People With Albinism and the Universal Periodic Review of Tanzania

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- This report is submitted for the Universal Periodic Review of Tanzania by NGO Under the Same Sun (UTSS)
- 2. 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.¹

Introduction

3. Attacks against people with albinism continue in 25 African countries, feeding a gruesome black market for body parts. This violence is most concentrated in Tanzania. Since 2006 there have been 158 reports of violence against people with albinism in Tanzania, including 76 killings, 63 survivors, one abduction, 18 grave violations. The actual number of attacks and killings is likely much higher. Many are never reported or documented. ² Attacks are increasing in the lead-up to the October general election.³

What is Albinism?

- 4. 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
- 5. 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. 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
- 6. In 2012, Tanzania conducted a national population and settlements census, finding 0.04% of the mainland population and 0.03% of the islands population had albinism. Prime Minister Pinda cautioned that these statistics likely under represent persons with albinism.
- 7. In Tanzania, as many as 1 in 1,400 are estimated to have albinism.⁶ With a population of 47.42 million, there are at least 33 000 people with albinism in Tanzania.
- 8. 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. There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable.

More Action Needed on Previously Accepted UPR Recommendations

- 9. Tanzania accepted five recommendations from UPR session 20.8 While some progress has been made, attacks and murders of people with albinism continue.
- 10. Previously accepted UPR recommendation: "Launch a nationwide education and awareness campaign to prevent stigmatization of persons with albinism to ensure their security and facilitate their equal access to education and employment."
- 11. Media reports suggest some education initiatives were launched in 2014 in Tanzania's northern areas with the highest concentration of attacks. This needs to be applied countrywide.
- 12. Tanzania's educational campaign efforts have been modest given the scale of the problem. In the past, the government of Tanzania has even taken credit for the awareness raising activities of albinism NGOs. Partnerships between albinism NGOs and government are welcome, but government has resources, authority and infrastructure unavailable to civil society and should be leading and funding such campaigns.
- 13. Previously accepted UPR recommendation: "Strengthen efforts to protect the rights of all peoples with Albinism"
- 14. The government and the Tanzania Albino Society formed a joint task force in 2014 for conducting special operations against the kidnap, abduction and murder of people with albinism. Such efforts have not proven sufficient to prevent attacks. They should be expanded well publicized to dissuade potential attackers.
- 15. Witchcraft legislation lacks clarity in definition and application, limiting its effectiveness.
- 16. Previously accepted UPR recommendation: "Continue to ensure full and complete protection of persons with albinism."
- 17. Tanzania's main mechanism for protecting people with albinism is to move them to shelters for internally displaced persons with albinism. UTSS does not support the warehousing of children with albinism, but advocates for their safety and dignity within their own communities.
- 18. Visits and assessments by UTSS of such shelters reveal overcrowding, unsatisfactory sanitary conditions, low teacher-to-student ratios and a lack of staff awareness of the specific medical needs and appropriate low-vision accommodations for people with albinism. Sexual and physiological abuse was also reported. Young children were observed with marks and lesions of untreated sun-damage.
- 19. Previously accepted UPR recommendation: "Consider strengthening efforts to put a halt to incidents of killings of persons with albinism."
- 20. Attacks and murders continue. Yet, only 7-10% of all cases are prosecuted. Such violence has increased in the lead up to the 2015 general election. Hundreds of people with albinism have

- gone into hiding. While there is somewhat more awareness of this gruesome problem than before the last UPR, Tanzania has yet to fully commit the resources of the state to eradicating it.
- 21. Previously accepted UPR recommendation: "Continuously conduct nation-wide human rights awareness campaigns with specific emphasis on the right to life of people with albinism."
- 22. This year, President Jakaya Kikwete attended International Albinism Awareness Day celebrations in an Arusha stadium.¹⁰ He was the only head of state to attend such an event and brought attention to the issue. This should be an annual tradition for high office holders.

Surge in Attacks in the Lead up to October 2015 General Election

- 23. Fearing election related attacks, many people with albinism have gone into hiding. New candidates and seasoned incumbents drive up demand for body parts during campaigns, in the belief that they will bring good luck at the polls.¹¹
- 24. UN High Commissioner for Human Rights, Mr. Zeid Ra'ad al Hussein, warned that this surge in attacks could be linked to the election. 12
- 25. "Violence and discrimination against people with albinism must be halted," Mr. Zeid said. "I call on the Tanzanian authorities to swiftly investigate and prosecute perpetrators of this terrible crime and to strengthen its protection measures for people with albinism, particularly in the lead up to general elections in the country."¹³
- 26. On May 27, 2015, Tanzania's deputy minister for Home Affairs addressed Parliament: "The killings are increasing during elections. I want to assure my fellow politicians that there won't be any parliamentary seat that will be won as a result of using albino body parts." ¹⁴
- 27. Rombo MP Joseph Selasini (Chadema) questioned official silence in response to reports linking politicians to attacks. ¹⁵
- 28. Kenyan MP Isaac Mwaura who has albinism said Tanzanian elections create demand, leading to attacks in Kenya: "You can clearly see people in politics going for these concoctions. People will kill people with albinism in return for what they believe is this good fortune, and that is totally wrong. This problem has now become a regional problem because of Tanzania not having taken strong measures to curb it." 16

Attacks Continue in Tanzania since last Universal Periodic Review

- 29. Since the last UPR in 2011, there have been 55 reports of violence against people with albinism in Tanzania: 11 killings and 44 attacks which include mutilations, abductions, grave robberies and sexual assaults linked to the victim having albinism. Recent examples of the scope and ferocity of violence follows.
- 30. On Tuesday, February 17, 2015, the mutilated remains of Yohana Bahati, a one-year-old baby boy with albinism, was discovered in Shilabela Mapinduzi Sub-Village, a few kilometers from his

home in Isabilo Sub-Village of Ilelema Village, Iparamasa Ward of Chato District, Geita Region. Both of Yohana's arms and legs were hacked off. Five unidentified men armed with machetes had attacked the homestead. The boy's mother was slashed in face and body. Yohana's father has been arrested. ¹⁷

- 31. On June 16, 2015, Margareth Khamis, a six-year-old girl with albinism went missing several days from Kona Nne Village, Ugembe Ward of Nzega District in the Tabora Region. Margareth's mother raised the alarm and villagers started a search. Police got a report of a buyer willing to purchase Margareth and intervened, rescuing her and arresting an uncle. 18
- 32. On May 14, 2015, Limi Luchoma, a mother of four with albinism had her right arm hacked off just below the elbow. She was attacked by two unidentified men in Kabunde Village, Mamba Ward, Mawiti 'A' suburb, Mlele District, Katavi Region. A witchdoctor who lives near by and one of Limi's brothers may be involved. ¹⁹
- 33. On March 7, 2015, Baraka Cosmas Rusambo, a six-year-old boy with albinism, had his right hand hacked off in Kipeta Village, Kipeta Ward of Sumbawanga Rural District in Rukwa Region. His mother also sustained serious machete injuries to her head. Seventeen suspects were arrested in connection with the mutilation, including the victim's father and uncle. ²⁰
- 34. In February of 2014, Masalu Masanja, 17, was gang raped by five men on her family farm in Gasuma Village, Bariadi District of Simiyu Region. A speech impairment prohibited her from calling for help. She was left with two STIs and pregnant. Government officials brought Masalu and her three brothers with albinism to Buhangija Center for displaced persons with albinism in Shinyanga. She was treated for the STIs and gave birth to a baby girl November 2014. ²¹
- 35. On December 27, 2014, Pendo Emmanuel, a four-year-old girl with albinism was abducted in Ndamhi Village of Fukalo Ward, Kwimba District, Mwanza Region. Fifteen suspects are in custody, including the victim's mother and two grandparents. Authorities are still looking for her.²²

Attacks Spilling beyond Tanzania's Borders

- 36. Since the last UPR, attacks have linked to Tanzanian demand for body parts have spread across borders, including in Kenya, Malawi and Mozambique
- 37. On September 13, 2015, Netani Mphepo, a 17-year-old girl with albinism narrowly escaped death at the hands of her teacher in the village of Symon Mphepo, Malawi. He tried to abduct her, having approached a Tanzanian National to sell her body parts for US\$10,000. The Tanzanian National notified police, who arrested the teacher. Netani Mphepo had dropped out of school in January, hoping to avoid such attacks. ²³
- 38. Enforcement, prosecution and protective measures inside Tanzania have had limited success, thought the market for body parts remains active. This is leading to attacks outside of Tanzania in order to feed local demand.²⁴

Questions for the Government of Tanzania

- 39. When will previously accepted UPR recommendations be fully implemented?
- 40. What mechanisms are in place to ensure the protection and respect for the right to life and security persons with albinism?
- 41. What steps are being taken to end the torture of children with albinism due to attacks and pervasive fear of attacks?
- 42. How will prosecution and conviction rates be increased for attackers of people with albinism?
- 43. How is the right to child participation respected when children are not consulted about transportation to shelters for internally displaced persons with albinism?
- 44. What steps are being taken to end the sexual and psychological abuse of children with albinism in the designated shelters?
- 45. How will the government improve the legal regulation of witchcraft?
- 46. When will a robust countrywide public awareness campaign about albinism be undertaken?
- 47. How is the government stopping parents from abandoning their babies with albinism?
- 48. How are low vision students with albinism being accommodated at designated shelters?

Recommendations:

- 49. **Census:** The government should conduct a census of designated shelters for internally displaced persons with albinism to monitor the welfare of children with albinism living there. Data must be stored securely to avoid facilitating attacks. International NGOs like UNICEF should be approached to provide support and secure data management.
- 50. **Security:** The government should improve Infrastructure at all shelters for internally displaced persons with albinism, including on-site potable water, locking doors, adequate lighting and qualified security guards.
- 51. Adequate living space: The government should address overcrowding, which is a problem at most shelters for internally displaced persons with albinism. Some facilities, like Mitindo have expanded living space. Others, like Buhangija are in the process of doing so. These are exceptions. Relocating children with albinism back to their families where it is proven to be safe could mitigate overcrowding. Adequate facilities must be immediately provided for all who cannot return home. Arrangements should be made so families of children can reside with them at the shelters. Children should not be unnecessarily separated from their families.

- 52. **Family Reunification:** The government should return children at shelters to their families as soon as is safe, pending a security assessment of their homes. Support should be sought from agencies such as the Red Cross, UNHCR and UNICEF.
- 53. **Better Wages, Incentives for Staff:** The government should ensure better compensation for support staff at shelters for internally displaced people with albinism. An insufficiently compensated or incented staff will experience rapid staff turnover. UTSS visits to shelters reveals that staff caring for children with albinism are neither incented nor trained.
- **54. Skin Cancer Training for Staff:** The government should ensure shelter staff are trained in skin cancer awareness, identification and prevention and make them aware of its deadly impact on children with albinism. Staff needs to be familiar with sunburn prevention, protection and treatment. Staff should be able to identify skin cancer and its precursors and know when to make referrals to health authorities and how to ensure follow-up. On-going training and monitoring will be required. Sun avoidance and the use of sun-protective clothing, widebrimmed hats and long-sleeved clothing can save lives.
- **55. Low Vision Training for Staff:** The government should ensure shelter staff are trained in the low vision needs of children with albinism. Staff must know that the majority of children with albinism have sufficient visual acuity to read print and should not be forced to learn Braille. Staff should allow for basic accommodations, such as using more verbal teaching methods and writing with large print on the chalkboard. Low vision training will also ensure that staff is able seek support from authorities, such as low vision devices or tinted sunglasses.
- 56. Social Welfare Workers at Shelters: The government should engage trained psychologists and social workers to assist children with albinism in dealing with the trauma from attacks. Support is also necessary for all children with albinism at shelters for internally displaced people with albinism, given the adverse psychosocial impacts of being hunted. Adequately resourced social service workers who are familiar with albinism would supplement the efforts of permanent staff. Social service workers should attend the shelters frequently and observe conditions and record any grievances from the children. This will be key in monitoring and eventually disbanding these shelters. Family reunification will also require support from social service workers.
- 57. **Investigate Sexual Abuse at Shelters:** The government should immediately investigate all incidences and allegations of sexual abuse at the shelters for internally displaced persons with albinism. The government should visit all shelters to audit conditions, given that the problem is likely more prevalent than reported. The government should seek to prosecute abusers, and discipline staff members against which credible complaints have been made, including retraining, suspension or termination of employment. UTSS will work with the government to develop an action plan for addressing this issue. Staff training and social workers are key in the prevention of and response to psychological, physical and sexual abuse. Without such training,

staff risks not detecting, enabling or contributing to such abuse. UTSS will work with the government to ensuring that this training takes place.

- 58. **Ongoing Evaluation and Monitoring of Shelters:** The government should institute an ongoing program of evolution and monitoring of shelters for internally displaced persons with albinism. The lack of monitoring means that abuse and poor conditions go under reported or not reported at all. Without information on conditions, these shelters may appear to be an appropriate policy response to attacks. However, children remain in these "temporary" shelters for years. The continued presence of the shelter system stands in sharp contrast to the officialdom's often-repeated claim that Tanzania is safer today that it used to be for people with albinism.
- 59. Funding for Production of Sun Screen and Protective Clothing: The government should fund and expand local production of sunscreen and sun protective garments. Currently, UTSS operates a local sunscreen production unit and a garment manufacturing shop at the Regional Dermatology Training Centre, Kilimanjaro Christian Medical Training Centre. These are small operations. Sunscreen is produced with hand mixers in a shipping container. NGOs are not resourced for this. With over 33 000 persons with albinism, demand is much greater than supply offered by this modest initiative. UTSS will advise government on the rollout of a countrywide production and distribution.

¹ This report is based on extensive research on the lives of people with albinism in Tanzania. It relies on data gathered by UTSS and its agents on the ground. UTSS visits, interviews and documents the accounts of people with albinism who have been attacked and their families. UTSS also provides help, including food, medical, educational, psychosocial and financial support. A note on limitations: There is no unified legal monitoring in place in East Africa to ensure the investigation and prosecution of attacks. NGOs are ill equipped and underfunded for these tasks. Comprehensive and unified information is therefore scarce. UTSS gathers information itself, from first hand sources, form other NGOs and form other government and media sources, and presents it as comprehensively as possible. It is UTSS practice to seek additional confirmations when referring to media reports

² Under The Same Sun (UTSS). "Reported Attacks of Persons with Albinism (PWA) – Summary" September 24, 2015 http://www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page.pdf accessed September 27, 2005

³ Igwe, Leo. "Elections in Tanzania, the Albino Killings and Witchcraft" News Ghana. Jun 5, 2015 http://newsghana.com.gh/elections-in-tanzania-the-albino-killings-and-witchcraft/ accessed on September 11, 2015

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

⁵ From the Convention on the Rights of Persons with Disabilities, Article 1, paragraph "e"

⁶ Under the Same Sun. "Frequency of Albinism / Rates of Occurrence: North America, Europe, Africa and Tanzania" http://www.underthesamesun.com/sites/default/files/Frequency%20of%20Albinism.pdf accessed on August 8, 2015.

⁷ Yakubu, Alkassim, Mabogunje and Oluwatope. "Skin Cancer in African Albinos" Acta Oncologica, Vol. 32, No. 6, pp. 621-622. 1993.

⁸ Database of UPR Recommendations; Session 20; Tanzania; Albinism http://www.upr-
info.org/database/index.php?limit=0&f SUR=172&f SMR=All&order=&orderDir=ASC&orderP=true&f Issue=All&s

<u>earchReco=&resultMax=300&response=&action_type=&session=&SuRRgrp=&SuROrg=&SMRRgrp=&SMROrg=&ple_dges=RecoOnly_accessed_September_22, 2015</u>

- ⁹ UNICEF/UTSS, "Sexual Abuse Cases Reported in Assessed Schools and Centres Hosting Internally Displaced Children with Albinism and Other Children with Disabilities, A Report to the Ministry of Education and Vocational Training (MoEVT)", May 26, 2011. Also see UNICEF/UTSS, "Situation Assessment of the Centres of Displaced Persons with Albinism in the Lake Zone and Tanga Regions: Findings From Under The Same Survey, 2011", October 2012.
- ¹⁰ Domasa, Sylivester. "TZ gov't vows to prioritize Albino issue." Afrikareporter. June 15, 2015 http://www.afrikareporter.com/tz-govt-vows-to-prioritize-albino-issue/ Accessed September 27, 2015
- ¹¹ Igwe, Leo. "Elections in Tanzania, the Albino Killings and Witchcraft" News Ghana. Jun 5, 2015 http://newsghana.com.gh/elections-in-tanzania-the-albino-killings-and-witchcraft/ accessed on September 11, 2015
- ¹² Lugongo, Bernard. "Govt official in Tz admitting that politicians could be behind attacks." The Citizen, May 28, 2015 http://www.thecitizen.co.tz/News/-Politicians-killing-albinos-/-/1840340/2732014/-/5hww9jz/-/index.html accessed September 27, 2015
- ¹³ UN News Centre "Mutilation, killing of Tanzanian boy with albinism strongly condemned by UN rights chief" http://www.un.org/apps/news/story.asp?NewsID=50128#.VgiL8HDZ_wh accessed on September 27, 2015
- ¹⁴ ibid Lugongo
- ¹⁵ ibid Lugongo
- ¹⁶ Rugiririza, Ephrem. "Tanzania bans witchdoctors to stem grisly albino murders." Agence France-Presse. January 14, 2015 http://news.yahoo.com/tanzania-bans-witchdoctors-stem-grisly-albino-murders-094203203.html# accessed September 27, 2015
- ¹⁷ UTSS interviews with Deputy Director of Public Prosecution Ms. Neema Ringo in Dar es Salaam and Iparamasa Ward Executive Officer (WEO), Christopher Mabuba who confirmed the attack.)

 ¹⁸ ITV News at 20:00 hrs. Tuesday, June 16, 2015; UTSS Phone Conversation with IRP Media Reporter.
- ¹⁸ ITV News at 20:00 hrs, Tuesday, June 16, 2015; UTSS Phone Conversation with IPP Media Reporter, Kabendara Simon, in Tabora
- ¹⁹ On May 16 18, 2015, a UTSS team inspected the scene of the attack, visited Limi in hospital and interviewed her, her family, neighbours, Village Executive Officer, Police & Government officials.
- ²⁰ UTSS interviews on March 9 &10, 2015, with Police, Community Development Officer, Social Welfare Officer, Office of the Director of Public Prosecution, Kipeta Ward Executive Officer, Baraka's mother, family and neighbours.
- ²¹ On June 6, 2014, UTSS staff interviewed with Masalu Masanja during a routine visit to Buhangija, a key government center housing displaced persons with albinism in Shinyanga Town, Shinyanga Region, Northwest Tanzania
- ²² UTSS interview with Tanzanian police and Ndamhi Village Executive Officer
- ²³ The Association Of Persons With Albinism Of Malawi (Apam); Mr. Bonface Ophiyah Massah, Executive Director
- ²⁴ Luvega, Derick. "Gang Attacks Albino 'for organs'". The Daily Nation. September 13, 2015 http://www.nation.co.ke/news/Gang-attacks-albino-for-organs/-/1056/2869110/-/4sj7nlz/-/index.html accessed September 27, 2015