



# Discrimination and Violence Against Children With Albinism in Cameroon

- This report is respectfully submitted by the NGO Under The Same Sun to the Committee for the Rights of the Child, Session 75 regarding Cameroon.
- Under The Same Sun (UTSS) is a civil society organization committed to ending the often-deadly discrimination against people with albinism. UTSS promotes, via advocacy and education, the wellbeing of persons with albinism who are misunderstood, marginalized, and even attacked and killed because of their genetic condition. While UTSS acts globally, much of our focus has been on the crisis faced by people with albinism in Tanzania.

## **Executive Summary**

- A small, vulnerable population of children within Cameroon experiences discrimination, stigma and sometimes violence because they have albinism - a lack of pigment in the skin, hair and eyes. Myth, superstition and fear abound.
- Across the region, people with albinism are ritually hunted, attacked and murdered. Their arms and legs, bones and blood, fingers and toes are commodities. Limbs and digits are hacked off to feed an illegal trade in the body parts of persons with albinism, which are sold across borders as bogus potions or charms. In Cameroon, some believe that sacrificing people with albinism can prevent volcanic eruptions.
- Discrimination also arises from false beliefs and the mystification of albinism's striking appearance. Negative cultural attitudes and practices can be found around the world. From Africa to Asia to North America, albinism conjures a spectre in the social imagination – a “blank slate” upon which cultural and religious fears and fallacies are inscribed. Many societies define those with albinism as “others” or outsiders. Children with albinism are easily recognized and targeted for bullying and persecution. This can lead to school dropout, unemployment and poverty.
- Ridicule, stigma and social exclusion are common. In Cameroon, mothers abandon babies with albinism, or refuse to breastfeed them. Insults can deeply wound the psyche of a child with albinism and signal their exclusion to other children and the community. The Bamileke insult for a person with albinism is *mbumbu*, a banana that ripens early. The Medimba insults: *mekat*, *ndock*, *nngang*, *mbemba mbak*, *ewa mange* and *les mergens* all refer to white people. *Nassara* means the same thing in Fulani.<sup>1</sup> Albinism does not signal a separate race. Children with albinism are the same ethnicity as their parents. Other derogatory names include *mokala* and *ngenggerou*.<sup>2</sup>



## What is Albinism?

- Albinism is a rare, non-contagious, genetically inherited condition characterized by a lack of pigmentation in the hair, skin and eyes. It occurs regardless of ethnicity or gender. Both parents must carry the gene for it to be passed on, even if neither have albinism themselves.<sup>3</sup>
- The majority of people with albinism are legally blind and very sensitive to light. Eyeglasses can only partially correct this problem. While most can read large print and don't generally require Braille, they have difficulty seeing a blackboard in a regular classroom. This limited vision often meets the criteria of a disability. In most cases, structural barriers prevent participation in society on an equal basis with others.<sup>4</sup>
- Across Africa, between one in 5,000 and one in 15,000 have albinism.<sup>5</sup> UTSS believes this range is a conservative estimate, since data is inconsistent across the continent, and not known in Cameroon specifically.<sup>6</sup> In the Western Province, research has found the incidence of albinism among the Bamileke is one in 7,900.<sup>7</sup>

## Skin Cancer: #1 Killer

- With no melanin or pigment for protection, skin burns immediately in the sun. Cameroon is sunny year round, located between two and 12 degrees north of the equator. Most Africans with albinism have severely sun-damaged skin, acquiring dramatic, visible skin damage at an early age. Fatal skin cancer will claim the vast majority before they reach 30 to 40 years of age.<sup>8</sup>
- There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable. Sun is the number one killer of Cameroonians with albinism and the damage is done before adulthood. Sunscreen, wide brimmed hats and sun protective clothing is essential, as is education and employment indoors.
- According to Douala dermatologist Dr. Samuel Ngwane, people are exposed to the majority of the sunlight they will receive over their lifetime by age 15. According to Ngwane, "if an albino child isn't protected from the sun during these early years, their skin becomes rough by age 20 and they start developing cancers of the face, the back and arms."<sup>9</sup>

## Myth, Superstition and Fear

- Across sub Saharan Africa (including in Cameroon) people with albinism are threatened by the mistaken belief that medicines and potions made from their body parts will bring wealth and good fortune. Many believe that albinism is a curse and those with the condition are ghosts that never die. In the most extreme, such myths result in violence and murder. But they also contribute to the marginalization of people with albinism from family and community life.



- But the birth of a child with albinism has not always been universally seen as a bad thing in Cameroon. According to *l'Association Mondiale pour la Défense des Intérêts et la Solidarité des Albinos (ASMODISA)*, among some tribes, “the appearance of a ‘white’ in a family of black was considered a blessing for the family, or even for the whole tribe. The newborn was then the object of curiosity of course, but his parents were respected and welcomed.”<sup>10</sup>
- But negative beliefs have predominated, with much more dramatic consequences. “People here in Cameroon know little or nothing about albinos,” says Chiara Gregoracci founder of the *Association of Handicapped Albino Youths of Cameroon and Africa (AJAHCA)*. “There is a lot of ignorance and superstition. They are treated as outcasts, and parents don’t send them to school. Mothers often refuse to breastfeed albino babies; and having albino children can sometimes lead to parents divorcing,” she says.<sup>11</sup>
- Ondobo Lucia recently became the guardian of her granddaughter, Tatiana, who has albinism. Tatiana’s mother had abandoned her daughter, as the father harboured misconceptions about albinism.<sup>12</sup> Abandonment of children with albinism is common.
- Some Fali (in the north) understand albinism as a curse that could afflict the rest of the family. Therefore, many Fali with albinism are killed at birth.<sup>13</sup>
- Among the Bamileke, those with albinism are often thought of as spiritual beings, ancestors or ghosts with supernatural powers. The birth of a child with albinism is seen as a punishment for the misbehaviour or misdeeds of the parents.<sup>14</sup>
- Many believe that the sacrifice of people with albinism can offer protection from, or appease the god of the mountain (Epasa Moto). Some with albinism were abandoned on Fako Mountain as offerings.<sup>15</sup> People with albinism are fearful when the volcano becomes active.
- The Betis of the Centre Province are reported to make charms from the hair and fingernails of people with albinism. Here, some believe those with albinism never die.
- Some cultures in Cameroon believe the birth a child with albinism is the result of incest<sup>16</sup>, that the mother was unfaithful or menstruating. During election campaigns, candidates for office may seek intercourse with a woman or girl with albinism who has never had sexual relations. Genitals are among valued body parts.<sup>17</sup>
- Model Natasha Ndalle told VOX News: “...about four years ago, a woman came begging for her hair to use in preparing traditional medicine... even her own mother admits regularly shaving her hair when she was younger for the same purpose. She says some men, running for elections or seeking job promotions, have offered her huge amounts of money for sex.”<sup>18</sup>



- These myths create barriers to employment. Employers often won't hire a qualified candidate with albinism. Akuma Charles, is a university graduate who can't get a job. He told *L'Effort Camerounais* "Wherever I have dropped my application for job opportunities, I am always called up for interviews but I have failed all those interviews just because of my colour [albinism.]"<sup>19</sup>
- School dropout is common, particularly when the poor eyesight of a student with albinism is not well understood by the school or teacher. Fear of attack can lead those with albinism to withdraw from community life and hide on the margins of society.
- This discrimination can also be an everyday phenomena. Two children were barred from attending summer camp in July 2016 due to albinism-related discrimination. l'Association Mondiale pour la Défense des Intérêts et la Solidarité des Albinos (ASMODISA) intervened and secured the children a place.<sup>20</sup>

### Attacks and Killings

- Over the last decade there have been eleven reports involving people with albinism in Cameroon: two killings, two survived attacks, six asylum cases and a grave robbery for body parts. These are anecdotal reports. The true scale of the violence is not known. Fear of reprisals and a lack of a trusted authority or interlocutor means that victims are unlikely to report. This is particularly true for children, who may not know how to report such crimes. Further, the perpetrators of attacks, incest, rape, etc are often family members.<sup>21</sup>
- These attacks in Cameroon are part of a wider, cross-border illegal market spanning 26 African countries. Since 2000, there have been 499 reported attacks, including 186 documented murders of people with albinism and 313 cases of missing persons, assault, mutilation, rape, attempted abductions, grave violations and other acts of violence.<sup>22</sup> These numbers are likely very low, as data is sparse and reporting inconsistent.
- ASMODISA is seeking an investigation into the 2016 death of a newborn with albinism in northern Cameroon, where the killing of infants with albinism was more common.<sup>23</sup>
- In August of 2009, the foot of a young girl with albinism was found in a garbage can in Douala. She had worked in a local snack bar. Her foot was kept in the morgue of the Laquintinie Hospital in Douala.<sup>24</sup>
- As of August 2013, a case was brought against a bailiff, Celstine Akono for allegedly seeking the hair of a girl with albinism. Colette Ambombo accused Akono of trying to obtain her hair for ritual purposes and that Akono had harassed and jailed her for refusing. Akono sued Ambombo for slander.<sup>25</sup>



- In 2013 a mother and her infant with albinism sought asylum in France after members of her community had attempted to kill the baby for ritual purposes during local elections.<sup>26</sup>
- On December 23, 2015, Christian Eric Tchidjo was granted refugee status in UK, having fled such a threatening environment.<sup>27</sup>
- Volcanic activity causes fear among Cameroonians with albinism. Simon told UTSS about his experiences: “Volcanic eruption is the occasion for the slaughter of numbers of PWA [persons with albinism] of both genders and various ages. The widespread belief is that eruption of the volcano is due to the wrath of the god of the mountain *Epasa Moto* (half-human). It is believed that only the blood of PWA can calm this wrath.” Simon’s real name is withheld at his request, for his protection.
- In 1999 Mount Cameroon erupted. Lava stopped just short of Buea, where Simon lived. Some thought the community was only saved by the sacrifice of people with albinism. When the mountain started to rumble again in 2007, locals with albinism went into hiding and Simon fled the country.”<sup>28</sup>
- Simon also reported to UTSS that “Soccer games are also the occasion for PWA [person with albinism] killings.”
- On August 21, 1977 the mutilated body of Ebongue Kouta Maurice, a ten-year-old boy with albinism, was discovered. He’d gone missing a few days earlier. His body was found at the exit of Goura village with genitals, heart and tongue missing. The body parts were to have been sold to a senior national army officer who wanted to make a magic potion for invisibility. A sibling of the deceased said: “the darkness of night hides some rather wicked facts. People with albinism continue to be killed in the secrecy of the night without other people being affected very much.”<sup>29</sup>
- During the fog of military conflict, such attacks are likely perpetrated by combatants in a misguided search for some good luck or strategic advantage, or by opportunists seeking to profit by the body parts trade, which now crosses borders throughout the region. Wars, elections, major sporting events and volcanic eruptions all appear to trigger attacks.

## Recommendations

### Address Skin Cancer

- Skin cancer is the biggest killer of Cameroonians with albinism. The government should increase funding for skin cancer projects such as that of L'Association pour le Développement et l'Epanouissement Social des Albinos. Their *Projet De Prévention et de Prise en Charge du Cancer de la Peau Chez la Personne Albinos* could be extended from the current 2015-2016 Yaounde pilot phase to the whole territory of Cameroon.



- The government should subsidize sunscreen with a Sun Protection Factor (SPF) of 30 or more, skin cancer screenings, skin cancer treatment, wide-brimmed hats and sun-protective clothing (long-sleeved shirts with high collars, long trousers, and long skirts) for all children with albinism.
- The President of the *Association of Female Albinos in Cameroon*, Marie Madeleine Wafo, says: “Most albinos die of cancer because they lack the means for treatment. If government could issue free health cards to be treated in hospitals, it will reduce the mortality rate.”<sup>30</sup>
- *L’Association pour la Promotion des Albinos au Cameroun* has produced 700 copies of booklets entitled 'Practical Guide on Prevention of Skin Cancer Among Albinos.' The government should help make of this document available across Cameroon.<sup>31</sup>

### **Invest in education**

- The government should invest in education for children with albinism as this population tends to have less access to education and employment and disproportionately experiences entrenched poverty. Getting a job indoors is key to lowering premature deaths due to skin cancer – and work inside requires education.
- In particular, spaces within safe, supportive, nurturing environments should be made available. Albinism civil society organizations should be consulted to identify children for this initiative.
- The government should consider as a model the UTSS Education Program, which funds education for 300 Tanzanian children with albinism, from kindergarten to graduate studies. This number represents only a small fraction of children with albinism in need of such opportunities. UTSS covers personal expenses, school supplies, uniforms, medical services (regular dermatology and optometry examinations) as well as sun protective clothing, sunscreen lotion and low vision devices.
- UTSS monitors the schools to ensure the environment is free of abuse and that students’ health, education and social well-being is being looked after. UTSS follows up to ensure staff, administrators, teachers and other children have a good understanding of albinism.

### **Train educators**

- The government, in consultation with albinism civil society organizations, should develop appropriate training for educators (teachers, administrators, staff, etc.) specifically suited to responding to the bullying and discrimination against students with albinism, which often leads to school dropout.
- Training should also make educators aware of the particular low-vision needs of children with albinism. Being legally blind is a physical disability and entitles one



to reasonable accommodation at school. Large print, glasses, magnifying glasses, monoculars and specialized computer equipment are helpful to most children with albinism. The child should be consulted on the best vantage point in a classroom from which to see i.e.: proximity to the blackboard; from the right, left or centre, and; out of bright, direct light. Blackboard notes, exams, assignments, etc. should be made available in appropriate print sizes. Extra time should be provided for written exams – an additional 50% is suggested. Providing a level academic playing field for children with albinism can help mitigate discrimination.

- Training should also make educators aware of the specific sun protection needs of children with albinism, such as: using sunscreen lotion with Sun Protection Factor (SPF) of 30 or more; ensuring kids are wearing wide-brimmed hats and sun-protective clothing e.g. breathable long-sleeved shirts with high collars, long trousers, and long skirts, and sun-avoidance in shade or in-doors. Implementing these measures should be done in such a way as not to compound marginalization.
- In some circumstances, the family will enable or even be the source of discrimination, aggression and violence. Children model adult behaviours, which are transmitted and reproduced via myths, insults, and cultural stereotypes. Educators and other non-family members should be empowered to protect children with albinism in such circumstances.

### **Collect data**

- The government should investigate, collect and publish data about violence and discrimination against people with albinism in Cameroon. Better data is needed on attacks, murders, employment, income, health, indicators of social well-being and demographics of people with albinism in Cameroon.
- Statistics on attacks and murders provided in this report are well documented but represent individual cases that underrepresent the true scale of the issue. The scale and character of discrimination faced by those with albinism in Cameroon is not well understood. Change need not wait for data, but ultimately, evidence-based policy requires it, particularly given the lack of data about this population.
- Such data should be made available to the civil society and the public. However, it needs to be anonymized in such a way as not to reveal the actual location or personal information about any individual with albinism. Civil society groups should be involved in data collection. UTSS is available to consult on the specifics of data collection and sharing. Such data must be stored securely. Caution must be taken, as hunters of people with albinism would find such information a great resource.

### **Raise awareness**

- The government should work with albinism civil society groups to build on the success of awareness-raising campaigns conducted over recent years, such as



the public service announcements on TV which aired across East Africa in the lead up to International Albinism Awareness Day 2015.<sup>32</sup>

- Public awareness TV and radio spots, seminars, “in-person” encounters and public health campaigns should be produced and strengthened to raise awareness about the condition and its stigma and to humanize and normalize albinism. Family members, legal guardians, caregivers, youth, schools, tribal organizations, trade unions, communities, mosques, churches, community leaders, the media and other civil society organizations should be targeted with de-mythologizing messages about human dignity and respect, focusing on simple genetic and medical explanations, offering easy ways to live with and care for the condition.
- UTSS congratulates the government for its work with civil society groups and urges the government to strengthen such partnerships. *L'Association pour la Promotion des Albinos au Cameroun* notes particular difficulties in outreach to the northern part of Cameroon.<sup>33</sup>
- The government should support efforts to disseminate factual information on albinism to various print media and TV and radio via interviews, pamphlets and brochures.
- High profile individuals with albinism should be approached to act as ambassadors or spokespeople, such Rene and Clifford Bouma (AKA Flash and Risky,) brothers with albinism who rap against the stigma associated with albinism<sup>34</sup> or model Natasha Ndalle.

### **Address Sexual Violence**

- Women and girls with albinism in Cameroon are often targets of sexual violence. According to OHCHR (2013), common myths associated with albinism include that “sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS.”<sup>35</sup> Survivors of sexual violence can experience increased health complications such as Post Traumatic Stress Disorder (PTSD), pregnancy and Sexually Transmitted Infections (STIs). Other myths persist about how sex with a girl or woman with albinism can bring good luck.
- A skin cancer prevention project of L'Association pour le Développement et l'Epanouissement Social des Albinos includes addressing sexual violence by ensuring “50 people (girls and boys, adult men and women) trained in the areas of sexuality in a gender approach and prevention of violence based on gender.”<sup>36</sup>
- Objectification and fetishization of girls with albinism is also a problem. Natalia Mbatcham explains how albinism excludes her: “...even in marriage and love, most men who seek us for love are adventurers who want to tell the public how we look like in bed.”<sup>37</sup>



## Challenge negative stereotypes

- The government and civil society organizations should challenge negative stereotypes about albinism in popular culture and film, which reinforce discrimination and fuel attacks.
- The government and albinism civil society organizations should encourage academics, journalists, film producers, film funders, film directors, online content creators and popular culture curators to abandon pernicious negative portrayals of people with albinism in favour of portrayals as neutral or positive characters, in roles unrelated to the condition.

## Conclusion

- Violence against children with albinism in Cameroon is underreported. Such violence is but the most extreme form of discrimination against this population. Many Cameroon albinism civil society groups suggest that the most extreme myths and associated incidences of violence are being challenged by more science-based explanations of albinism. However, in all aspects of social, economic and cultural life, children with albinism in Cameroon remain highly marginalized, stigmatized and excluded by virtue of their condition. They remain vulnerable to violence and remain fearful.

## Contact

Under The Same Sun – International HQ  
200 – 15127 100 Ave.  
Surrey BC Canada V3R 0N9  
Tel: +604-336-8868

Under The Same Sun – Tanzania  
Taasisi Road, Mikocheni B,  
Kwa Warioba, PO Box 32837,  
Dar es Salaam, Tanzania  
Tel: +255-222-780224

[info@underthesamesun.com](mailto:info@underthesamesun.com)  
[www.underthesamesun.com](http://www.underthesamesun.com)

<sup>1</sup> Under the Same Sun “Names Used for PWA”

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- <sup>32</sup> A/HRC/26/L.7 International Albinism Awareness Day



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<sup>33</sup> Association pour la Promotion des Albinos au Cameroun, “Notre Contribution Sur La Situation Des Personnes Vivant Avec L’albinisme Dans Notre Pays Le Cameroun.” Report to UTSS: September 5, 2016

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<sup>35</sup> Persons with albinism: Report of the Office of the United Nations High Commissioner for Human Rights. 12 September 2013 at paragraph 17.

<sup>36</sup> L'Association pour le Développement et l'Epanouissement Social des Albinos. « Projet De Prévention et de Prise en Charge du Cancer de la Peau Chez la Personne Albinos »

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