

Witness

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Albino

The Desperate Plight of the Tanzanian Albinos

Photographs by Ana Palacios

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Tanzania is a country of forty million people belonging to more than a hundred different tribes and speaking a hundred and twenty-seven languages. It is also a favorite destination for honeymooners eager to share the unforgettable experience of a safari in the Serengeti, snorkeling in the crystalline waters of Zanzibar and climbing Mount Kilimanjaro with a local guide.

What many people do not know is that Tanzania has one of the largest communities of people with albinism in Africa and they are concentrated on the slopes of Kilimanjaro. “There is no reliable census for Tanzania, but it is believed that there are over a hundred thousand people affected with albinism.” says José Luis de la Serna, President of WakeAppHealth. “Paradoxically, these are black people with very white skin.” The Tanzanian government has found it necessary to set up special centers to protect people with albinism who have had to flee their villages for fear of being butchered by traffickers in human bodies selling their limbs and organs to witchdoctors to prepare their ‘prized’ good luck potions. However, the real killer they face every day is the sun, which consumes their lives, causing people with albinism to develop skin cancer before the age of thirty if they are not properly protected.

Albinism, which seems so exotic in the West, is a deadly serious matter for those who suffer from it in Africa. It is a genetic condition consisting of a lack of pigmentation in the skin, eyes, and hair. It causes serious eyesight problems,



Kabanga. The Tanzanian government has found it necessary to set up special centers to protect people with albinism. Around a hundred albinos live at the Center.

such as photophobia, strabismus, myopia, and nystagmus (involuntary eye movements). An affected person’s skin has little or no melanin, which is a very effective blocker of solar radiation, and this makes them extremely vulnerable to the harsh effects of the sun. Without some other artificial protection – sunscreen, long-sleeved clothing, sunglasses, hats, etc – from an early age children with albinism are very likely to suffer severe sunburn, which can lead to skin cancer, or the eye damage that will leave them totally blind. “The African sun,” says Mafalda Soto Valdés, Director of the Kilimanjaro Suncare Project, “is extremely aggressive for delicate, unprotected skin. Without this pigment in the skin, and because of the strength of the sun, they develop skin cancers from an early age. The real murderer of African people with albinism is not a heartless hunter of body parts but sunlight, the element that is usually prized as a source of life. With appropriate photoprotection their life expectancy would be exactly the same as that of the rest of the Tanzanian population.”¹



Children and a caregiver sit together in one of the dormitory rooms at Kabango.



Bethod and Biko listen to Celine Dion on their old radio cassette player. They're the oldest children at the center. Men usually stay for a shorter time than women at these refuges and they try to form a family outside in the community.

Genetics plays dice, and those unlucky enough to be born with albinism in Africa are doomed to lose the game. Skin cancer does not hurt, so people with the condition can be burned and begin to die without being aware that their life is in danger.

What is more, people with albinism in Africa are the victims of serious social discrimination. There is little awareness that albinism is a genetic condition. Many Africans don't know why people with albinism are so similar in color to their colonizers, and this ignorance creates myths and superstitions of all kinds. Some think they are the children of Lucifer, or that the mother had been with a white man; others believe they were conceived during menstruation, or that their condition is a form of divine punishment. A 'white' child is a stigma for the family: they are cared for less, given less to

eat, and educated less. In some tribes, indeed, albino children may be killed at birth, abandoned, or offered for ritual sacrifice. Many people with albinism are named Mavuto ("problem" in the Chewa language of Central Africa).

This is just the first of a series of social disadvantages they will encounter in different stages of their life. Receiving little stimulus at home, they have difficulties in school because they can't see the blackboard properly, and most fail to reach secondary school.



A mother nurses her child. Many women have to flee to complexes like Kabanga to seek protection when they give birth to an albino baby. The women who live at Kabanga take care of their own children and also act as "guardians" for other albino children who have been abandoned at the center.



The daily routine at Kabanga gathers the women around the community kitchen to prepare their only meal of the day. On three days a week they have a piece of bread with their tea. The government provides basic food for this community every day so they can survive, as they can't be self-sufficient with the produce they get from the center's vegetable plot.



Bath time starts at sunset in Kabanga. This is the safest time of day when albino children can take their clothes off without being afraid of getting their skin sunburnt.

Many are thus deprived of access to a decent job. It is hard for them to find a partner, since their condition as “damned” beings scares others. Their own neighbors say that people with albinism do not die, they fade away, or that to touch one is to risk becoming white or falling ill. Living in such a social and cultural context is not conducive to self-esteem and some people with albinism experience the discrimination they are subjected to as natural.

Albino children grow up being constantly stared at and insulted by



Bestida and son, Ezekiel are at Kabanga to care for Angela, her albino daughter.



A child takes water from a communal fountain.

members of their own community and become adults with a grave lack of self-esteem, self-excluded from a society that does not accept them and which they in turn are unable to accept. In Tanzania these adults-cum-children do not finish their schooling and swell the 85% of the population living on less than a dollar-and-a-half a day.² This is another reason why education and the fostering of awareness in these communities are so important.



Baswira Ntoteye takes shelter inside one of the huts. Father figures tend to be absent from the center, because it is normally women who flee to these centers with their albino children to protect them.

Another danger has recently emerged to threaten these albinos. The so-called “albino elixir” has become fashionable. It seems that in addition to traditional formulas, African witch doctors occasionally innovate with new formulas. In 2007 they began using albino body parts as ingredients in the concoctions they claimed would bring wealth and good fortune, and before long people with albinism were being murdered and dismembered to supply this macabre demand. On the black market an albino arm can sell for as much as two thousand US dollars, a sum that in very poor countries can silence many consciences and make any neighbor a potential murderer. Sometimes, tempted by so much money, the albino person’s own family may betray them to the traffickers. In the last five years over one hundred people with albinism have been killed to feed the market in body parts, sowing the seeds of panic and triggering an exodus of “people with albinism” (PWAs) from remote villages, to big cities where they are less likely to be noticed or to centers like Kabanga, where the government provides police protection and they are safe. “On a continent where a woman may be worth fifty cows or forty camels, where the vital organs of a child have a price, and where human

rights are often conspicuous by their absence, a person with albinism can also be “commodified,” because according to some beliefs there are parts of the albino’s body that will bring luck to whoever possesses them,” says José María Márquez, Director of the NGO, África Directo. Márquez recounts a story of an albino boy who told him that he didn’t go to school during the rainy season because the cornfields are higher. The director was confused by this because in principle it would seem safer to walk when the clouds are an ally against a sun that strikes people with albinism without mercy. “But,” said the boy, “if someone cut off my arm I would bleed to death without anyone seeing me.” That little boy had already accepted the high probability that sooner or later he would be mutilated, but he would rather it happened when he could perhaps get help in time to save his life.³ It is a horrifying fact – the dozens of mutilations and killings suffered by the albino population every year as a result of the trade in supposedly magical albino body parts.⁴ At the NGO, África Directo, they are fighting for the rights of people with albinism.



Lusia Josamu, who has the problems with nystagmus and poor vision typical of the genetic condition of albinism, tries to thread colored beads onto fishing line.



Without some other artificial protection (sunscreen, long-sleeved clothing, sunglasses, hats, etc.) from an early age albino children are very likely to suffer severe sunburn, which can lead to skin cancer, or the eye damage that will leave them totally blind. (above)

In the waiting room at Moshi Hospital, patients with albinism have access to educational brochures that give them a clearer understanding of their particular genetic condition. (left)

The Kabanga Center, near Lake Tanganyika, in the west of the country, is a cheerful place and home to some two hundred people. Here many individuals with albinism can find shelter. They eat, sleep, work the land, tend their own gardens, make their own clothes, run their own community kitchens and canteens, and have classrooms and play areas, but this lively village is actually a fortress which gives shelter to frightened people who have nowhere else to go.

In Kabanga, around a hundred PWAs live alongside people with visual and auditory functional diversity and psychological problems. Genetic chance has made them exceptional beings and has brought them together here in order to survive. Many of them have had to flee from their homes for fear of being butchered simply for having albinism; others ended up here after being abandoned by their families, who were ashamed of them.

The Tanzania Albinism Society has registered eight thousand men,

women, and children with albinism. However, many more PWAs – most of the people affected – are entirely unaware of the Society’s existence, while others prefer to hide. The Tanzanian Albino Charity has estimated that there are about one hundred thousand cases of albinism in Tanzania, which means that a great many people are still in emergency situations. The Tanzania Red Cross Society, in its 2009 report, called for foreign aid to help assist this highly vulnerable community and the NGO, AIPC Pandora, responded by initiating its cooperation project. Their first urgent task is to foster awareness: to help people understand that the children who are called “ghost Africans” are just kids like any others. In addition, the NGO has been involved in the provision of a computer classroom, running socio-educational activities, engaging women in productive activities and strengthening the institutional fabric. It has also raised funds for the construction of a dining room and multi-use space, a bakery, and a well.



An albino person's skin has little or no melanin, which is a very effective blocker of solar radiation, and this makes them extremely vulnerable to the harsh effects of the sun.



The plastic surgeon, Dr. Pedro Fernández Conti, runs a training workshop on how to remove and suture tissue.



Mafalda Soto, the founder of Kilisun, during a special consultation with school student Salim Rashid with different prototypes of sunscreen formulas.

The RDTC is a training center for dermatologists that has been supported by the International Foundation of Dermatology (IFD) since the nineties and covers the whole of East Africa. It has been run by Henning Grossman for twenty years. He and the Tanzanian dermatologist, Daudi Mavura, welcomed Dr. Pedro Jaén's team with open arms. The high incidence of skin cancer usually begins with a pre-cancer in childhood that affects the whole of the albino community by the age of eighteen. This is a cancer that in West has a cure rate of close to 100%, but in Africa reduces the life expectancy of this group to less than thirty years.⁵

The RDTC developed a system of prevention and early diagnosis of skin cancer for people with albinism. The outreach program took the form of twice-yearly visits to some thirty dispensaries in the area covered by the RDTC. During these visits, coordinated by a dermatologist with the aid of

nurses, social workers, and volunteers, children were taught the importance of protection from the sun, healthy habits, and adequate clothing. About twelve hundred people with albinism were provided with sunhats, sunglasses, and sunscreen, and at the same time had their skin checked and were treated for precancerous lesions. Thanks to these preventive measures some of them did not develop skin cancer, but there were still many more PWAs whom the program did not reach and that were dying of inoperable skin cancer.⁶

The team has also developed a training program in dermatologic surgery in the form of workshops. The workshops include a theoretical component in which the principles of skin cancer and possible therapeutic treatments are explained. These theoretical sessions are complemented by workshops in which dozens of patients with albinism are operated on. Local doctors participate actively in these operations, and over time acquire the necessary skills to carry out interventions without our help.⁷



Until 2013, Kilisun was manufactured in a makeshift laboratory set up in a freight container, in quantities barely sufficient to provide sunscreen for two hundred people.



The Kilisun production laboratory, Kilimanjaro Sunscreen Production Unit, was opened in July 2013. In 2016 it distributes its products to two thousand three hundred people with albinism.

Getting a child to put on sun cream, and a hat and sunglasses every single day of his or her life is not easy. They may say they've put on cream when they haven't, the hats get lost, the glasses get broken. Like most children anywhere, children with albinism find the whole thing a nuisance. The difference is that for these kids, if they don't cover up they're likely to die before the age of thirty, which is the life expectancy of a person with albinism in Tanzania.

Another big problem is that a bottle of sunscreen costs as much as two chickens. You can feed ten people with two chickens. These simple figures from a primary school arithmetic lesson explain why many people choose to eat rather than get sun protection, and why it was essential to distribute throughout the country free sunscreen, specially produced to meet the specific needs of people with albinism, and to make people aware of the vital importance of its constant use. This is the work in which the NGO, África Directo, and the pharmacist, Mafalda Soto, are immersed with the Kilisun Project, in collaboration with the Tanzanian RDTC.

Until 2013, Kilisun was manufactured in a makeshift laboratory set up in a freight container, in quantities barely sufficient to provide sunscreen for two hundred people. (top right)

Grace Manyika checks the jars before sending the product to the distribution centres. (bottom right)





Sang'uti Olekuney gives a demonstration of how to apply Kilisun correctly at a mobile clinic in Old Moshi Secondary School.



Since 2008, when this team of doctors started going out to Moshi, it is estimated that their surgical skills have saved the lives of over 500 albinos. (above)

After an injection of methotrexate, dermatologist Luis Ríos measures a tumor on Dada Molel, a 22-year-old Maasai woman from Arusha, to monitor her response to the treatment. (top right)

At about the same time, a team of concerned dermatologists, plastic surgeons, anesthesiologists, pathologists, and nurses, led by Dr. Pedro Jaén, head of the Dermatology Department at Ramón y Cajal University Hospital, began to take an interest in this community. They knew that the greatest enemy of people with albinism is the sun, because solar radiation causes thousands of deaths every year. They chose the Regional Dermatologic Training Centre (RDTC) at Moshi Hospital in northern Tanzania to treat and operate on PWAs with skin cancer. The team first visited Moshi in 2008. Throughout these visits, they have seen almost a thousand patients and saved countless lives. They are referred to as the “life squad.”

In addition to operating on urgent cases, they run theoretical and practical workshops in dermatologic oncology and dermatology, thus making a valuable contribution to the training of the few dermatologists working in East Africa.



Dr. Luis González, a specialist in anaesthesia and intensive care, and Dr. Luis Ríos evaluate the treatment of the patient after surgery.



Before excising a tumor, Dr. Carmen Carranza gives a shot of anaesthetic to Joseph Tecieta, a 33-year-old patient from Kidubula.



Dr. Ríos prepares an injection of methotrexate, a chemotherapy treatment he will apply to the squamous cell carcinoma that Dada Molel suffers in the right malar region.

Helena and her daughter Jessica arrived at Kabanga only a few weeks ago. Helena was afraid that people would hurt her baby and she left the rest of her family behind to spend a few years here. Then, if the witch-doctor hunts continue, Helena will go back to her village to look after her other children and Jessica will have to stay at the center. This is a safer place for an albino girl.





Zawia, wearing green clogs, and her friends finish school at five in the afternoon and go straight back to Kabanga, where they feel safer playing before a government cook serves dinner for everyone at six o'clock sharp in the communal dining room.

In Tanzania, nine out of ten people with albinism die of skin cancer before reaching the age of thirty. Although dermatologic services are improving year on year, they are still in short supply and expensive, beyond the reach of most people. The best treatment for skin cancer, in Tanzania as in the rest of the world, is prevention. But in Tanzania prevention is not simply a matter of rubbing on some protective cream on the sunniest days; people with albinism need to wear hats, sunglasses, and long sleeves every day. At the same time it is not easy for them to stay indoors, because children have to go to school, women have to walk long distances to collect water, and subsistence farmers



For a child a toy can be made out of anything. (top)



Aisha Adam is one of the lucky children at Kabanga because she lives with her mother and her three brothers. It's one of the few cases of some kind of family group living at the center.

cannot stop working the land that grows their food. The fact is that the daily use of sunscreens is essential, and these creams which have to be applied several times a day, also need to be extremely safe as well as resistant to water, high temperatures, and contamination. Taking all of these measures is not easy, and most people with albinism do not understand the origin and implications of their condition and are not aware of the need for photoprotection. The availability of sunscreens is very limited, and when they can be found they are prohibitively expensive; what is more, not many people know how to use them.



In 2015, thirteen thousand jars of sun cream were distributed to more than 3000 people with albinism, reaching even the most remote areas of Tanzania, with the aim of reducing the incidence of skin cancer and improving people's quality of life.

Prevention and treatment are essential to avoid the physical damage suffered by the albino population, but they cannot solve the problem as a whole. They must be combined with the grassroots work of fostering awareness among non-PWAs to help end the discrimination and violence inflicted on people with albinism. And getting rid of prejudice means education, starting in primary schools. There is also an urgent need for forceful action by the justice system to end the impunity of the "hunters".



Epafroïda is always in a good mood. She takes pride in her appearance, loves fashion, and wants to save some money so she can set up her own textile business in the market at Kasulu, the nearest village to Kabanga. (left)

Two children wait in their dormitory before mealtime. (above)

Improving the daily lives of people with albinism in Africa is a comprehensive project that can only be carried out by thinking for the long term and taking transversal actions. It requires the participation of primary and secondary actors, which means that the message must be spread through all possible channels.

Notes

- 1 Mafalda Soto Valdés, "Prevention, The Best Treatment," in *Albino* (Editorial Tenov S.L., 2016)
- 2 Ibid
- 3 José María Márquez, "A Protective Cloud," in *Albino* (Editorial Tenov S.L., 2016)
- 4 José Luis de la Serna, "The Responsibility of Communicating," in *Albino* (Editorial Tenov S.L., 2016)
- 5 Pedro Jaén, "Prevention," "Surgery & Training against a Curable Disease," in *Albino* (Editorial Tenov S.L., 2016)
- 6 Ibid
- 7 Ibid
- 8 Mafalda Soto Valdés, "Prevention, the best Treatment," in *Albino* (Editorial Tenov S.L., 2016)



Eleven-year-old Kelen loves dancing in the half-built bedrooms at Kabanga, away from the sun.

Ana Palacios

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Represented by Espacio Foto, her work on cooperation in development has been published in *The Guardian*, *Days Japan*, *Daily Mirror*, *Daily Mail*, *XL Semanal*, *El País*, *Tiempo*, *Yo Dona*, *Mundo Negro*, etc.

She has published two books: *Albino*, about the pledge of the albinos in Tanzania and *Art in Movement*: about the art as a social change in Kampala.

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NGOs and Supporters:

Dr. Pedro Jaén, Head of the Dermatology department,
Ramón y Cajal in Madrid (Spain)

África Directo - <http://www.africadirecto.org>

AIPC Pandora - <https://www.aipc-pandora.org>

Kilisun - <http://ponteensupiel.com/?lang=en>

Regional Dermatology Training Centre (RDTC) of Tanzania

Diputación Provincial de Huesca - http://www.dp_huesca.es

Ayuntamiento de Huesca - <http://www.huesca.es>

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