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LETTER TO PRINCIPAL

Stigma of Albinism in Africa

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Dear Editor:

Albinism is a rare genetic condition characterized by partial or total loss of pigmentation (of skin, hair, and eye color), due to absence or reduction of melanin synthesis and distribution. It is hereditary and appears with the combination of two carriers of the recessive gene, and presents with significant, but variable, visual impairment, which is common to all known types of this genetic condition. Additionally, many types of albinism show failures in pigment production, of melanin, hence the highly characteristic appearance of many people with albinism. Lacking pigment in Europe may even go unnoticed in Scandinavian countries. But in Africa, the lack of pigmentation stands out markedly. And its consequences are also different.(1)
Albinism is classified into two major groups:(2)

- Oculocutaneous albinism (OCA), which is the most severe form, as it affects the eyes, hair, and skin. The inheritance of this condition is autosomal recessive, meaning that the chromosomes of both father and mother must carry this trait. When both parents carry the albinism gene (and neither parent has albinism), there is a one in four chance, in each pregnancy, that the baby will be born with albinism. Currently, seven forms of oculocutaneous albinism are recognized through DNA analysis: OCA1, OCA2, OCA3, OCA4, OCA5, OCA6, and OCA7.

- Ocular albinism (OA), which is much less common, affects only the eyes, while skin and hair have normal or slightly reduced pigmentation. This type of albinism is caused by a change in the GPR143 gene, which plays a very important role in eye pigmentation. This gene is located on the X chromosome; therefore, to suffer from ocular albinism, only one copy of the GPR143 gene inherited from the mother is needed. It is due to this that most people with OA are men.

People with albinism clinically present three fundamental problems:(2)

- Vision problems, as a consequence of abnormal development due to lack of melanin pigment. The main problems are nystagmus, strabismus, photophobia, refractive error (myopia or hyperopia), macular hypoplasia, and occasionally optic nerve deviation. Specialists recommend using two types of glasses: one for indoor use, with colored lenses that reduce luminosity by 15 %, and others that reduce it by 80 %, for outdoor use.

- Skin problems, mainly burns due to sun exposure; if these burns become frequent, they may evolve over time into skin cancer. These people must protect themselves with appropriate clothing to shield themselves from solar rays. They must also use sunscreen throughout their lives.

- Social problems, because these people are poorly regarded by society. The discrimination and violence generated around people with Albinism is very delicate, especially in African countries that hold the belief that their bodies contain magical powers; indeed, in 25 African countries, hundreds of people with Albinism are attacked, assaulted, mutilated, and murdered.

When a person is born with a mutation, a change in their genes that entails some alteration or disability for their life, that genetic condition acquired from birth will have the same consequences, wherever they may have been born in this world. The reality, however, is unfortunately different. There are regions of the Earth, entire continents, where everything is more difficult and complicated. Africa is the paradigmatic example.(1,3) Babies with albinism habitually disappeared after birth. But recently, everything changed for the worse. Women and girls with albinism and mothers who give birth to children with albinism are exposed to extreme forms of violence, such as the amputation of their limbs while alive. This violence is the result of erroneous beliefs, for example, that sexual relations with a woman with albinism can cure HIV/AIDS. Women are often blamed after giving birth to a child with albinism and are accused of being unfaithful or of bringing a curse upon the family. As a result, they are rejected by their husbands and abandoned by their communities. They are confined to poverty and further exposed to assaults and other forms of violence and discrimination.

People with albinism in Africa became the object of horrendous interest, fueled by magic and ignorant beliefs, being persecuted, kidnapped, mutilated, and murdered in order to trade with parts of their bodies, which supposedly grant good fortune to their possessors. The response in many cases from the community of people with albinism has been to seek refuge and protect themselves collectively, which inevitably leads to establishing families among people with albinism and, given that in Africa most of these people have the same type of albinism, then all their children will also present albinism, artificially increasing the proportion of people with albinism that should exist in the population.(4)

The lack of protection against solar radiation causes burns and skin lesions, which, if not treated appropriately (as usually occurs in Europe), may become malignant and end in skin cancer, which lamentably and unnecessarily ends the lives of many people with albinism in Africa prematurely. Their uniqueness was historically a source of rejection. In turn, people with albinism face multiple human rights problems, such as experiences of stigmatization and discrimination and harmful practices related to accusations of witchcraft and ritual attacks.(3)

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In the 2016 UN report on the enjoyment of human rights by people with albinism, it was detailed that the belief prevails that the greater the innocence of the victim whose parts are to be used, the greater the potency of the potion or amulet. Therefore, children, already vulnerable to attacks, are preferred targets of greater value in trafficking. This specialized market increases to nearly 80,000 US dollars in what is frivolously known as the "complete albino set," which includes limbs and organs of the victim. UNHCR (the UN Refugee Agency) estimates that this market moves nearly 9 million euros each year, and that it finds its peak in times of crisis and increasing inequalities.(4,5)

In 2019, the Executive Council of the African Union went further, adopting a continent-wide policy known as the Plan of Action to End Attacks and Other Human Rights Violations Affecting People with Albinism in Africa (2021-2031) and its implementation matrix. The new Plan of Action is incorporated into the broader architecture of the African Union on disability, which gives greater legitimacy to the need to implement its measures.(3)

On June 13, 2025, the International Albinism Awareness Day will be commemorated. The objective is to raise awareness about this genetic condition that affects 1 in 20,000 people worldwide, that is, an estimated total of 400,000 people. The ratios change considerably with regard to the African continent, and more specifically to the sub-Saharan Africa region, where 1 in 4,000 people has some type of albinism.(2,3,4,5)

African civil societies do not cease in their struggle to remind that it is necessary and urgent that albinism be recognized as such, that people with albinism and their rights be protected from the standpoint of educational, health, labor, and security assistance. Cutting inequality at its root in Africa, which finds in the mysticism surrounding albinism a scapegoat, and ensuring that legislative frameworks do not become mere formalities and that this marks the beginning of the end of violations and the denial of the humanity of albino men and women on the continent is urgent.(6,7)

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