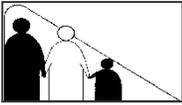


**The Situation of Persons with Albinism in Zambia: A Report to the
Committee on the Elimination of All Forms
of Racial Discrimination**

Joint Submission by:

ORGANIZATION	LOGO	CONTACT
<p>ALBINISM FOUNDATION OF ZAMBIA</p>	 <p>Albinism Foundation of Zambia <i>Breaking the Silence on Albinism</i></p>	<p>John Chiti Chairperson Plot 1000/14 Chifundo Road Email: afzlusaka@gmail.com Tel: +260 977 977 026 /+260 965 655 125 Lusaka</p>
<p>ZAMBIA ALBINISM MATTERS ORGANIZATION</p>	 <p>ZAMO <i>All lives matters</i></p>	<p>Tapela Banda Emai: zambiaamo@gmail.com Tel: +260975126719 Lusaka</p>
<p>UNDER THE SAME SUN</p>	 <p>UNDER THE SAME SUN</p>	<p>Peter Ash Founder/CEO Email: info@underthesamesun.com Website: www.underthesamesun.com Tel: +1(604)336-8868</p>

- This report was drafted by the NGO Under the Same Sun (UTSS) in collaboration with Albinism Foundation of Zambia (AFZ) and The Zambia Albinism Matters Organization (ZAMO) on the implementation of the International Convention on the Elimination of All Forms of Racial Discrimination with regards to enjoyment of Human rights by Persons with Albinism herein referred to as PWA in Zambia.

Questions for the Government of Zambia

- To what extent does the recent State Budget cater for promoting the welfare of PWA regarding protection from harmful practices?
- What progress has there been in empowering and raising awareness on albinism?
- What strategy is there for addressing discrimination of PWA?
- What support is there for PWA who lost their body parts form attacks?
- .Can we carry out a census of persons with albinism so that we know their actual number?

What is Albinism?

- Albinism is a relatively 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. In Africa, estimates on the occurrence of albinism range from 1 in every 5,000 people to 1 in every 15,000. In some populations in the region, it may be as high as 1 in 1,000.¹ There are no up-to-date reliable statistics on the number of persons with albinism.
- People with albinism are born visually impaired and with no melanin or pigment for protection, their skin burns immediately in the sun. Many acquire dramatic visible skin damage at an early age and fatal skin cancer claims majority of them by the age of 40.
- According to previous studies on albinism and original fieldwork data, the subjectivity and life experiences of people with albinism are strongly

¹ Preliminary Report of the United Nations High Commissioner for Human Rights, "Persons with Albinism," September 12, 2013 at para 14, http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_ENG.doc, and Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, "Albinism in Africa as public health issue", BMC Public Health, vol. 6, No. 212 (August 2006). www.biomedcentral.com/1471-2458/6/212

shaped by their different physical appearance and attributes². In Africa, having “white” skin color in societies where an African is expected to be black subjects people with albinism (PWA) to intense racial discrimination on the basis of color as defined under Article 1(1) of the CERD. The physical appearance of PWA is subject to erroneous beliefs and myths resulting from superstitions which favor their marginalization and social exclusion³. In 28 sub-Saharan African countries, PWA have been facing witchcraft-related harmful practices, including physical attacks, killing, maiming, rape, grave robbery, trafficking in persons and trafficking in body parts⁴.

Situation in Zambia

- There are about 25,324 people with albinism in Zambia, according to the country’s last census, conducted in 2010.
- Noting the efforts made by the Zambia government to promote the welfare of PWA in the country including prohibiting racial discrimination of persons as well as offenses causing bodily harm through The Constitution as well as Penal Code of Zambia; supporting the publishing of a handbook called “Living with Albinism in Zambia: Information for children and young people” which aims to teach children about healthcare, sun damage and the differences between them and their family and peers; Including PWA in the 2010 Census of Population and Housing; Occasional purchase and free distribution of sunscreen lotions to PWA; and hosting cancer clinics where PWA go for cancer treatment and covering medical bills for some of them. However, there are a number of issues that are yet to be adequately addressed.
- **Regarding CERD Article 5(b): The right to security of person and protection by the state against violence or bodily harm**
By October 2018, 13 reports of attacks against people with albinism have been reported in Zambia.
On February 12, 2011, a 10 year old girl with albinism by the name of AB was brutally murdered for ritual purposes in Kanyama, Zambia. Her mutilated body had been thrown away and was found several days after the attack, wrapped in a sack with several body parts missing⁵.

² Giorgio Brocco, Albinism, stigma, subjectivity and global-local discourses in Tanzania, 2016

³ Summary on albinism in Senegal sent to UTSS by Ms. Maah Koudia Keita, founder of Care Albinos, a local albinism group in Senegal on February 2, 2019

⁴ Report of the Independent Expert on the enjoyment of human rights by persons with albinism, A/73/181, para.7, 2018

⁵ Dickson Konkola, founder & president of National Albinism Initiative Networking of email: dicksonkonkola@gmail.com ; mobile: +260-97-380-4324

In December 2011 a 7 year old girl with albinism was brutally killed in Lusaka, Kanyama Town-ship, Zambia. The girl had gone missing three days earlier but was discovered dead and disposed of in an isolated drain in a sack, with body parts missing⁶.

In 2012 a woman with albinism was ritually murdered by her husband in the Sibuyunji district of the central Province of Zambia. Her husband took several body parts, leaving the mutilated remains in their home as he fled. No arrest has been made to this day⁷.

On June 3, 2013, a twenty year-old man with albinism by the name of YK from Machinjiri, Blantyre, Malawi, escaped his traffickers in Chipata, Zambia⁸.

On December 18, 2014 a 17 year old boy with albinism by the name of NB died after injuries he sustained during a kidnapping attempt the previous day on his way home from the market in Chipata, Eastern Province, Zambia⁹.

On May 26, 2015, a 37 year old woman with albinism by the name of CZ was killed during a ritual attack at her home in Kalumbu Village, Chief Magodi's area, Lundazi District, Zambia. Both of her hands were mutilated and several teeth were forcibly extracted from her¹⁰.

On December 12, 2015, a 46 year old man with albinism from Lusaka, Mandevu area, Zambia, survived an attack near his home where his finger was chopped off¹¹.

On December 22, 2015, a 36 year old man with albinism by the name of JS was attacked & killed in Mandevu, Lusaka's Zani Muone West area, Zambia. He was left to die after his right forearm was cut off, most likely with an axe, for what appears to be ritual purposes. His body was found on the roadside the morning after his attack¹².

In January of 2016 a 15 year old boy with albinism narrowly escaped abduction and possible death in the Matero Township of Lusaka; about 3km from Mandevu, Zambia¹³.

⁶ John Chiti, Director of the Albino Association of Zambia

⁷ Report to the UN by NATIONAL ALBINISM INITIATIVE NETWORKING OF ZAMBIA (NAINZ); January 20, 2016; page 2; FINDECO House 17th Floor, Room 13, Cairo Road; Cell: +260 955 544 773 / 973 804 324

⁸ TAAM MALAWI -albinismassociationmw@gmail.com

⁹ Dickson Konkola, founder & president of National Albinism Initiative Networking of Zambia in conversation with UTSS and his report titled: "REPORT ON THE INVESTIGATION OF THE RITUAL MATTERS OF PEOPLE LIVING WITH ALBINISM IN CHIPATA"; email: dicksonkonkola@gmail.com ; mobile: +260-97-380-4324

¹⁰ : allAfrica; Zambia: Albino Murdered; by Julius Phiri; May 29, 2015;

<http://www.lusakatimes.com/2015/06/02/human-rights-commission-condemns-killing-of-albino-in-lundazi/>

¹¹ Report to the UN by NATIONAL ALBINISM INITIATIVE NETWORKING OF ZAMBIA (NAINZ)

¹² Zambia Daily Mail; *Albino killed, arm chopped*; by Online Editor KELVIN KACHINGWE, Lusaka; Posted in Editor's Choice, News on December 24, 2015; <https://www.daily-mail.co.zm/?p=53668>

¹³ Report to the UN by NATIONAL ALBINISM INITIATIVE NETWORKING OF ZAMBIA (NAINZ); January 20, 2016; FINDECO House 17th Floor, Room 13, Cairo Road; Cell: +260 955 544 773 / 973 804 324

In March of 2017, a 16 year old boy with albinism by the name of G narrowly escaped abduction and possible death near his home in Matero, Lusaka, Zambia¹⁴.

On November 4, 2017, a 19 -year- old woman with albinism by the name of MK survived a brutal attack where her right hand was chopped off by unknown assailants in Buyoyo Village, Chief Chikwa's chiefdom, Chama District, Muchinga Province, Zambia. Police sources said that two suspects are currently in custody while the other is on the run¹⁵.

On Saturday, January 27, 2018, relatives of LK, a deceased person with albinism, noticed that the grave in Mutuwambwa village, Western Zambia, had been tampered with. Police found that the casket, together with the body, was missing¹⁶, and

On an unknown date between June 23 and October 30, 2018, the grave of a woman with albinism by the name of JM was violated in the Nyimba district within the Eastern Province of Zambia. Police officers discovered a missing body in her coffin¹⁷

- **Regarding CERD Article 5(d)i: The right to freedom of movement and residence within the boarder of the state**

Due to fear of being targeted in ritual attacks targeting them, PWA live in fear and don't enjoy their freedom of movement¹⁸. They have constant fear of being attacked even with family members because most attacks involve family or close friends. Some parents are even afraid to send their children to school especially in rural areas where children have to walk some distance to go to and from school.

During a radio awareness program in February 2018 a woman approached the Albino Foundation of Zambia and shared her story about an attempted attack on her 2 year old boy with albinism that forced her to flee her home in the village to seek refuge in a police camp with her son who consequently had to stop school. This is the situation for many PWA¹⁹.

- **Regarding CERD Article 5(d)iv: The right to marriage and choice of spouse**

Fear of attacks impedes Zambians with albinism from enjoying their right to marry and choice of spouse. In 2012 a woman with albinism was

¹⁴ John Chiti, Executive Director of Albino Foundation of Zambia

¹⁵ Lusakatimes.com; *An unknown people attack an Albino adolescent girl in Chama District*; November 7, 2017; <https://www.lusakatimes.com/2017/11/07/unknown-people-attack-albino-adolescent-girl-chama-district/>

¹⁶ John Chiti, Executive Director of Albino Foundation of Zambia

¹⁷ *Albino Exhumed in Nyimba*; October 31, 2018; by Chris Phiri; Zambia Reports:

https://zambiareports.com/2018/10/31/albino-exhumed-nyimba/?fbclid=IwAR2ySEv9jR9F88nIS95LUhED5cMmeQ_sNqX2-ErZBc0ESxzH_ZZlk2s1zzl

¹⁸ John Chiti, Executive Director of Albino Foundation of Zambia

¹⁹ *ibid*

ritually murdered by her husband in the Sibuyunji district of the central Province of Zambia²⁰. In November 2017 another woman from Chama district was attacked and her right hand chopped off where she identified one of her assailants as a man who had previously proposed marriage to her on several occasions²¹.

- **Regarding CERD Article 5(e)i: The right to work and free choice of employment**

Some employers are reluctant to hire persons with albinism for reasons related to their different appearance, especially in posts where the employee is in contact with the public²². Direct sun exposure makes PWA prone to visible skin anomalies that people often falsely regard as skin diseases. Employers had the lowest proportion of the employed albino population at 1.0 percent²³.

Misconceptions about persons with albinism, notably that they are less productive, carry curses or can infect others with their condition, may deter employers from hiring them. It is even more difficult for persons with albinism to find a decent job when they have not been given the chance to complete higher education

- **Regarding CERD Article Article 5(e)(v); Right to Education and training**

In an action research study in Zambia (Miles, 2011)²⁴, one teacher of a boy with albinism expressed her fears of having ‘an albino’ in her class ‘I was not so free with him, I feared his hands, he had sores on them...my belief was that whenever you see an albino you have to spit saliva on your chest’. Fear driven by superstitious beliefs has a negative impact on the way PWA are treated in education in sub-Saharan countries. Scarcity of correct information about the condition at community level inevitably increases the probability of teachers drawing on local superstitions and myths²⁵. Moreover, some parents are afraid to send their children to school especially in rural places where children have to walk some distance to go to and from school²⁶.

²⁰ Report to the UN by NATIONAL ALBINISM INITIATIVE NETWORKING OF ZAMBIA (NAINZ); January 20, 2016; pg 2

²¹ Albino Foundation of Zambia

²² A/72/169 , the social development challenges faced by persons with albinism, Zambia being among contributors to the report

²³ 2010 Zambia Population and Housing census report

²⁴ Miles, S., 2011. Exploring understandings of inclusion in schools in Zambia and Tanzania using reflective writing and photography Int. J. Inclus Educ. 15 (10) 1073–1102

²⁵ P. Lynch et al. / International Journal of Educational Development 39 (2014) 226–234

²⁶ Albino Foundation of Zambia

Recommendations to the Government of Zambia

- **Education:** Teachers and educators should be educated on albinism and proper handling of students with albinism in their care. Students with albinism should not be forced to use Braille.
- **Employment:** The Government should ensure proper accountability of employers in adhering to the principle of equality and equity where PWA are involved in seeking for employment and holding actual employment posts.
- **Public Awareness:** The Government should embark on an intense nationwide public awareness raising campaign so as to debunk false myths about albinism, and educate Zambians about its nature, challenges and possible solutions. This will curb existing ignorance which is the root cause of discrimination of people with albinism.
- **Protection:** Local authorities should increase security for PWA residing within their areas. Communities should be sensitized on raising alarm and immediately reporting attacks to the police. The police should also ensure the security and anonymity of whistleblowers.
- **Legal assistance:** Investigation of attacks against people with albinism should be thorough and serious, and court cases in that regard should be expedited. Victims of such attacks should be provided with pro-bono legal representation.
- **Redress:** Victims of mutilation of body parts and dependents of murdered victims should be provided with redress including full medical care for injuries sustained,, psychiatric counseling, monetary compensation, and where necessary, reallocation to safer areas of residence.
- **Inclusion in decision making:** PWA should be empowered and given opportunities to participate in decision making through appointment as well as contesting for leadership positions. They should also be well consulted and included in planning, implementation and monitoring of government schemes and programs
- **Policy:** Zambia should in consultation and cooperation with relevant stakeholders, develop a national policy for people with albinism to

expressly address their discrimination. The next national census should gather more accurate data on PWA.

- **Healthcare:** The Government should establish special skin care and low vision clinics for PWA, as well as increasing dermatologists and optometrists specialized in albinism. Skin cancer treatment should be strengthened. Nurses and midwives should be trained on albinism and provision of counseling to parents where babies with albinism are born. This will reduce chances of rejection and abandonment of such mothers and their babies.
- **Special procedures:** The Government should cooperate with The United Nations Independent Expert on the Enjoyment of Rights of people with albinism by allowing her to make country visits to Zambia to share her expertise.