



Discrimination Against Women and Girls **With Albinism in Malawi**

- This report is respectfully submitted by Under The Same Sun regarding the Convention on the Elimination of All Forms of Discrimination Against Women (Malawi).
- 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, women and girls with albinism¹ are particularly vulnerable to discrimination. They are isolated by stigma, myth and cultural prejudice. In some places, including Malawi, they are physically assaulted and killed.
- In Malawi, there has been a spate of attacks this year. Over the past few years there have been 18 recorded incidences: five killings, ten attacks, two abductions, one still missing and one grave robbery to obtain body parts.²
- Across 25 African countries, there have been 422 reported attacks since 2000. This includes 162 documented murders of people with albinism and 260 cases of missing persons, assault, mutilation, rape, attempted abductions, grave violations and other acts of violence.³ 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. Victims are most often women and girls with albinism.
- Mothers of children with albinism are often persecuted. Women and girls with albinism experience sexual violence as a result of persistent myths and discrimination.
- Marginalized, girls with albinism lose self-confidence, drop out of school and isolate themselves from classmates, family and community. Alone, they are even more vulnerable. With less education, they are further alienated from the labour market.

UTSS recommends action in the following areas:

1. Public education initiatives to increase awareness about albinism
2. Policy measures to address multiple and intersecting forms of discrimination faced by women and girls with albinism



3. Protective mechanisms, such as self defence training
 4. Legal support for victims and witnesses
 5. Redress, rehabilitation and medical, social and psychological support
 6. Partnerships between government and women with albinism and NGOs
- With the right educational environment, girls with albinism can themselves become powerful advocates against bullying. As women, they can become role models within their respective societies; strong voices against discrimination. Doctors and members of parliament with albinism will help displace myths and stigma. Their success will be the most powerful force for social change.

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.⁴
- 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 participation in society on an equal basis with others.⁵
- Across Africa, between one in 5,000 and one in 15,000 have albinism.⁶ UTSS believes this range is a conservative estimate, since data is inconsistent across the continent. With a total population in Malawi of 17.3 million, there are between 1,153 and 3,461 Malawians with albinism, based on the above range.
- 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.⁷ There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable.

Many Forms of Discrimination

- **Blame the Mother:** A lack of awareness about albinism negatively impacts parents of children with albinism. The mother often gets the worst of this. She may be blamed for her child’s paleness or for having contracted a curse. The father may accuse her of infidelity and even abandon her. This can also lead to an increase in domestic violence against the mother. The community may also isolate, ostracize or expel the mother of a child with albinism to avoid the perceived curse. Sometimes a mother will just remove herself.



- **Vulnerability to Attack:** Treated as a pariah and without a community or family, the mother and her child with albinism become more vulnerable to attack. Attacks tend to occur on those who are removed or isolated from the community.
- **Poverty:** Mothers of children with albinism often face abject poverty after they give birth. This exposes their child with albinism to further poverty entrenchment due to structural barriers to education, employment and community integration.
- **Sexual Violence:** 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.”⁸
- **Health Risk:** Low education and associated barriers to indoor employment leave women and girls with albinism vulnerable to skin cancer, which kills most Africans with albinism before they reach 30 to 40 years of age.⁹ Victims of sexual violence also experience increased health complications such as Post Traumatic Stress Syndrome (PTSD), pregnancy and the contracting of Sexually Transmitted Infections (STIs).
- **More Vulnerable, Less Recourse:** Women with albinism have been recognized by both the CEDAW and the ACERWC¹⁰ as being particularly vulnerable in conflict and disasters. They are affected by violence more frequently and more severely than others. This violence is often committed without social sanction, prosecution or consequence.¹¹
- **Reprisals:** Family members are often complicit in attacks on children with albinism. Mothers often face threats of reprisal and violence after testifying against their husbands or family members. Reprisal can come from the family of the husband or the community at large.
- **Displacement:** Girls and women with albinism as well as mothers of children with albinism have been displaced. Across the 25 countries where attacks are reported, many have gone into hiding. Many more are seeking asylum in countries outside the region.
- **Marginalization:** Words hurt. In 2014, UTSS gathered 182 different insulting names for a person with albinism. A few examples reported from Malawi include: *Kapu* (White man) *Napweri* (pigeon pea that has just been boiled), *Mzungo* (white skin), *Yellow Man* and the literal *Alubino*.¹²

Attacks in 2015 in Malawi

- On September 4, 2015, police reported finding the body parts of a person with albinism in Pazani village in the area of traditional authority Mduwa in Mchinji district.¹³



- During the night of January 21, 2015, Ida Thomas, a 9 year old girl with albinism was attacked in her sleep in Chalela Village, Chikhwawa district. She is believed dead. Blankets were found at the scene covered in blood.¹⁴
- The body of Malita Makolija was found with head, arms and legs missing, buried near an anthill. She was 68 and had albinism. She had gone missing on January 18, 2015 from her home in Masali village, near traditional authority Mwambo in Zomba District.¹⁵
- In September 2015, a four-year-old boy with albinism narrowly escaped abduction when his mother intervened. The boy's stepfather wanted to sell his son's body parts. The mother contacted authorities, disrupting the plan and saving her son.¹⁶
- On September 13, 2015, Netani Mphepo narrowly escaped death in the village of Symon Mphepo, Traditional Authority (T/A) Kampingosibande, Mzimba district. She was abducted by her teacher, who was arrested trying to arrange the sale of her body parts for K 6,000,0000 or US\$10,000. The 17-year-old girl with albinism had dropped out of school, fearing such attacks on people with albinism.¹⁷
- Also in September, two men kidnapped an 11-year-old with albinism in Ipyana. The boy was dragged into a forest, where the attackers started hacking his throat and arm. The boy's cries drew attention and saved his life. Police have two in custody.¹⁸
- On August 6, 2015, Esime Zulu was abducted in the Dedza district. Police have arrested four men, including the six-year-old's father. The men were trying to leave the country for Mozambique where they intended to sell the boy.¹⁹
- On March 5, 2015, Chakupatsa Stanely was rescued from three kidnappers in Murukhu Village, Machinga Region. The two-year-old was abducted from her mother's home. The mother screamed for help, bringing nearby villagers to investigate. Two of the assailants fled into a maize field and are still at large and one was arrested. He has since committed suicide in custody.²⁰
- On March 4, 2015, a 12-year-old girl with albinism narrowly escaped abduction in Kalambo village in the area of Kawinga. Assailants broke into her mother's house as the girl slept. After hearing footsteps, the mother went to check on her daughter, only to find her missing. The mother started shouting for help, which brought people from the village who started chasing the abductors. After a long chase, the kidnappers left the girl and fled.²¹
- On January 5, 2015, Mina Jeffrey was kidnapped by three men, in Machinga district, Saiti village. One of the kidnappers was her uncle. The 11-year-old managed to escape the men and was found. As a consequence of the incident, eleven school children with albinism have dropped out of different schools in the area, due to fears for their safety.²²



- On January 16th, 2015, Ibrah Pillo was kidnapped from her parent's home in Matindira - Chindambo Village, traditional authority Kawinga Machinga district. The two-year-old is still missing.²³
- On August 6, 2015, the grave of Thomson Mwakanemaa was desecrated in Malawi's Northern district of Karonga. A shovel, hoe and his bones were found at the gravesite. His brother confirmed that he had albinism and died in 2009 at the age of 58.²⁴

Questions for the Government of Malawi

Awareness and Public Education

- What programs are in place to educate the public on albinism and its genetic origins, with a view to ending discrimination and stigmatization?
- What programs are in place to educate communities (particularly those in rural areas) to protect women who give birth to children with albinism from human rights abuses (particularly abandonment and expulsion)?
- What programs are in place to dispel the belief that sexual violence against a woman with albinism can cure HIV/AIDs ?

Health

- What health education programs are in place for mothers of children with albinism? Do such programs cover information about the condition and care of children with albinism? Is such education provided by hospitals, nurses, midwives?
- What programs are in place to prevent and treat skin cancer for people with albinism in rural areas or those who live in isolation?

Protection

- What protection mechanisms are in place to prevent attacks and sexual violence against women and girls with albinism?

Recommendations

Awareness and Public Education

- Raise public awareness about albinism among the general public.
- Raise awareness about albinism among traditional and conventional midwives, in healthcare centers, clinics, special ante-natal and post-natal training programs and in maternity wards.
- Develop and distribute literature and information on raising a child with albinism.



- Raise awareness among men about the genetic origins of albinism (particularly in rural areas) through government funded open-door education workshops and other venues. Promote the role of men in ensuring the care and protection of mothers of children with albinism as well as that of the children themselves.

Policy Measures

- Adopt specific measures and policies to address multiple and intersecting forms of discrimination against women and girls with albinism, including adequate access to healthcare, education, social services, employment and education.
- Adopt comprehensive policies and plans to end violence and discrimination against women and girls with albinism.
- Adopt comprehensive policies and measures to combat sexual violence against women and girls with albinism.
- Develop peer education workshops and health education programs that empower women with albinism to accept their genetic condition in order to raise self-confidence.
- Encourage women with albinism to form self-help groups to promote their issues, needs and rights.
- Support the self-organization of income-generating activities by providing women with albinism with skills-training in communication, organization, management, leadership, public speaking, marketing, capacity building, assertiveness and confidence.
- Consult women with albinism and albinism NGOs in the development of any policy measures that may affect persons with albinism.

Protection

- End atrocities against people with albinism.
- Provide training to women and girls with albinism in self-defense and attack avoidance / risk management.

Legal

- Provide adequate witness protection to women with and without albinism who have been affected by violence and wish to testify against perpetrators.
- Provide legal counsel at no cost to survivors and witnesses of attacks who testify during trial to ensure procedural fairness and justice.
- Provide education to women with albinism on existing legislation, policy, law and human rights mechanisms so they can better advocate for themselves.



Redress and Rehabilitation

- Provide remedial support to women who have been victims of attacks including rehabilitation services in the form of medical, psychological and social support and assistance in regaining their livelihood.
- Ensure people with albinism are free to determine where they live.

Partnership

- Actively strengthen partnerships with civil society organizations that work directly with people with albinism.

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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” October 7, 2015. Violence is under-reported.

³ Ibid UTSS 2015

⁴ 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 Hong, Zeeb and Repacholi. “Albinism in Africa as a public health issue” *BMC Public Health* 2006, 6:212 www.biomedcentral.com/1471-2458/6/212 Accessed on October 10, 2015

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

⁸ Persons with albinism: Report of the Office of the United Nations High Commissioner for Human Rights. 12 September 2013 at paragraph 17.

⁹ Yakubu, Alkassim, Mabogunje and Oluwatope. “Skin Cancer in African Albinos” *Acta Oncologica*, Vol. 32, No. 6, pp. 621-622. 1993.

¹⁰ CEDAW Report: A/63/38, 2008. ACERWC: African Committee of Experts on the Rights and Welfare of the Child.

¹¹ ACERWC, “The Addis Ababa Declaration on Ending Discrimination and Violence Against Girls in Africa,” Addis Ababa, Ethiopia, 5 November 2013.

¹² A/RES/69/158 Protecting children from bullying

¹² Under the Same Sun. “Names Used for PWA” 2014 <http://www.underthesamesun.com/node/492> accessed August 19, 2015.

¹³ MARAVIPOST REPORTER “SUSPECTED ALBINO BODY PARTS FOUND IN MCHINJI” September 4, 2015 <http://www.maravipost.com/life-and-style/odd-news/9622-suspected-albino-body-parts-found-in-mchinji.html> accessed on October 18, 2015



¹⁴ UN Human Rights Office, Malawi e-mail to UTSS. March 1, 2015

¹⁵ Communication between UTSS and Bonface Ophiyah Massah, Executive Director of THE ALBINO ASSOCIATION OF MALAWI –TAAM

¹⁶ Chisoni, Bernard: “*Two in Custody for Conspiring to Sell Albino Child*,” allAfrica; *Malawi*, September 30, 2015; <http://allafrica.com/stories/201510010992.html>

¹⁷ “Malawi teacher charged with trying to sell albino girl for \$10,000” Agence France Presse. Sep. 15, 2015 <http://www.dailystar.com.lb/News/World.ashx> accessed September 16, 2015

¹⁸ Kumwenda, Tiwonge, “Abducted Karonga Boy Throat Cut,” September 4, 2015; allAfrica, <http://allafrica.com/stories/201509041222.html>

¹⁹ Malawi24 – All the latest in Malawi news; “*Malawian father arrested for selling his albino baby*”; By Archangel Nzangaya; August 8, 2015; <http://malawi24.com/2015/08/08/malawian-father-arrested-for-selling-his-albino-baby/>

²⁰ UTSS interview with Bonface Massah, Chair of The *Albino* Association of Malawi; also see The Maravi Post <http://www.maravipost.com/national/malawi-news/law-and-order/8366-malawi-police-claim-accused-albino-abductor-has-died-when-he-jumped-from-their-moving-car.html> and <http://www.maravipost.com/national/malawi-news/society/8361-malawi-police-in-machinga-district-nabs-albino-kidnapper.html> and UNHR <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15673&LangID=E>

²¹ allAfrica; *Malawi: Albino Rescued From Kidnappers in Machinga, Malawi Police Say*; March 5, 2015; <http://allafrica.com/stories/201503060469.html> Accessed on October 22, 2015

²² Communication between UTSS and Bonface Ophiyah Massah, Executive Director of The *Albino* Association of Malawi

²³ Communication between UTSS and Bonface Ophiyah Massah, Executive Director of The *Albino* Association of Malawi

²⁴ Malawi24 – All the latest in Malawi news; “*Unknown people in Karonga exhume albino bones*”; By Luke Bisani: August 8, 2015; <http://malawi24.com/2015/08/08/unknown-people-in-karonga-exhume-albino-bones/>