

## THE SOCIOPROFESSIONAL INTEGRATION OF PEOPLE WITH ALBINISM AND GOVERNMENT ACTIONS IN GUINEA

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### ABSTRACT

Albinism is a rare genetic condition characterized by a deficit in melanin production, resulting in a partial or total absence of pigmentation of the skin, hair and eyes. This condition affects people regardless of race, ethnic origin or sex, and presents significant social, medical and economic challenges. This article aims to examine albinism on a global scale, with particular emphasis on the situation in Guinea and the measures taken by the Government to combat discrimination and improve the living conditions of people suffering from it. Here, the main objective of this article is to raise awareness of the situation of people with albinism, by highlighting the challenges they face and highlight the actions undertaken by the government to support them. It is also about contributing to strengthening solidarity within the global community, as well as raising awareness of the need to protect the human rights of people with albinism and to combat violations committed against them. This article is based on a major argument based on the idea that people with albinism are often victims of discrimination, stigma, and social exclusion because of their distinct physical appearance. The myths and misconceptions associated with albinism fuel marginalization and physical attacks, which seriously undermine the rights and safety of people with Albinism. Thus, in this context, government action in Guinea and elsewhere is essential to guaranteeing the protection of the rights of people with albinism. These measures include raising public awareness, access to health care and education, and promoting social inclusion and employment for this vulnerable population. Based on the purpose of this article, a methodology will be established based on research, investigation, survey and reading of existing works to highlight the importance of protecting the rights of persons with albinism and combating discrimination and stigma. But also call for collective action by Governments, civil society and the international community to promote equal opportunities and respect for human rights for all people with albinism.

**Keywords:** Albinism, Stigmatisation, Discrimination, Violence, Awareness, Empowerment, Government Action.

### I. INTRODUCTION

Albinism can be defined as a relatively rare, non-communicable genetic disease. It affects people all over the world, without distinction of gender, race or ethnic origin. Regardless of whether they have albinism themselves, if both parents are bearers of the associated gene, there is a 25% chance that their child will be born with Albinism. Albinism is characterized by a deficit in melanin production and insufficient pigmentation of the skin, hair and/or eyes. Most people with albinism therefore have a pale appearance in relation to their family and community, with light skin and hair. Most people with albinism have blue, nut or brown eyes. However, certain lighting conditions may highlight the blood vessels located at the bottom of the eye, sometimes giving the eyes a reddish or purple appearance. The levels of pigmentation vary depending on the type of albinism. Different types of albinism include, among other things, oculocutaneous albinosity that affects the eyes, hair and skin, ocular albinizm which affects only the eyes and Hermansky-Pudlak syndrome that affected the eye, hair, and skin and contributed to bleeding problems. The most common and visible type of albinism is oculocutaneous. Because their skin lacks melanine, people with albinism are vulnerable to skin cancer. (The melanin in the skin protects from the sun.) Skin cancer poses a fatal danger for most people affected. The lack of melanine in the eyes, along with the unusual development of the retina and nerve connections, contribute to a visual impairment that is variable, from mild to severe, and many people with albinism are legally considered to be blind, so they are directly classified in the category of indicapes. This situation of albinos makes them the weak and pitiful layers of communities.

The Republic of Guinea is a country in West Africa. It borders Sierra Leone and Liberia to the south, Côte d'Ivoire to the east, Mali to the northeast, Senegal in the north and Guinea-Bissau in the west. Guinea is indeed the first country in the world to pass a specific law to protect and promote people with this genetic disease. In Guinea, the number of people with albinism is estimated at more than 2,000, a figure that remains very

approximate. More generally, attacks, severe stigma and discrimination against people with albinism have been in 27 African countries. According to data collected by the Office of the United Nations High Commissioner for Human Rights (OHCHR), over the past ten years, more than 700 cases of murder, mutilation and other forms of violence have been in African countries. These statistics underestimate the magnitude of this phenomenon of discrimination, violence and abuses of physical and psychological dignity and people with albinism. On the occasion of the World Albinism Awareness Day, Mr Lacinet Touré who is one of the members of the NGO "Defence of Albinisms" organized a press conference in which he discussed the stigmatization and marginalization of this vulnerable layer in society. Mr. Lancinet Touré recalled some of the acts that they suffered throughout the day. It is with a beacon of grief that he says this: "Some, for example, when a woman is in a family state, you see a person waiting for albinism, she spit, that if she doesn't, that her child that is in her belly will become albino. And a woman too, when she walks too much at night, they will say that her child will become albinos, these are prejudices again. When you go to the mining areas, it's so recurrent, there are people, they can go consulted with charlatans, marabouts, who are sitting on the spot, he doesn't have to eat, so he says you have to send an organ from a person with albinism, you're going to have diamonds and all that. They can go and kill us, there have been children who have been killed like this". As mentioned in the abstract of this article, the purpose of this article is to explore, analyze and highlight the inequalities and discrimination experienced by people with albinism in Guinea, as well as to talk about the government policies in force in Guinea in terms of the socio-professional integration of people with Albinism, but also to participate directly or indirectly in their social, cultural, political and professional integration through the opinions and recommendations that will be established in this article. This article also aims to understand how and how these policies affect discrimination and social stigma, access to education and, in particular, integration into the labour market and society. It seeks to identify the challenges faced by people with albinism and to assess the extent to which current government initiatives are tailored to their specific needs. Another significance of this article is that albinism remains a taboo subject in African communities, in Guinea. This problem dates back to several centuries. The presence of an albinos in a family in Guinea is a source of curse, divine punishment, witchcraft, and even of wealth for the person who has sexual intercourse with that albino. However, several non-governmental organisations, in collaboration with international organizations, have been created to protect albinos in Guinea. With the emancipation and schooling actions of some albinos, a qualitative but slow evolution is observed in this part of the discriminated population. The next lines of this article will consist of a general idea of albinism in Africa but also of Albinism in Guinea while focusing on the challenges faced by albinos in Africa and Guinea (stigmatisation and discrimination, the challenges, health, access to education, employment and economic opportunities, access to health care).

### 1-Albinism in Africa

Albinism is known as a genetic condition that can affect any population in the world, regardless of race or ethnic origin. However, in Africa, where this condition is visible, the origins of this genetic modification date back several centuries and are often linked to cultural beliefs and genetic factors. From a genetic point of view, albinism is caused by mutations in the genes responsible for the production of melanine, the pigment that gives color to the skin, hair and eyes. As a result, people with albinism produce little or no melanin at all, resulting in very light skin, blonde or white hair, and light eyes ranging from blue to pink. Based on genetics, we will see that in Africa, where marriage between close relatives is sometimes practiced, the risk of albinism transmission is higher in populations where this practice is widespread. Children of parents with the albinism genus are at increased risk of developing the condition, although not all children from these unions are necessarily albinistic. It should be noted that the origins of albinism in Africa are multifactorial, combining genetic factors with cultural beliefs and social practices. It is therefore in this sense that albinism in Africa presents a complex socio-cultural and medical landscape. In many African societies, albinism is surrounded by myths, superstitions, and cultural beliefs, some even viewing it as a curse or a sign of bad premonition. This misperception has fueled stigma, discrimination and even violence against people with albinism. Cultural beliefs and superstitions have also contributed to shaping perceptions of albinism in Africa. This poses enormous challenges for these people.

One of the most notable challenges facing people with albinism in Africa is the high risk of skin cancer due to the lack of melanine, which protects against the harmful ultraviolet rays of the sun. Many African countries

have high levels of sunlight, which increases the risk of skin lesions and cancer in people with albinism. This situation requires thorough education and access to protective measures such as sun protection and protective clothing.

In addition, people with albinism often face social stigma and discrimination, which can manifest themselves in various forms such as exclusion from social activities, limited access to education and employment opportunities and even physical violence. Some communities have misconceptions that associate albinism with supernatural powers or curses, leading to discrimination and marginalization.

In recent years, efforts have been made by Governments, non-governmental organizations (NGOs) and international organizations to address the challenges facing people with albinism in Africa. These efforts include awareness-raising campaigns aimed at dispelling myths and educating communities about albinism, promoting the rights and protection of people with albinos, and providing health services and support programmes tailored to their specific needs.

Despite these efforts, much remains to be done to full inclusion and equality for people with albinism in Africa. This requires sustained efforts to combat stigma and discrimination, improve access to health care and education and promote policies that protect the rights and well-being of people with albinism. In addition, promoting greater acceptance and understanding within communities is essential to creating a more inclusive society in which people with albinism can thrive and realize their potential.

#### **The challenges faced by albinos in Africa**

To address the challenges faced by people with albinism on the continent and to promote a more inclusive and respectful society of human diversity, it is essential to understand the origins and ancient perceptions of Albinism in Africa. One of the most notable challenges facing people with albinism in Africa is the high risk of skin cancer due to the lack of melanine, which protects against the harmful ultraviolet rays of the sun. Many African countries have high levels of sunlight, which increases the risk of skin lesions and cancer in people with albinism. This situation requires thorough education and access to protective measures such as sun protection and protective clothing. In addition, people with albinism often face social stigma and discrimination, which can manifest themselves in various forms such as exclusion from social activities, limited access to education and employment opportunities and even physical violence. Some communities have misconceptions that associate albinism with supernatural powers or curses, leading to discrimination and marginalization.

Speaking of government efforts, in recent years, efforts have been made by governments, NGOs and international organizations to address the challenges facing people with albinism in Africa. These efforts include awareness-raising campaigns aimed at dispelling myths and educating communities about albinism, promoting rights and protecting people with albinos, and providing health services and support programmes tailored to their specific needs. But despite these efforts, much remains to be done to ensure the full inclusion and equality of people with albinism in Africa. This requires sustained efforts to combat stigma and discrimination, improve access to health care and education and promote policies that protect the rights and well-being of people with albinism. In addition, promoting greater acceptance and understanding within communities is essential to creating a more inclusive society in which people with albinism can thrive and realize their potential.

For example, in Tanzania, in this country in South-East Africa, albinos are mutilated or murdered. The remains of their bodies enter the composition of magic remedies, sold by the witches at exorbitant prices.

Isolated villages in Tanzania use different counselors, healers, witches, or connoisseurs, known as waganga in Swahili, to solve problems ranging from the stale cow to the abstinent wife. Recommendations may include root spraying, herbal infusions or even animal blood. But also human bodies from people suffering from albinism. Some albinos believe that hair, bones, genitals or thumbs possess special powers. These pieces of beings born with a melanine production deficit in a country where the majority of inhabitants are black are often used to inflate a fishing net, reveal the presence of gold in a field, earn income, or win votes to a politician in elections. How did these parts of the body develop their magical reputation? There is no precise information, but researchers place the use of this technique as a commodity in the early twentieth century, when small farmers felt that fishing or gold mining presented more opportunities, but also presented greater risks. As a result,

people with this genetic skin depigmentation disease are subjected to mutilation or even massacre, sometimes by their own families. In a country where the average annual salary is around 2,500 euros, the remedy based on albino body parts can amount to up to 100,000 Tanzanian shillings (environ 40 euros). A single arm of albinos can generate up to 4,000 euros for a wizard.

In an excerpt edited by the editorial office of the National Geographic newspaper, the mother of a 4-year-old albinos feels unsafe after motorcyclists tried to kidnap him in front of his house, complaining: "I can't even trust my family members because they're ready for anything when they need money." Tanzanian prosecutor Beatrice Mpembo recalls that since 2007 only 21 people have been convicted for the murder of albino, in just six cases. For the judge, this figure is due to the lack of cooperation of the families. In fact, only 5% of those arrested are convicted. And no one dares to give the names of the instigators of these violence: the wealthy customers of the waganga.

Dans le n° 221 du magazine National Geographic, daté de février 2018, le combat des ONG sur le terrain pour faire cesser ces violences.

### **Albinism in Guinea**

In Guinea people with albinism have names according to the national languages, for example in Soussou they are called fonfi or foté, in Malinke they are called Mööningbé, in Poular they are called pouli...

Albinism is defined as an inherited condition that alters the skin's pigmentation, resulting in a deficiency in the production of melanine, a substance responsible for the coloring of the skin and its protection from sunlight. This condition affects not only humans, but also various animal species such as birds, fish, and even certain reptiles such as snakes, crocodiles and camelons. In Guinea, people with albinism are among the most vulnerable and often faced with conditions of extreme poverty.

The skin vulnerability of people with albinism, characterized by a very sensitive skin to heat and sunlight, exposes them to skin stains or pimples, as well as an increased risk of skin cancer. This physical difference from non-albinos creates a social vulnerability due to stigma and discrimination in society. The myths created by African society, in Guinea, around these people classify them and limit them in many aspects of their lives.

## **II. THE CHALLENGES FACED BY ALBINOS IN GUINEA**

Being affected by albinism in Guinea, as in many other countries, presents unique and often complex challenges. Albinism is a genetic condition characterized by the partial or total absence of pigmentation in the skin, hair and eyes. In Guinea, people with albinism face a number of difficulties, including social, medical and economic. In this article, we received some point such as:

1. Stigmatisation and Discrimination: People with albinism in Guinea are often subjected to stigma and discrimination because of their distinct physical appearance. False beliefs and superstitions often surround albinism, which can lead to negative attitudes and discriminatory behaviour on the part of society.
2. Health: People with albinism are more susceptible to the harmful effects of the sun due to the lack of melanine in their skin. This puts them at increased risk of sunburn, sunbath and skin cancer. In Guinea, where the climate is often sunny, protection from ultraviolet rays is important for people with albinism.
3. Access to Education: Children with albinism in Guinea may encounter obstacles to accessing quality education due to stigma and discrimination. Schools may not be equipped to meet the specific needs of children with albinism in terms of vision and sun protection.
4. Employment and Economic Opportunities: Adults with albinism may also face difficulties in the labour market due to discrimination and lack of access to equitable employment opportunities. Stigmatisation can limit their professional and economic prospects.
5. Access to Health Care: Access to health care for people with albinism in Guinea may be limited, in rural areas. Health services may not be sensitized to the specific needs of people with albinism in terms of early detection of skin cancer and treatment of vision problems.

In our search for the writing of this scientific article, we have received some testimony published by the journal lelynx:

Camara M'Mah, a graduate Sonfonia student, says she has problems with the painting. "I've always been sitting in front of me since primary school. The girls laughed at me, saying that I was blind." She asks the government



to create a specialized health facility, to distribute free sunscreen, sunglasses and protective clothing, because in Guinea, she says, it is not easy to avoid the sun and the sun is “our deadly enemy”.

Seydou Konaté, who lives in Siguri, known for being warm and sunny, does not find a job: “If you ask, they tell you that you are not fit to work. As a result, our children don't go to school. I lost two albinos friends to cancer (one in 2020 and another in 2021), they were unable to take care of themselves because of lack of resources and we cannot have resources without a job.”

The number of people with albinism is officially 1,600, according to Mr. Mohamed Diaby, National Director of Vulnerable Persons, who quotes the General Census of the Population 2014, published in 2017, but we estimate that this number is evolutionary and will exceed 1,600 people by 2024. This figure is obviously unreliable. In Conakry alone, dozens of people with albinism are begging in the streets, in the sun. A real health problem, many of them die from cancer. Dr. Ibrahima Traoré, dermatologist at the Dermatological Clinic, explains that the skin of people with albinism is very vulnerable to UV rays from the sun, which promotes skin cancer. Some albinos regret that they consider the 21st century as fruit a curse or good to be sacrificed these are the words of a young 13-year-old albino named Aicha.

Today, some people are engaged in the cause of people with albinism, which has resulted in the creation of an agency called all beauty services, which is now the first mixed agency in Guinea to work on the socio-professional integration of those people and participation in the fight against discrimination on all sides. This agency has another component that is the promotion of the albino people by making them work with people without albinism that where comes the name of a mixed agency. They are facing several shortcomings, such as: the lack of funding and subsidy from the State and international organizations, the absence of resources to help its people with albinism is an obstacle to my project. Despite this, they are able to identify some people with albinism as participants in events. Despite these challenges, efforts to raise public awareness, promote inclusion and protect the rights of people with albinism in Guinea are increasing, but also through the subsidization of individuals and volunteers willing to participate in this cause. Local and international organizations work together to provide medical, educational and social support to people with albinism, while promoting policies and laws to combat discrimination and ensure equal opportunities for all.

### III. CONCLUSION

Finally, equality and non-discrimination are fundamental human rights principles for people with albinism, due to their visual impairment and the need to take preventive measures to reduce their vulnerability to skin cancer. States are obliged, under international human rights law, to respect, protect and guarantee the fundamental rights of persons with albinism and to prevent any violation of those rights. Given the complexity and complexity of human rights problems faced by persons with albinism, States are encouraged to adopt a multisectoral and collaborative approach to fulfilling their obligations, including through best practices and cooperation with civil society, other States and international and regional organizations. In particular, States are encouraged to develop national albinism action plans. A national action plan should provide a framework for governments to set targets, set deadlines, assign responsibilities to specific entities and allocate the necessary resources, financial or otherwise, to their objectives. Despite the deplorable conditions in which the albinos live, which has the consequence of a precarious life that goes against human rights, the state of Guinea has therefore passed laws of 35 articles to protect its people through the National Assembly. Among these laws we have:

Article 2: This Act aims to guarantee inclusion, equal opportunities for persons with albinism, protection and promotion of their rights against all forms of discrimination and stigma.

Article 3: The primary obligation of the State is to guarantee respect for and enjoyment of the rights of persons with albinism. Parents have the primary responsibility to ensure the education, protection and guidance of their children with albinism.

Article 7: A child with albinism who is a victim of negligence, violence, exploitation or from poor parents is placed under State supervision through the Albinism Ministry, with a view to providing the necessary protection and education for his or her social inclusion and development, in collaboration with public sectors and civil society organizations.

Article 13: Reasonable measures and arrangements must be taken by their employers to enable persons with albinism to perform their duties, taking into account their vulnerability.

Article 15: The State guarantees the compulsory schooling of children with albinism from the required age throughout the territory of the country. This schooling is followed by accompanying measures in the form of assistance of any kind, the modalities of which are defined by regulation. This accompaniment must enable the beneficiary to have access to a vocational or academic training that can guarantee a sustainable employment.

Article 20: Children with albinism shall be placed in the same conditions as any other child, in accordance with the African Charter of the Rights and Welfare of the Child and the United Nations Convention on the Rights of the child.

Article 24: It is forbidden for any person to force an albinos to beg or to exploit the begging of an albino. Any offender shall be punished in accordance with the provisions of the Penal Code.

Official document published by

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To conclude this article: What does the life of a parent or person with albinism look like in a society that wrongfully persecutes and stigmatizes them?

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