



Children with Albinism & the Right to Health

Summary report on Tanzania
With implication for other parts of Sub-Saharan Africa



Submitted to

**Imma Guerras - Delgado,
Advisor on Child Rights**

Office of the United Nations High Commissioner for Human Rights

Re: Human Rights Council Resolution 19/37

From Under The Same Sun (UTSS)

Date: August 31, 2012

Introduction

Children with albinism (“CWA” - commonly referred to as “albinos”) are a particularly endangered group due to the difficult circumstances in the sub Saharan Africa region. A good number are killed at birth, others abandoned in early childhood, still others are killed by exposure to sunlight and skin cancer. More recently, scores with albinism including children have been killed due to the witchcraft-related belief that their body parts can be used to create wealth and good luck when used in witchcraft potions. To date there have been 71 documented killings of Persons With Albinism (PWA), 30 Survivors and 17 grave robberies. A majority (over half) of these victims are under the age of 18.

The Highest Standard of Health for CWA

UTSS subscribes to the understanding of “health” as addressed in the *Economic and Social Council’s General Comment*ⁱ which includes not only physical needs: food, clothing, housing and medical care but mental health and the necessary social services.

ALBINISM

- Albinism is a rare, non-contagious, genetically inherited condition occurring in both genders regardless of ethnicity, in all countries of the world. Both the father and mother must carry the gene for it to be passed on even if they do not have albinism themselves.
- The condition results in a lack of pigmentation in the hair, skin and eyes, causing vulnerability to sun exposure and bright light. Almost all PWA are visually impaired, with the majority being classified as “legally blind.”
- While numbers vary in North America and Europe it is estimated that 1 in every 20,000 people have some form of albinism in both continents.
- In Tanzania, and throughout East Africa, albinism is much more prevalent, with estimates of 1 in 2,000 people being affected.
- The term “person with albinism” (PWA) or “Children with albinism” (CWA) is preferred to the term “albino” because the former puts the person before the condition rather than equate him to it.

HEALTH CHALLENGES FACED BY CWA

The following are the main challenges faced by CWA in the sub-Saharan Africa region. They also remain active barriers to their attainment of the highest standard of health.

(1) Fatal Skin Cancer

The absence of melanin in CWA is one of the most endangering aspects of their lives and one of the largest threats to attaining the highest standard of health in the sub-Saharan Africa region.

Lack of melanin in skin means CWA

- Do not have natural protection from the sun.
- Start to get sun-burned at a very early age.ⁱⁱ
- Life expectancy is grossly shortened. In Tanzania for example, only 2% will celebrate their 40th birthday. Many die much younger.

(2) Ostracism in Social Services

A. Educational Institutions

Ostracism here is largely due to the visual impairment that comes with having albinism.

- Lack of melanin in the eyes means CWA
 - Always have problems with vision that are not completely correctable with eyeglasses.
 - Have low vision and are classified in many countries as “legally blind.” Most do not require Braille but do not have sufficient vision to safely drive a car.
 - In most cases can still use the residual vision they have for many tasks including reading. But proper accommodative practices by educational institutions are necessary for CWA to harness their visual capacity (which varies by person) and this type of support is largely absent in the sub-Saharan African region.
- Due to significant vision impairment most PWA cannot read from the blackboard in a normal classroom set-up. As a result
 - Most drop out of school at an early age

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- Most do not have enough education to find work indoors and end up working outdoors in the harsh sunlight they are supposed to avoid in the first place.

B. Social Challenges

- CWA are at risk of severe isolation because their condition is often misunderstood.
- Social stigmatization occurs due to appearance, especially because other family members and their fellow citizens generally have dark skin and appearance.
- Myths and beliefs – both age old and recent – continue to de-humanize PWA including children.
- Myths include the belief that PWA never die - they simply vanish. They are not human, but ghosts, apes, or other sub-human creatures.
- As a result of some of these myths, Infanticide and physical attacks causing death and bodily harm are common place in the region.

C. The loss of bodily Integrity, Dignity and the Right to Life

- The perception that PWA body parts can be used for witchcraft to produce luck and wealth has led to killings of PWA, with most documented deaths in the last 10 years.
- Recently the focus of these attacks has been on CWA.
- The use of CWA in witchcraft is likely due to the reasons that they are
 - More vulnerable, easy to find and relatively easy to capture because they are often left to play outside un-supervised, are not always cared for by their parents because they have albinism, and do not always have the strength to physically fend off attackers.
 - The use of children is also likely linked to the pursuit of their innocence. An innocent victim is generally deemed more potent in producing the intended witchcraft result. A similar use of innocence is evident in non-albinism witchcraft practices in the region.ⁱⁱⁱ

GOOD PRACTICES UTSS UNDERTAKES TO PROMOTE CWA'S RIGHT TO HEALTH

(1) Sustainable Solutions to Sun protection

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- Financing and supporting the creation of a Local Sunscreen Production Unit in collaboration with local stakeholders and medical practitioners. Current location is in Kilimanjaro, Tanzania.
 - In the meantime, we advocate
 - the use of, and collection of sun protective gear and sunscreen lotion from all over the world to fulfil the current needs in this area.
 - These include sunscreen lotion with Sun Protection Factor (SPF) of 30 or more, wide-brimmed hats, breathable long-sleeved shirts with high collars, long trousers, and long skirts.

(2) Advocacy and Accommodation

- We advance through media, the “truths about albinism” to end myths that de-humanize and put CWA at risk of mutilation and death.
- We advocate-
 - That families and schools must make an effort to include children with albinism in group activities. Sensitivity to low vision and sun exposure must be taken into account during these activities.
 - Contact with other PWA, or with others who have PWA in their families can be most helpful.

(3) Health Education

- We advocate the education of
 - CWA who would not otherwise understand their own genetic condition and self-care.
 - This includes education on their special needs in the classroom as well as how to use sunscreen lotion, sun protective clothing, the practice of sun avoidance and reporting of suspicious burns and scars on skin to a medical professional.
 - Teachers, parents and service providers on how to care for and accommodate the special needs of CWA in the classroom.

(4) Collaborative effort with like-minded groups

- We work with local UNICEF office, other albinism serving groups and government officials in the execution of all of the above listed practices.

These range from collaboration for material support to collaboration for knowledge acquisition and dissemination.

(5) Disability approach

- We advocate the classification of albinism as a disability. This is a crucial practice model in bringing awareness and much needed accommodation to CWA.

About This Brief Report

We have written this brief report in response to the call of the Human Rights Council and OHCHR flowing from Resolution 19/37 on the Rights of the child (letter dated June 19, 2012 from the UN OHCHR signed by Christian Courtis, Officer in Charge, Human Rights and Economic and Social Issues Section).

It is because we are based in Tanzania that this report focuses on that country. Yet, some anecdotal evidence has been gathered from encounters with other PWA from other countries through self-reports, meetings at conferences, and our cross-continental advocacy efforts. As such, we are able to provide some, albeit relatively limited information, from other parts of the region of sub-Saharan Africa. Initial comparisons of PWA experiences in Tanzania and outside of it strongly indicate that Tanzania appears to be a microcosm for the issues that PWA generally face throughout the region

Most of the information in this report is an extraction from a Comprehensive Report UTSS sent to Mme. Marta Santos Pais, UN Special Representative of the Secretary-General on Violence against Children, (June 19th, 2012). Further information on children with albinism and on the genetic condition of albinism can be obtained from that report which is available on our website: www.underthesamesun.com

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ⁱⁱ Regional Dermatology Training Centre (RDTC) at Kilimanjaro Christian Medical Centre (KCMC), Moshi, Tanzania, “Proposal for the Enhancement and Support of the Local Sunscreen Production Unit at RDTC at KCMC,” March 2012 [un-published].

ⁱⁱⁱ “Child Witchcraft Allegations on the Rise,” <http://www.irinnews.org/Report/89858/RIGHTS-Child-witchcraft-allegations-on-the-rise> Accessed March 26, 2012



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