

The Civil and Political Rights of Ghanaians with Albinism

- The following contribution to the List of Issues Prior to Reporting on Ghana is respectfully submitted by Under The Same Sun to the Centre for Civil and Political Rights.
- 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.

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.ⁱ
- 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.ⁱⁱ
- Across Africa, between one in 5,000 and one in 15,000 have albinism.ⁱⁱⁱ UTSS believes this range is a conservative estimate, since data is inconsistent across the continent. With a total population in Ghana of 27 million, there are between 1,800 and 5,400 Ghanaians 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.^{iv} There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable.

The Unrealized Civil and Political Rights of Ghanaians with Albinism

• Fifteen years have passed since Ghana ratified the *International Covenant* on *Civil and Political Rights* (ICCPR). Yet, for Ghanaians with albinism,



these rights remain unrealized.^v Under the ICCPR, they have the right to life,^{vi} freedom from torture^{vii} and security of the person.^{viii} They have the right to equality before the law and to its protection from discrimination.^{ix}

- Ghanaians with albinism have been attacked and murdered for ritual purposes. But this happens less frequently than in some other African nations. However, ongoing discrimination, stigma, marginalization and myths about people with albinism create the preconditions for attacks.^x Ghanaians with albinism live in fear of violence that has swept across other parts of Africa.
- Across 25 countries, there have been 419 reported attacks since 2000. This includes 161 documented murders of people with albinism and 258 cases of missing persons, assault, mutilation, rape, attempted abductions, grave violations and other acts of violence.^{xi} 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.
- The Ghana Association of Persons with Albinism (GAPA) celebrated the first International Albinism Awareness Day in Accra on June 2015 with a public awareness march and discussion forum. Attendees included government officials, civil society, media, families, hundreds of people with albinism from Ghana's ten regions and Member of Parliament Samia Nkrumah. Police provided protection during the march. Placards read: "Send children with albinism to school"; "Persons with albinism are human beings"; "Albinism is not a curse" and; "Say no to societal prejudice." ^{xii}
- Ghanaians with albinism experience prejudice every day, in the names they are called. *Ofri* is an Ashanti term of derision for a person with albinism that means "scorched or marked person." In Anlo-Ewe, *Gesoshi* refers to the supernatural: an incomplete being. Other terms of derision reported from Ghana include: cassava dough-white person, White person, White / red person, commanded from thunder and one conceived during mother's menstrual period.^{xiii} These are just a few names reported to UTSS. But such discrimination can enable violent attacks.
- Former Board Member of the Ghana Federation of the Disabled, Mr. Suleiman Adam has albinism. He told Obaapa Radio that persons living with albinism are not welcome in any sphere of Ghanaian society: education, health, employment, religion and social life. There is total discrimination.^{xiv}

Violence Against Ghanaians with Albinism

• On February 17, 2015, the body of Kofi Yeboah, 35, a person with albinism, was found in Amanase-Boketey near Suhum in the Eastern Region. A local pastor is suspected. Local police have tended not to



respond to such crimes. After public and media pressure, the homicide unit at police headquarters in Accra took over the investigation. ^{xv}

- In June 2015, Yussif Fatau, a seventeen-year-old student with albinism managed to gain admittance to Atebubu Senior High School. However, he was denied residency at the boarding house. Leaders from the Traditional Authority told the landlord that Fatau should be evicted. The landlord complied. Ghanaians with albinism are also often barred from assuming chieftainships or leadership positions.^{xvi}
- In 2014, Nana Agyare Osei Tutu III, Chief of Bukruwa, warned that people with albinism in his region are at risk of being killed for ritual purposes. He said he could not guarantee their safety and recommended they leave the area. The chief said that taboos against people with albinism are pernicious and he doesn't know how to stop them. ^{xvii}
- Wahab is 33 and has albinism. He's from Sapala, where he was ostracized from his family and community, and survived three attempts on his life. "When I was born, people thought I was an evil child so they were just finding all ways and means to make sure they kill me when I was young," he said.^{xviii} Barriers to health care have left him with sun-damaged skin.
- However, in the northern Kasena-Nankana region, local chief Naba Henry Abawine Amenga-Etigo announced an end to the practice of infanticide of babies with disabilities. He said suspected or attempted infanticides would become a police matter.^{xix}
- Attacks often increase in the lead-up to elections, as is the case in Tanzania's October 2015 general election. 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.^{xx} But this happens in Ghana as well. There were allegations of ritual sacrifices of people with albinism in the 2008 elections. ^{xxi}
- In 2009, a two-year-old boy with albinism was kidnapped. After a week, Akua Linda was spotted with the boy and apprehended at the Kejetia Bus Terminal in Kumasi. She confessed that she and an accomplice had conspired to sell his body parts.^{xxii}
- In 2010, Newton Kwamlia Katsekua, Executive Director of the Ghana Association of Persons with Albinism was attending a funeral in Akwamufie, eastern Ghana. During the funeral ceremonies, four different parties warned him that local tradition does not tolerate people with albinism. They told him to hide or leave. He hid in a car for the next nine hours. Later, he reported the incident to several authorities but has never received a reply.^{xxiii}

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• There are likely more cases that UTSS is unaware of.

Specific Information on the Implementation of ICCPR

Article 2, paragraph 1: Recognition of civil and political rights without discrimination

- The government should work with albinism civil society groups (such as GAPA) to build on other awareness-raising campaigns conducted in the region, such as public service announcements on TV which aired across East Africa in the lead up to June 13, 2015, the first International Albinism Awareness Day.^{xxiv}
- 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 and medical explanations, offering easy ways to live with and care for the condition. The government could utilize public education mechanisms and infrastructure already in use for public health campaigns.
- The government, along with albinism civil society groups, should undertake a labour market survey to determine levels of employment of people with albinism. UTSS has found that it is generally significantly lower than the rest of the population.
- The government should identify jobs particularity suited to employees with albinism; indoors and not requiring full vision. Specific training programs could be established to give Ghanaians with albinism the skills or qualifications they would need for such vocations or professions. Tax incentives, credits and subsidies could be offered to employers who hire employees with albinism.

Article 6, paragraph 1: Right to life & Article 7: Prohibition of torture and ill treatment

- Ghana should investigate, collect and publish data about all attacks, assaults, attempted abductions, rapes, attempted rapes, murders, attempted murders and grave desecrations of people with albinism. Better data is needed on violence against Ghanaians with albinism.
- The government should, along with albinism civil society groups, develop and report on strategies to investigate, prosecute and punish attacks and threats with a particular focus on violence against women and girls with albinism, or the mothers of children with albinism. Punishment for such



crimes should at minimum be proportionate to the offense and outcomes ought to be made public as deterrence.

- Lack of natural protection from the sun means that life expectancy for most Africans with albinism is between 30 and 40 years. Health care workers, community workers and social workers need to be familiar with sunburn prevention, protection and treatment. These workers should be able to identify skin cancer and its precursors and know when to make referrals to health specialists and how to ensure follow-up.
- Discrimination against Ghanaians with albinism is often reinforced through popular culture. The government and civil society organizations should challenge negative stereotypes about albinism in popular culture and film, which reinforce discrimination and empower bullies. Academics, journalists, film producers, film funders, film directors, writers, online content creators and popular culture curators should be encouraged to abandon pernicious negative portrayals of people with albinism in favour of portrayals as neutral or positive characters, in roles unrelated to the condition.

Article 9: Right to security of the person

• The government should work with civil society groups to develop strategies to protect threatened individuals with albinism and ensure their safety within their home communities.

Article 26: Equality before the law; protection from discrimination

- UTSS echoes the call of Committee on the Rights of Persons with Disabilities for Ghana to investigate, prosecute and punish all attackers; provide healthcare, counseling and free legal aid; and raise awareness about the dignity and rights of persons with albinism, ensuring albinism NGOs are involved.^{xxv}
- Teachers of children with albinism need to know about sun care and low vision. The government should ensure educators are trained in skin cancer awareness, identification and prevention and that they are aware of its deadly impact on children with albinism.
- The government should ensure teachers are trained in the low vision needs of children with albinism. Educational 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.
- Educators 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.



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<u>Closing</u>

 As the first sub-Saharan country to break from European colonial powers, Ghana has a history of independence that could point to a different reality for Ghanaians with albinism. In places like Tanzania, things are worse. Ghana could be a leader in Africa in securing the political and civil rights for people with albinism.

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http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx Accessed on October 10, 2015

vi Ibid ICCPR Article 6, para 1. "Everyone has the right to life..."

^{vii} Ibid ICCPR Article 7 "No one shall be subjected to torture or to cruel, inhuman or degrading punishment..."

ⁱ Brilliant, Murray H. "Albinism in Africa: A Medical and Social Emergency." International Health, 2015; 7: 223-225

 ^{II} From the Convention on the Rights of Persons with Disabilities, Article 1, paragraph "e"
^{III} Hong, Zeeb and Repacholi. "Albinism in Africa as a public health issue" *BMC Public Health* 2006, 6:212 <u>www.biomedcentral.com/1471-2458/6/212</u> Accessed on October 10, 2015
^{IV} Yakubu, Alkassim, Mabogunje and Oluwatope. "Skin Cancer in African Albinos" Acta Oncologica, Vol. 32, No. 6, pp. 621-622. 1993.

[•] International Covenant on Civil and Political Rights (ICCPR) Article 2, para 1. "Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

 $^{^{\}rm viii}$ Ibid ICCPR Article 9 of the Covenant provides for the right of every person to security of person."

^{ix} Ibid ICCPR Article 26 "All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."



* Today Ghana News "Albinos in Ghana face extinction" October 30, 2014 <u>http://todayghananews.com/2014/10/30/albinos-ghana-face-extinction/</u> accessed on October 9, 2015

^{xi} Under the Same Sun. "Reported Attacks of Persons with Albinism (PWA)-Summary" October 7, 2015. Violence is under-reported.

^{xii} Ghana Association of Persons with Albinism. "Report Of The Maiden Edition Of The International Albinism Awareness Day Celebration 'Persons With Albinism Worthy Of Respect And Dignity'." June 2015

xiii Under the Same Sun. "Names Used for PWA" 2014 2014

http://www.underthesamesun.com/node/492 accessed August 19, 2015.

xiv ibid Today Ghana News 2014

^{xv} Sources: Newton Kwamla Katseku, Executive Director of the Ghana Association of Persons with Albinism – GAPA, interviewed on June 6 & July 24, 2015. And Suhum police report number 112967.

xvi Chronicle Newspaper "Albinos banished from Atebubu" June 5, 2015

http://www.ghanaweb.com/GhanaHomePage/NewsArchive/Albinos-banished-from-Atebubu-361085 Accessed on October 7, 2015

^{xvii} Koomson, Fiifi "Albino killing craze stares at Ghana" Modern Ghana <u>http://www.modernghana.com/news/207231/1/albino-killing-craze-stares-at-ghana.html</u> accessed on October 9, 2015

xviii Akoyam, Felix "Unwanted: How albinos are killed for rituals in Ghana." JoyNews 01-05-2015 <u>http://www.myjoyonline.com/news/2015/May-1st/unwanted-how-albinos-are-killed-for-rituals-in-ghana.php#sthash.N7wyZywg.dpuf</u> accessed on October 7, 2015 xix BBC News "Ghanaians Ban 'Spirit Child' Killing" April 29, 2013 http://www.bbc.co.uk/news/world-africa-22335634 accessed on October 9, 2015

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

^{xxi} Akomolafe, Femi "African Albinos: A Threatened Species". June 11, 2010 <u>http://alaye.biz/african-albinos-a-threatened-specie/</u> Accessed on October 7, 2015

xxii Daily Guide "Girl Arrested for Stealing Albino" Ghana Pundit. July 23, 2009 <u>http://www.modernghana.com/news/228901/4/girl-arrested-for-stealing-albino.html</u> Accessed on October 9, 2015

^{xxiii} Source: Newton Kwamla Katseku, Executive Director of the Ghana Association of Persons with Albinism – GAPA, interview on June 6 & July 24, 2015 ^{xxiv} A/HRC/26/L.7 I

xxv Committee on the Rights of Persons with Disabilities "Concluding Observations in relation to the initial report of Kenya" 4 September 2015