



A Joint Submission to the 94th Session of the Committee on the Rights of the Child on the situation of children with albinism in Togo

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Submitting organizations:

Africa Albinism Network and Association Nationale des Personnes Atteintes d'Albinisme au Togo (ANAT)

The [Africa Albinism Network \(AAN\)](#) works to protect the rights of people with albinism in Africa from targeted violence, ritual attacks, and discrimination through the promotion of the [AU Plan of Action on albinism \(2021-2031\)](#) human rights advocacy and the capacity development of albinism groups.

The **Association Nationale des Personnes Atteintes d'Albinisme au Togo (ANAT)** has a vision to achieve a Togo where all individuals with albinism enjoy moral, physical, social, and economic well-being and fully participate in the country's development with an emphasis on access to health, education, and other socio-economic rights.

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Questions for the Government of Togo:

1. What steps have you taken to ensure implementation of the AU Plan of Action on albinism which calls for specific measures for people with albinism (2021-2031)?

2. What steps have you taken to ensure that the National Strategic Plan on albinism which was drafted by ANAT and other CSOs is being implemented, because it is an important avenue to implement the AU Plan of Action on albinism?
3. What steps have you taken to ensure sustainable access to health such as skin cancer prevention measures for people with albinism?
4. What steps have you taken to destigmatize albinism e.g., by engaging in continuous awareness-raising campaigns for a minimum of three years as was done in Tanzania and recommended by the UN Independent Expert on albinism?
5. What steps have you taken to invite the UN Independent Expert on the enjoyment of human rights by persons with albinism to Togo to assess the situation of people with albinism?

Introduction

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 remains 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

Methodology

This report is derived from the work and observation of its authors, the state party report submitted to the Committee on the Rights of the Child, as well as credible research findings, trusted media reports, and valuable insights provided by the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism.

The human rights situation of children with albinism in Togo

Children with albinism in Togo belong to a less visible group of individuals with disabilities who face multiple and intersecting barriers to accessing their human rights. One of the significant challenges for children with albinism in Togo is the fear of ritual attacks and killings. There have been reported cases of individuals with albinism being targeted for their body parts due to superstitious beliefs that associate them with magical properties.³ A majority of these cases reported are anecdotal and we only have full details for one case that occurred in 2017, there is little capacity and resources to follow up on these anecdotal reports. This situation creates a dangerous and hostile environment for them. Moreover, children with albinism in Togo may experience limited access to education, healthcare, and social services, which further exacerbates their vulnerability.

Presently, there is a lack of comprehensive nationwide data on individuals with albinism, encompassing children in particular. The only available data stems from ANAT, a co-author of this report, which has data showing 726 individuals with albinism, including 280 children. However, this information is updated quarterly through the organizations' limited efforts, does not include government support and therefore does not accurately represent the entire population of persons with albinism in Togo.

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

³ <https://www.underthesamesun.com/wp-content/uploads/2023/07/Attacks-of-PWA-Extended-07.05.23.pdf>

On the night of September 23, 2017, four individuals broke into the home of a farmer while two others stood guard. They abducted a 2-year-old child with albinism and all six of them fled the scene. Despite the spontaneous mobilization of the neighbours, who were alerted by the distressed cries of the child's parents, they were unable to apprehend the perpetrators during the pursuit. The assailants, in an attempt to confuse any leads that could lead back to them, took several detours and eventually arrived at a field located south of the city of Dapaong. There, they buried the lifeless body of the child after fatally assaulting him.

While the case mentioned above is the only officially reported instance involving a child with albinism in Togo,⁴ ANAT has verified the occurrence of numerous unreported attacks targeting individuals with albinism, including children. Unfortunately, there are currently no established mechanisms to document these cases, and there is a lack of resources and capacity to conduct follow-ups to confirm these incidents. As a result, a significant number of attacks against persons with albinism remain undocumented and unaddressed.

This suggests that the full extent of violent crimes targeting children with albinism in Togo is unknown, as most attacks against persons with albinism are believed to go unreported for various reasons, including the involvement of family members and a culture of silence around such crimes. 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 due to their colouring and appearance is widespread due to ignorance and myths associated with the condition. Some communities in Togo believe that persons with albinism are “ghosts” or have magical

⁴ Combined fifth and sixth periodic reports submitted by Togo under article 44 of the Convention, due in 2017* CRC/C/TGO/5-6. para 136

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 also believed that persons with albinism prevent rainfall and are the cause of famine. As a result, they are not allowed to reside in such communities and those born with the condition are either killed or banished.

ANAT believes that almost all individuals with albinism are subjected to derogatory nicknames or labels. A parent of a student with albinism testified that their child is often asked to bring their own food to avoid sharing the food with others at school. Some individuals with albinism have reported being abandoned by their fathers at birth due to their condition. These testimonies illustrate the pervasive stigmatization and discrimination that individuals with albinism face, highlighting the need for awareness, education, and comprehensive policies to protect their rights and promote inclusivity.

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

Skin cancer prevention and treatment:

In Togo, children with albinism face a significant risk of ultraviolet-induced skin damage because their skin lacks melanin, which provides natural protection against the sun's harmful rays. Additionally, this age group tends to spend more time outdoors in the sun, increasing their exposure to harmful ultraviolet radiation. Consequently, 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.⁵

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.⁶ In Togo, 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 behavior increase skin

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 Human Rights Council (HRC) 'Persons with albinism. Report of the Office of the United Nations High Commissioner for Human Rights' A/HRC/24/57 (2013) para 27.

cancer risks among this group.⁷ Unfortunately, sunscreens are not readily available and accessible to children with albinism in public hospitals and clinics. Families of children with albinism depend on albinism groups and their partners to receive free sunscreen on an irregular basis and upon availability.

A recent study conducted among persons with albinism in Togo indicated a 95.2% of the participants including children presented with various skin lesions in sun-exposed areas such as head and neck regions.⁸ The same study indicates that persons with albinism including children residing in urban centers have access to more information on albinism as well health facilities than their counterparts in rural and remote regions of the country.⁹ There are no specific healthcare services available for children with albinism. These children receive care within the regular healthcare system established by the government. However, the costs of dermatological and ophthalmological care are high, making it difficult for many children with albinism to access these services. To address this issue, ANAT, with the support of their non-governmental (mostly foreign) partners, provides free dermatological and ophthalmological care to individuals with albinism, within their areas of operation and on an irregular basis/as services are available.

The lack of healthcare infrastructure and medical resources in rural areas can hinder the timely diagnosis, treatment, and management of skin cancer cases among children with albinism. This disparity in access to medical facilities might result in delayed interventions and potentially poorer health outcomes for affected children living in remote regions.

Addressing this issue requires a comprehensive approach, including efforts to improve healthcare infrastructure in rural areas, raise awareness about albinism and its associated health risks, and establish outreach programs to ensure that all children with albinism have equitable access to medical care, regardless of their geographical location. Facilitating health awareness and training concerning people with albinism among government authorities, non-governmental organizations, and healthcare

⁷ Saka et al, 'Skin cancers in people with albinism in Togo in 2019: results of two rounds of national mobile skin care clinics,' BMC Cancer (2021) 21:26 <https://doi.org/10.1186/s12885-020-07747-8>.

⁸ As above

⁹ Saka (in 7 above)

providers is vital to bridge the healthcare gap and provide the necessary support for children with albinism across the country.

Article 28: Right to education for children

Togo is currently taking steps towards inclusive education, including measures for children with albinism. It was not until 2020 that the Ministry of Education issued a dedicated circular note promoting inclusive education. While the dissemination and implementation of this circular have commenced, a comprehensive evaluation of its impact is yet to be conducted.

According to ANAT, children with albinism have reportedly faced various challenges. Testimonies from these children revealed experiences of discrimination and stigmatization by their classmates. Their unique needs were largely overlooked, as they were given tasks that exposed them to the sun, and their learning materials and exam papers were provided in small print without considering their visual impairment. Moreover, they were often seated far away from the blackboard, rather than being placed closer to facilitate their learning process.

A study conducted among the Ewes of Southern Togo revealed that 63.3% of the research participants acknowledged that children with disabilities receive inadequate education. Additionally, 16.9% of respondents indicated that children with disabilities from low-educated households have never attended school.¹⁰ Given their heightened vulnerability, children with albinism are likely to be among the most affected in this scenario, as they face stigma and discrimination due to their condition, compounded by their low vision and myths associated with albinism.

It is crucial to continue to raise awareness and to advocate for inclusive education practices in all schools to ensure that children with albinism have equal opportunities for education and are not subjected to discrimination or exclusion.

Recommendations to the Government of Togo

¹⁰ <https://irispublishers.com/ijer/fulltext/inclusive-education-and-dignity-of-children-with-disability-in-togo.ID.000501.php>

Articles 6 and 37 Preserving the right to life and upholding freedom from torture & inhuman and degrading treatment & punishments and ensuring access to justice:

The government of Togo should:

- Continue to strongly condemn the incidences of attacks and related forms of violence, including killings and mutilations against children and other persons with albinism in the country.
- 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. Togo is urged to allocate a dedicated budget to ensure the implementation of this National Action Plan on Albinism and other program interventions on albinism and to develop robust monitoring and evaluation frameworks to track progress.
- Use the current National Strategy on Albinism developed with wide consultation by CSOs as an avenue to implement the AU Plan of Action on albinism. The Strategy already exists and so would fast-track the process of developing a National Action Plan.
- Implement recommendations to end attacks and harmful practices, as listed in the PAN African Parliament Guidelines on Eliminating Harmful Practices Related to Accusation of Witchcraft and Ritual Attacks.
- Work with civil society to address the root causes of discrimination and violence against people with albinism in Togo and to 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 continuously for a minimum of three years.
- Support civil society working on issues regarding persons with albinism and should assist persons with albinism in training about their rights including incorporating their issues into national mechanisms available for their protection.

Article 28: Rights of the Child to Education:

The government of Togo 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 devices such as monocular to maximize the use of their vision;
- Train or support the training of teachers and educators on albinism and proper protection to accommodate their disability - in skin and eyes - and also to prevent social stigma in schools. Ensure that resources are at the disposal of schools to meet the specifications needed for the inclusion of persons with albinism, notably by providing textbooks and exams with larger fonts and assistive devices for low vision to read the blackboard such as monocular and specialized glasses with photoprotection from the sun and glare, sun protective uniforms such as long-sleeved shirts, sunglasses and wide-brimmed hats.

Article 24: Rights of the child to highest attainable standard of Health:

- Ensure access to health services and adaptive devices for reasonable accommodation such as visual aids as described above under education.
- Provide low-cost and barrier-free access to quality sunscreen with an appropriate protective spectrum for all persons with albinism particularly children in rural areas and with emphasis on skin cancer screening, prevention, and treatment.
- Provide available and low-cost, barrier-free access to specialist services for low vision and dermatological care including skin cancer treatment and prevention. Psychosocial support should also be made available to persons with albinism in their communities.
- Train nurses and midwives on albinism and provision of counselling to parents when babies with albinism are born. This will reduce the chances of rejection and abandonment by mothers of children with albinism.

Data collection:

- We urgently request that Togo systematically collect, disaggregate, and disseminate data on persons with albinism including children with albinism using the guidance note by the Washington Group.¹¹

Social protection:

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

Cooperate with Special Procedures:

- We implore Togo 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 their mandate effectively.

¹¹ <https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/>