

UNDER THE SAME SUN

# Universal Periodic Review: Ugandans With Albinism

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1. This report is respectfully submitted for the Universal Periodic Review of Uganda by NGO Under the Same Sun
2. 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.<sup>1</sup>

## **Introduction**

3. Discrimination, marginalization and violence plague the lives of Ugandans with albinism – a condition characterized by little or no pigment in the skin, hair and eyes. This lack of natural protection from the sun means most will die of skin cancer before reaching middle age. In the Great Lakes region, mythology and fear about albinism is common. People with the genetic condition are thought to be ghosts; a curse on the family and community. Many children with albinism are abandoned. Mistaken beliefs about albinism have fueled an illegal market in body parts across the region. Low vision and structural barriers to education, employment and participation in society cause cycles of poverty.
4. People with albinism are attacked and ritually murdered - their body parts made into bogus potions by charlatan entrepreneurs. Consumers believe these potions bring good luck. Since 2006 there have been 439 reports of violence against people with albinism across 25 countries, including 166 killings, 273 abductions, mutilations, rapes and grave violations.<sup>2</sup> The actual numbers are likely much higher since many go unreported. A corpse can be worth up to \$75 000 US.
5. Attacks increase in the lead up to elections across the region. Some candidates purchase the potions, hoping for good luck at the ballot box. Demand for the body parts of Ugandans with albinism may be fueled by elections in neighbouring countries and by Uganda's 2016 general election. Fear of attacks lead people with albinism to hide, hindering mobility, educational opportunities, employment and participation in community life.
6. The mistaken belief also persists that having sex with a person with albinism can bring wealth or cure HIV/AIDS. This has exposed people with albinism to sexual assault for this purpose.<sup>3</sup> Often, Ugandans with albinism are derisively called "bazungu,"<sup>4</sup> which refers to a person of European descent and is pejorative in this context.
7. Until recently, albinism was unacknowledged by human rights statutes. But in 2013 and 2014 The United Nations Human Rights Council adopted resolutions 23/13, 24/33 and 26/10 and the African Commission on Human and Peoples' Rights adopted resolution 263 calling for the prevention of attacks and discrimination against persons with albinism. On 18 December 2014, the General Assembly adopted resolution 69/170, proclaiming every June 13<sup>th</sup> as International Albinism Awareness Day.
8. The CRPD encompasses albinism. Yet, there is little awareness of this - as well as a lack of understanding of albinism as a condition.

## **What is Albinism?**

9. 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. It is estimated that 40 000 Ugandans have the condition.<sup>5</sup>
10. 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. In most cases, structural barriers prevent full participation in society on an equal basis with others.
11. With no natural sun protection, fatal skin cancer will claim the vast majority of Africans with albinism before they reach 30 to 40 years of age.<sup>6</sup> There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable in most African countries.
12. According to researcher Kelly Allen: “Unlike ethnic, linguistic and religious minorities, albino persons are typically born to non-albinos, and in communities dominated or entirely composed of non-albino persons. This isolates affected persons from on early age. The isolation is particularly felt in Uganda’s majority, rural population.”<sup>7</sup>

#### **Previously Accepted UPR Recommendations**

13. UTSS applauds Uganda for accepting a recommendation from Spain in the previous UPR: “Adopt measures to guarantee the rights of persons with disabilities, in particular, to fight against all forms of discrimination faced by women with disabilities, and regarding the lack of equal opportunities for minors with disabilities, with a particular attention to albino children.”

#### **Examples of Violence Against Ugandans with Albinism**

14. Data is scarce about attacks and murders of Ugandans with albinism. They are underreported but most likely similar to rates in other countries in the region, particularly given the cross-border nature of the trade in body parts. Some with albinism were likely killed as part of the spike in ritual murders in Uganda reported since 2007.<sup>8</sup>
15. The Uganda Albino Association’s Charles Okure suggests that in Tanzania, killings are out in the open “but here [Uganda] they kill us secretly and cut off some of our body parts for ritual purposes.”<sup>9</sup> According to Judah Ssebyanzi, one of Association’s founders, the dangers can prohibit data collection: “We do not follow up on cases of missing persons for our own security.”<sup>10</sup> The following examples represent only a part of the problem.
16. Elizabeth Kwagala, 26, has albinism. She feared her husband was plotting to sacrifice her. She overheard two strangers conspiring with her husband to kill her and immediately hid with her two children. The would-be attackers couldn’t find her, so they turned on her husband Hassan Sebbi, beating him and accusing him of sabotaging their chance to get rich. Eventually, the two men gave up and left. Kwagala came out of hiding to find her injured, furious husband. “He slapped and kicked me hard before calling me an evil spirit,” she recalled to a journalist. “He then demanded that I leave his house immediately with the children after claiming that they were not his.”<sup>11</sup> Pregnant with Sebbi’s third child and with no employment prospects or support, Kwagala and her children were soon destitute. Kwagala was herself abandoned by her parents at just two-months-old.

17. Medius Kyarisima, 50, of Kabale District, Kinyamari Butanda Sub County, describes how her husband Godfrey Ndabahwerize tried to kill four of their children in April 2014 with a machete: “my husband threatened to kill our four albino children, saying they were a disgrace to his family. When I tried to reason with him, he picked a panga and cut me on the right side of my nose.” Kyarisima packed up her children with albinism and sought refuge at her mother’s home.<sup>12</sup>
18. Bernard Mwanje of Ngole village, Buyende district, is the father of five children with albinism. He had to pull his eight-year-old son out of school: “Semujju was going to school, but we stopped him after kidnappers waylaid him thrice.” On another occasion, two men tried to grab one of the other children with albinism. The family raised the alarm and the would-be kidnappers fled. Fearing for his children’s safety, Mwanje stays at home to protect them. This means he cannot work.<sup>13</sup>
19. Unity Mukyotera, 14, was attending Hakahumiro Primary School in Bufundi Sub County when her mother heard of plans to kidnap her. People with albinism in Kabale district are fearful following reports of increased demand of their body parts for rituals in Rwanda and Tanzania.<sup>14</sup>
20. After Faridah Nantumbwe, 35, gave birth to a fourth child with albinism, her husband abandoned the family, calling the children a curse and preventing Nantumbwe from farming the family’s land.<sup>15</sup>
21. Jalia Namukoma was shocked when she gave birth to a baby with albinism: “I had reached the extent of refusing to breastfeed the baby, thinking it was a spirit,” she said in Ngole village, Buyende district. After having more children with albinism, she recalls: “I thought of abandoning them.” Social worker Rebecca Namuddu says that albinism’s stigma “has led to most parents of albino children abandoning them.”<sup>16</sup> But Namukoma grew to love all of her children. Their father was not so tolerant, leaving the mother and children over the condition.<sup>17</sup>

### **Questions for the Government of Uganda**

22. How is the previously accepted UPR recommendation being implemented?
23. How is the government of Uganda implementing recent UN resolutions on albinism?
24. How will the government improve the representation of Ugandans with albinism in law, Parliament and in government?
25. How is data about attacks on Ugandans with albinism being collected?

### **Recommendations**

#### **Invest in education**

26. The Government of Uganda should invest in education for children with albinism. Education is the key to future indoor employment and avoiding lower life expectancy from skin cancer. Safe, supportive, nurturing educational environments should be made available for children with albinism.

#### **Train educators**

27. The Government of Uganda, in consultation with local albinism NGOs, should train for educators (teachers, administrators, staff, etc.) in needs of children with albinism. Being legally blind is a physical disability requiring reasonable accommodation at school, including large print, glasses, magnifying glasses, monoculars and specialized computer equipment. Training in sun— protection and sun-avoidance is also necessary.

### **Collect data**

28. The Government of Uganda should investigate, collect and publish data about attacks, murders, abductions, assaults and other incidents involving Ugandans with albinism. Better data is needed. Often, albinism NGOs are unable to investigate reports due to safety concerns for the security of staff with albinism.<sup>18</sup> Data should be stored securely.

### **Health**

29. The Government of Uganda should make sunscreen and sun protective garments more readily available to Ugandans with albinism. The vast majority of Ugandans with albinism will die from skin cancer.
30. The Government of Uganda should immediately cease any taxation of sunscreen as per Africa Albino Foundation Uganda's recommendation.<sup>19</sup> But even untaxed, sunscreen is prohibitively expensive and hard to access. Sunscreen should be imported or manufactured and publically subsidized. Distribution should occur in partnership with albinism NGOs like The Nazigo Albino Persons Association.
31. The government of Uganda should subsidize sun-protective garments.
32. The Government of Uganda should consider as a model the health services of Standing Voice, a Tanzania and UK-based NGO with a specialization in mobile clinics targeting persons with albinism in both rural and urban settings. Standing Voice could provide requisite training to health care providers such as optometrists, ophthalmologists and dermatologists in Uganda.

### **Partnerships**

33. Civil society can partner in the successful implementation of these recommendations. Thus, their activity should be enabled, not frustrated. Some have commented that the Non-Governmental Organizations Registration (Amendment) Act 2006 has made the work of NGOs more difficult. The Government of Uganda should consider a streamlined, less onerous process, or the de-regulation of NGOs.
34. NGOs like Under the Same Sun can be key partners with government and local actors. The Africa Albino Foundation of Uganda is involved in medical concerns and awareness raising via education. The Nazigo Albino Persons Association is community-based and focuses on awareness raising and providing sunscreen. The Uganda Albinos Association is a national awareness-raising group focusing on skin cancer, of which five of its members died in December 2014 alone. The NGO Source of the Nile Union of Persons with Albinism advocates for quality services. Advantage Africa provides support to some 300 individuals with albinism in the Busoga sub-region. This support includes improved livelihoods, access to hats, high-factor sunscreen, dermatology and other health care services. Via home visits and teacher training, adults and children are taught the signs of skin damage due to sun exposure and sun protection.<sup>20</sup>

## Parliamentary and Government Representation

35. The Government of Uganda should create a special parliamentary representative for people with albinism, such as the five Disabilities Members of Parliament. Under the Same Sun applauds the Government of Uganda for having the vision to create such a parliamentary mechanism but wishes to see it extended to represent Ugandan citizens with albinism.
36. The Uganda Albino Association (UAA) reports that persons with albinism have not been able to achieve adequate representation via the Disabilities Members of Parliament, in part because of low awareness of albinism being a disability.
37. In 2010, the Uganda Albinos Association petitioned the Deputy Speaker of Parliament to this effect,<sup>21</sup> noting that “despite the presence of such relevant laws and parliamentary representatives for disabled persons, albinos are still discriminated against and not included in decision-making processes that affect their wellbeing.”<sup>22</sup>
38. The government of Uganda should consider the suggestion of the UN Independent Expert on albinism and create a task force on albinism consisting of members of various relevant Ministries: disability, education, justice, health among others. This task force can help the government carry out its short to medium term goals and assist in implementing other recommendations herein. The task force should have a budget and should consist of as well as consult with civil society including people with albinism.<sup>23</sup>

## Legislative Change

39. The Government of Uganda should make an amendment to the Persons With Disabilities Act 2006 to include persons with albinism. UTSS supports the 2013 recommendation of the National Union of Disabled Persons of Uganda: “Parliament should take steps to urgently revise the definition of disability in accordance with Article 1 of the CRPD, to incorporate an inclusive definition of disability and persons with disabilities that is firmly rooted in the human rights-based approach to disability and encompasses all persons with disabilities, including those with psychosocial disabilities, albinos and little people.”<sup>24</sup>
40. Legislation should be created to address the abandonment of children with albinism by their parents.<sup>25</sup>

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- <sup>13</sup> Gwebayanga, Tom. "Carrying the Cross of 10 Albino Children." *New Vision*, September 8, 2015  
[http://www.newvision.co.ug/new\\_vision/news/1309187/carrying-cross-albino-children](http://www.newvision.co.ug/new_vision/news/1309187/carrying-cross-albino-children)
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<sup>23</sup> Report of the UN IE during 31st ordinary session of the UN Human Rights Council, 4 March 2016

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