Agneta Dionizi – not even two - escaped her attackers.³⁴

- Just a few days before the submission of this report, Netani Mphepo narrowly escaped. On September 13, her teacher was arrested trying to arrange the sale of her body parts for US\$10,000. The 17-year-old Malawi girl had dropped out of school, fearing such attacks on people with albinism.³⁵
- Just a few examples reveal how bullying can lead to horrific violence against children and youth. But it doesn't have to be this way.
- The bullying of children with albinism happens almost everywhere. There are rare exceptions, like the San Blas Islands of Panama, where albinism is revered not ridiculed. But worldwide, most children with albinism urgently need protection from bullying.

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¹ The term “person with albinism” (PWA) is preferred to “albino,” which is often used as an insult.

² Under the Same Sun. “Reported Attacks of Persons with Albinism (PWA)-Summary” September 16, 2015.

³ This has been documented by various civil society organizations and national human rights institutions operating in sub Saharan Africa, and in the preliminary report published in September 2013 by the OHCHR.

⁴ For a more detailed discussion of rates and types of albinism, please see Brilliant, Murray H. “Albinism in Africa: A Medical and Social Emergency.” *International Health*, 2015; 7: 223-225

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