



Submission to the 96 Pre-Sessional Working Group Session of the Committee on the Rights of the Child on the situation of children with albinism in Mali

Submission by **Africa Albinism Network, Association pour la Promotion, la Protection et l'Insertion Sociale des Personnes Atteintes d'Albinisme (SOS ALBINOS) and Association malienne pour la protection des personnes atteintes d'albinisme AMPA** to the Committee on the Rights of the Child on the situation of children with albinism in Mali.

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Submitting organizations:

Africa Albinism Network, Association pour la Promotion, la Protection et l'Insertion Sociale des Personnes Atteintes d'Albinisme (SOS ALBINOS) and Association malienne pour la protection des personnes atteintes d'albinisme AMPA welcome the opportunity to jointly submit this report for consideration during the 96th Pre session of the Committee on the Rights of the Child (CRC Committee) state review of Mali

- **Africa Albinism Network:** The [Africa Albinism Network \(AAN\)](#) protects people with albinism in Africa from targeted violence, ritual attacks, and discrimination. Hundreds of cases of killings, mutilations, and discrimination have been reported against them in the last decade across 29 countries in the region. Perpetrators target mostly women and children. To protect people with albinism, the Network works with local organizations to implement the African Union Plan of Action to End Attacks against people with albinism and to integrate the issues into local disability frameworks of support. It also conducts high-level advocacy at the AU and UN to ensure government support in this process while developing the capacity of albinism groups to take this work forward in a supported, strategic and sustainable manner.



- **Association malienne pour la protection des personnes atteintes d'albinisme**
AMPA's goal is to improve the living conditions of people with Albinism, to facilitate their social insertion into the Community, and to fight for their rights and protection.
- **Association pour la Promotion, la Protection et l'Insertion Sociale des Personnes Atteintes d'Albinisme (SOS ALBINOS)**. The organization aims at the promotion, protection, and social integration of children with albinism, through the implementation of projects and the creation of Medico-Social infrastructures for care for children with albinism in Mali.

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Introduction

This submission focuses on the ongoing difficulties and obstacles faced by children with albinism in Mali when it comes to accessing their basic human rights. These children belong to a less visible group of individuals with disabilities. The information presented is based on the first-hand knowledge and experience of the contributing organization, as well as reliable research, credible media reports, and insights from the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism. The submission specifically highlights the government of Mali's failure to ensure that children with albinism in the country are able to enjoy their rights to inclusive education, proper healthcare, personal safety, social security benefits, and, most importantly, the right to life.

The human rights situation of children with albinism in Mali

Albinism is a relatively rare, non-contagious, genetically inherited condition in which a person produces little to no melanin, resulting in little to no pigmentation, in the skin, hair, and eyes. This lack of melanin often results in a pale or “white” appearance compared to other members of their family, community, or ethnic group causing hypervisibility. In addition, the lack of melanin results in two congenital and permanent health conditions: visual impairment of varying degrees as well as high vulnerability to skin damage from ultraviolet rays, including skin cancer. Albinism affects people worldwide regardless of race, ethnicity, or gender.¹

In Africa, estimates of the occurrence of albinism, range from 1 in every 5,000 people to 1 in every 15,000. In some populations in the region, including in Southern Africa, it may be as high as 1 in 1,000.² Up-to-date reliable statistics on the number of persons with albinism remain a challenge on the continent.

¹ Report of the Independent Expert on the enjoyment of human rights by persons with albinism Worldwide A/74/190.

² 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_EN_G.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



There is no formal disaggregated data on persons with albinism in Mali. However, albinism organisations through an app have registered over 2400 persons with albinism in some selected cities and towns in the country.

Compliance with the provisions of the UN Convention on the Rights of the Child

Articles 6 & 37: Right to life and freedom from torture or cruel, inhuman, or degrading treatment or punishment of children

There have been twenty recorded attacks against persons with albinism for ritual purposes in Mali since 2000, eight of which were murders involving children below the age of 16. The following attacks recorded involved child victims in 2021 – 2022:

- On December 28, 2021, during a demonstration in a village of the Kati circle, a 2-year-old child with albinism was abducted and murdered. The child's parents had brought him along to a wedding celebration in Kati Kalifabougou when an unknown individual snatched him away, leaving him missing. Determined to find their child, the parents sought the help of the villagers and conducted a search leading to the arrest of the suspect by the local gendarmerie. The suspect confessed to the abduction and murder, disclosing the burial site of the child's body. Due to the evidence and confession, the suspect was convicted and handed over to the authorities.
- On April 12, 2022, a 15-year-old boy with albinism's lifeless body was found in his neighborhood. An investigation led to the arrest of a suspect who confessed to shooting him, alleging that the boy intended to steal his donkey. An autopsy conducted on the body revealed that he had been both shot and slaughtered, with his blood drained.

The full extent of violent crimes targeting children with albinism in Mali is unknown, as most attacks against persons with albinism are believed to go unreported for various reasons, including the involvement of family members, a culture of silence around such crimes as well as a lack of formal monitoring mechanisms to accurately track and report cases. These attacks are often driven by erroneous beliefs that the



body parts of persons with albinism when used in witchcraft rituals can bring riches, success, power, or sexual conquest. The body parts of children are considered even more potent because of their innocence. These myths and the resulting attacks are often perpetuated and fuelled by unscrupulous traditional healers. Children with albinism are at a heightened risk of being attacked, their safety and security is thus an issue of grave concern that needs to be addressed.

Article 2: Prohibition against discrimination on the basis of colour

Stigma towards persons with albinism is widespread due to ignorance and myths associated with the condition. Some communities in Mali believe that persons with albinism are “ghosts” or have magical powers; that they are the result of incest or a curse. Others also hold the belief that the hair and blood of a child with albinism are sources of power and wealth. It is common to see people spitting on themselves upon coming into contact with a person with albinism because of the belief that they are a source of misfortune. Children with albinism face discrimination based on the colour of their skin but because they are a minority and marginalized group in society, discrimination against them is simply overlooked and unreported.

Article 24: Right of the child to the enjoyment of the highest attainable standard of health

Skin cancer prevention and treatment:

Children with albinism in Mali are at high risk of ultraviolet-induced skin damage due to the lack of melanin in their skin and the fact that this age group has more time and opportunity to be outdoors in the sun. They are highly susceptible to developing skin lesions that have both cosmetic and health complications, with a high risk of developing skin cancer in later years.³ Skin cancer is a primary cause of early death in most persons with albinism in Africa. The United Nations posits that most persons with albinism do not live past the age of 40 due to skin cancer-related illnesses.⁴ In

³ Lack of adequate sun protection for children with oculocutaneous albinism in South Africa <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-8-225>.

⁴ Report by I. Ero, independent expert for the United Nations, 2015.



Mali, there are no official statistics about skin cancer-related deaths among persons with albinism, but research shows that harsh climatic conditions coupled with poor sun protective behaviour increase skin cancer risks among this group.⁵ The correct and consistent application of good quality sunscreen reduces the vulnerability of persons with albinism to the effects of ultraviolet radiation (UVR) from sunlight.

Sunscreen is not listed as an essential medicine in Mali as a result it is not accessible free of charge to children with albinism in public hospitals and clinics. In the few instances where public hospitals issue free sunscreen, they source the sunscreen from donors and do not purchase it themselves leading to sporadic availability. In the absence of the government providing free sunscreen most families of children with albinism the majority who live below the poverty line struggle to buy the sunscreen themselves for their children. The responsibility to ensure children with albinism from impoverished households access sunscreen thus ends up falling on Organisations representing persons with albinism who source sunscreen from donors and private companies to distribute to their constituencies. The only dermatology and skin cancer treatment hospital and NGOs in Mali are found in urban areas e.g., Bamako, making it even more difficult for children with albinism in rural areas to access treatment and sunscreen.

Article 28: Right to Education for Children

According to a report submitted to the Committee on the Rights of the Child, the government of Mali admitted that the number of children with disabilities who benefitted from government interventions is very low.⁶ This suggests children with albinism are less likely to benefit from these interventions. Children with albinism in Mali are not provided with low vision support to maximize the use of their vision such as standing or hand-held magnifiers, special reading glasses and textbooks, and

⁵ Lack of adequate sun protection for children with oculocutaneous albinism in South Africa <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-8-225>

⁶ Rapport valant troisième à cinquième rapports périodiques soumis par le Mali en application de l'article 44 de la Convention, attendu en 2012. CRC/MLI/3-5 Para 133



other materials in large font size. No costs adaptations such as having the student sit at the front row in class, and providing them with notes of material written on the blackboard are often overlooked. They are often excluded from physical education on the basis of their low vision.

Students also experience bullying and stigmatization within the school setting which also increases dropout rates. Students with sunburn and second-stage squamous cell cancers experience greater stigma. The schools often do not provide avenues for the students to speak about the trauma, humiliation, and pain experienced and receive the necessary psychosocial support.

Recommendations to the Government of Mali

We appreciate the effort made by the government of Mali to give effect to the rights of children set out in the Convention of the Rights of the Child through the enactment of laws and policies to protect the rights of all children. However, a lot needs to be done in terms of the implementation of these laws and policies.

Preserving the right to life and upholding freedom from torture & inhuman and degrading treatment & punishments and ensuring access to justice

- The government of Mali should continue to strongly condemn the incidences of attacks and related forms of violence, including killings, mutilations against children and other persons with albinism in the country;
- As advised by the UN Expert on albinism in past reports the government of Mali is encouraged in consultation with persons with albinism to develop, adopt and implement a National Action Plan on Albinism based on the AU Plan of Action on Albinism to ensure the effective protection and promotion of the rights of persons with albinism with particular attention to children and members of their families. Mali is urged to allocate dedicated budgets to ensure the implementation of this National Action Plan on Albinism and other programme interventions on albinism and develop robust monitoring and



evaluation frameworks to track progress; The Government of Mali should note that existing Plans among civil society organizations could fast-track the process of developing a National Action Plan.

The government of Mali is called on to work with other ECOWAS leaders to integrate existing or develop regional strategies to promote regional cooperation for the prevention, detection, investigation, prosecution, and punishment of cross-border crimes affecting persons with albinism in the region, notably trafficking of persons, children and body parts. To this end we specifically urge Mali to strengthen cross-border police cooperation through bilateral and multilateral agreements and to allocate adequate resources to better tackle trafficking in persons and body parts of persons with albinism; Other recommendations in this regard are available in the PAN African Parliament Guidelines on Eliminating Harmful Practices Related to Accusation of Witchcraft and Ritual Attacks.

- To ensure access to justice for children with albinism immediate and impartial investigation of attacks against children with albinism should be conducted to curb the delay in the delivery of justice in the criminal justice system.
- Child victims of such attacks should be provided with pro-bono child-appropriate legal representation. The Government should provide adequate protection to witnesses and victims.

Public Awareness:

- The government of Mali, civil society organisations and communities of people with albinism and other key stakeholders should work together to address root causes of discrimination and violence against people with albinism in Mali and increase knowledge and awareness on albinism including by embarking on an intense nationwide public awareness raising campaign to debunk false myths and beliefs about albinism and its cause.
- Government should support civil society working on issues regarding persons with albinism and should assist persons with albinism in awareness-raising about their rights including national mechanisms available for their protection.



Education:

- Mali should take all measures necessary to enhance access to inclusive, equitable, and quality education for children with albinism and to provide comprehensive reasonable accommodation at all levels of education, including in the form of low vision support to maximize the use of their vision;
- Teachers and educators should continue being educated on albinism and proper protection as well as accommodation of the visual impairment of students with albinism in their care;
- Ensure that resources are at the disposal of schools to meet the specifications needed of persons with albinism, notably by providing textbooks and exams with larger fonts and assistive devices for low vision to read the blackboard.

Health:

- We call upon Mali to ensure access to health services and adaptive devices for reasonable accommodation such as visual aids and appropriate sunscreen for all persons with albinism particularly in rural areas and with emphasis on skin cancer screening, prevention, and treatment as well as specialist services for low vision and dermatological care. Psychosocial support should also be made available to persons with albinism in their communities;
- The Mali government should, at a minimum, provide free sunscreen of an appropriate protective spectrum to enable persons with albinism to participate as equal members of society in daily life and to enjoy their rights to health and life.
- Adequate, accessible, and affordable diagnostic, preventative, and curative skin cancer treatment should be provided to all persons with albinism.
- The Government should subsidize costs for accessing skin care and low-vision health services for persons with albinism, as well as removing barriers to access to dermatologists and optometrists specialized in albinism.



- Nurses and midwives should be trained on albinism and provision of counselling to parents where babies with albinism are born. This will reduce chances of rejection and abandonment of mothers of persons with albinism.

Data collection:

- We urgently request that Mali systematically collect, disaggregate, and disseminate data on persons with albinism including children with albinism using the guidance note by the Washington Group⁷

Social protection:

- We urge Mali to design, implement, and strengthen social safety net mechanisms and programs that are inclusive of children with albinism.

Cooperate with Special Procedures:

- We implore Mali to cooperate fully with the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism and the AU Special Envoy on Albinism (once appointed) in the discharge of their mandates and to give serious consideration to implementing their recommendations, to provide the mandate holders with all necessary information relating to the mandate and to react promptly to their communications and urgent appeals in order to enable them to fulfil the mandate effectively.

⁷ <https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/>