

# **Children with Albinism in Africa: Murder Mutilation and Violence**



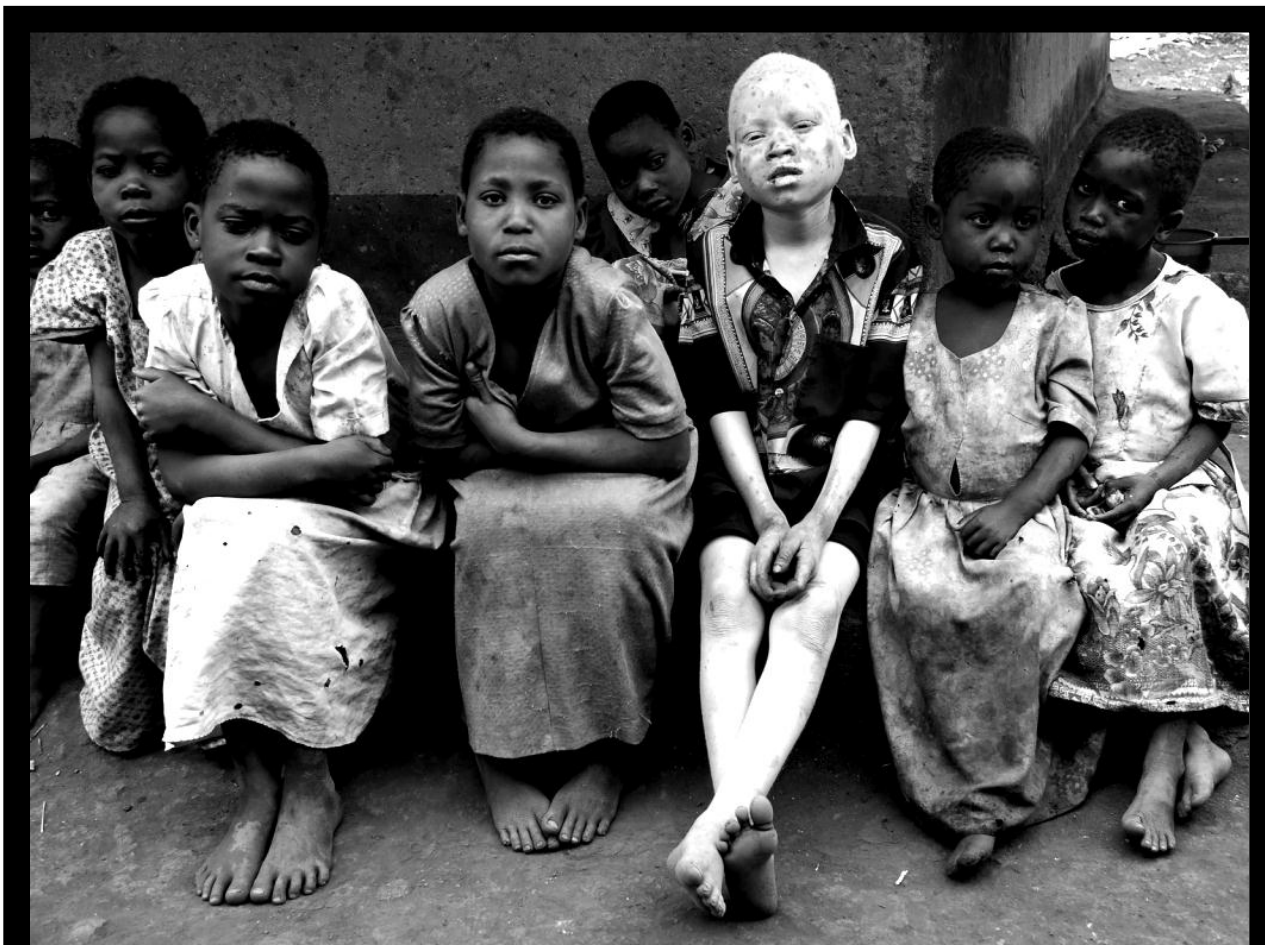
## **A report on Tanzania**

**With parallel references to other parts of Sub-Saharan Africa**



**Submitted to:  
Mme. Marta Santos Pais  
UN Special Representative of the  
Secretary-General on Violence against Children**

**June 19, 2012**



Between the years 2007 and 2010, roughly 3 persons with albinism were attacked per month. Most of them were hacked to death. Graves were also robbed.

Since 2011, the number of deaths have reduced but a new turn in the attacks has commenced. Perpetrators are now focusing less on killings and more on mutilation - hacking off limbs and other body parts. The main target of this new trend are children.

<b>TOTAL DEATHS DOCUMENTED TO DATE (Tanzania):</b>	<b>71</b>
<b>TOTAL DEATHS DOCUMENTED (Rest of Africa):</b>	<b>35</b>
<b>MUTILATIONS &amp; ATTEMPTED MURDER (Tanzania):</b>	<b>29</b>
<b>MUTILATIONS &amp; ATTEMPTED MURDER (Rest of Africa):</b>	<b>03</b>
<b>GRAVE ROBBERIES (Tanzania):</b>	<b>17</b>

**TOTAL ATTACKS DOCUMENTED TO DATE (Africa): 155**

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## Abbreviations

HPS: Hermansky-Pudlak Syndrome
IDP: Internally Displaced Persons
NGO: Non-Governmental Organizations
OA: Ocular albinism
OCA: Oculocutaneous Albinism
PWA: Person(s) with albinism
UN: United Nations
UN CRC: United Nations Convention on the Rights of a Child
UTSS: Under The Same Sun

## Definition(s)

Children: Persons who are 18 years and younger per Article 1 of the UN CRC

## Accessibility

We have generally produced this report in large print to enhance readability for PWA and other persons with low vision. If this report is inaccessible for a particular person or purpose, please contact UTSS to discuss how we can be of assistance.

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## About This Report

This report was written for the UN Special Representative of the Secretary-General on Violence against Children, Mme. Marta Santos Pais. The intent of the report is to present a detailed and comprehensive overview of the situation in Tanzania concerning persons living with albinism (PWA), particularly children. It is hoped that the report will assist Ms. Santos Pais in her mandate and reports on violence against children.

The report is also for the general perusal of all UN bodies and Non-Governmental Organizations (NGOs). It is the hope of Under The Same Sun (UTSS) that it will contribute to the raising of awareness on the plight of PWA on the continent and that efforts will be pursued with speed and compassion to end the killings of, and discrimination against PWA.

Data and evidence in this report are not only from credible media sources and academic research of scholars; they are also based on the research and field observation of UTSS as an organization on the ground in Tanzania.

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.

**Therefore the Tanzania-focus in this report should not lead to a conclusion that the bulk of the issues PWA face are isolated to Tanzania. Rather, all parallel references to other countries in the region should be some indication that the problems PWA face, while highlighted in Tanzania, is one that exists beyond that country's borders – thus warranting international response from the UN.**

Peter W. Ash, Founder & CEO  
Under The Same Sun  
Vancouver, Canada

## Executive Summary

Albinism in humans is the absence of melanin or colour in any or all of the person's skin, hair and eyes. It is a world-wide genetic trait affecting all races and genders. It results in the birth of a child whose appearance is markedly pale (mostly white) compared to both parents.

In countries where the population has dark-coloured skin, hair and eyes, PWA stand out easily making them easy targets of taunts, discrimination and dangerous myths.

In Tanzania and several parts of Africa, some of these myths are fatal. For example, the myth that the body parts of a PWA can, when mixed in witchcraft potions, lead to wealth and other desirables.

Since 2007, belief in these myths has resulted in 71 documented deaths in Tanzania, 38 attacks including deaths in other African countries, 32 attempted murders with some victims left mutilated in Tanzania and other parts of Africa; and 17 documented grave robberies in Tanzania. Children are the majority of victims targeted and killed with roughly two-thirds of recorded murders being children.

Since 2008, the number of recorded killings seemed on a decline. Yet there are challenges that prevent celebration over this apparent decline. First, freedom of the press in the region is generally poor; second, police investigation is often corrupt, lacks will and support as most informants and some police fear witchdoctors. Third, the use of witchcraft in a country like Tanzania is so deeply etched in the minds and practices of the people that efforts to thwart witchcraft practice is often a very steep climb. Fourth, the killing of PWA, particularly children often takes place in illicit settings: by the mid-wife shortly after the birth of such a child, or by the poisoning of the child, or by other actions of relatives. The participation of family in the death of a child with albinism means that the primary caregiver and source of information of the child is unlikely to report the child's death or propel investigation. Fifth, most deaths occur in rural parts where information gathering and infrastructure is poor – thus providing cover to criminal activity.



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These challenges can be reduced and eventually surmounted by the efforts of the national government in preventing and prosecuting crime, as well as providing adequate protection to their citizens with albinism. A census is a crucial first step in this regard but comes with the risk of exposing the location of PWA to profiteers of attacks against PWA. A safe and secure system can be developed and safeguarded with the help of the UN.

Other ways in which the UN and other international bodies could be of particular assistance is putting pressure on national government to quickly prosecute crimes against PWA, assist in public education schemes about albinism to counter dangerous myths, and support displaced PWA.

# 1. Albinism: Definition, Challenges and Some Solutions

## 1.1 Definition

- 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 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) is preferred to the term “albino” because the former puts the person before the condition rather than equate him to it (See Appendix A for further discussion on this issue).

## 1.2 Why do PWA have a “white” appearance ?

- Most children with albinism are born to parents who have normal skin, hair and eye color for their ethnic backgrounds. A PWA is unable to produce the usual amounts of pigment or colour called *melanin* that is normally found in his or her race.
- That said, the degree of “whiteness” in PWA varies. Some PWA are able to provide trace amounts of melanin while others rarely produce any.
- There is no known cure for the absence of melanin in PWA.



Figure 1 - Albinism Worldwide

### 1.3 Types of Albinism (More Common)

- There are various types of albinism. This is because the amount of residual pigment in each PWA varies from person to person. There are 4 main types of albinism. The two most common forms are colloquially known as type 1 and type 2.
- Type 1: PWA in this group generally have no melanin activity and have white hair, white skin and eyes that are transparent with a pinkish appearance which is merely a reflection of the redness of veins in the eyes.
- Type 2: PWA in this group generally have traces of melanin such that skin colour is white or creamy in appearance and hair is yellow or blonde.

#### The Most Common Type of albinism in Africa

- Africans tend to exhibit type 2 but other types including type 1 are also present.

### 1.4 Types of Albinism (Less Common)

- **Albinism affecting the eyes.** This is called Ocular albinism (OA), and is relatively un-common. Most cases are recorded in males. Children with OA may have skin and hair colour that are normal but slightly lighter than those of other family members.
- **Albinism with HPS:** Researchers have also identified a type of albinism that comes with additional characteristics. One of these is known as *Hermansky-Pudlak Syndrome* (HPS). In addition to having albinism, persons with HPS also have a tendency to bleed and a tendency to have lung disease.<sup>i</sup> HPS is a less common form of albinism but should be suspected if a person with albinism shows unusual bruising or bleeding. HPS is reportedly worldwide but UTSS and the HPS Network have no evidence that there are such cases in sub-Saharan Africa or that research has been done to find such cases in the region.<sup>ii</sup>

### 1.5 General Challenges of Albinism – Problems PWA face

#### Skin Problems

- Lack of melanin in skin means PWA do not have natural protection from the sun.

#### Solutions

- PWA need to take precautions to avoid sun damage to their skin.

- Precautions include the use of sunscreen lotion with Sun Protection Factor (SPF) of 30 or more, wearing wide-brimmed hats and sun-protective clothing e.g. breathable long-sleeved shirts with high collars, long trousers, and long skirts. They also need to practice sun-avoidance by seeking shade and in-door employment.

### **Vision Problems**

- People with albinism always have problems with vision that are not completely correctable with eyeglasses.
- Vision problems associated with albinism is a result of abnormal development of nerve connections between the eye and the brain which in turn is a result of the lack of colour/melanin.
- The degree of vision impairment varies with each type of albinism and on how much residual pigments remains in the eyes.
- Most PWA have low vision and are classified in many countries as “legally blind.”
- Most however can use the vision they have for many tasks including reading.
- Most PWA do not require Braille.
- A very small number of people with albinism have sufficient vision to drive a car.

### **Solution**

- Same as solutions under “Educational Challenges” below.

### **Medical Challenges**

- In many countries, most people with albinism have normal life spans and have the same types of general medical problems as the rest of the population.
- In countries with sunny & hot or tropical climates like Tanzania, PWA who do not protect themselves from the sun may develop life-threatening skin cancers. This is the case in Tanzania where most PWA are unable or unaware of the need for skin protection from the sun. As a result, there are epidemic rates of skin cancer among PWA in the country, such that life expectancy for most PWA is estimated to lie between 30 and 40 years.

### **Social Challenges**

- People with albinism are at risk of severe isolation because their condition is often misunderstood.

- Social stigmatization can occur, especially within communities where other family members and the general society generally have dark skin and appearance.

#### **Solutions**

- 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 others who have PWA in their families can be most helpful.

### **Educational Challenges**

- Due to significant vision impairment most PWA cannot read from the blackboard in a normal classroom set-up.

#### **Solutions**

- Teachers and educators must make extra effort to re-organize the classroom so that PWA are positioned in front of the class and moved closer to the blackboard as needed. They ultimately have to ask the PWA if they can see better from the right, left or centre of the room.
- Re-positioning must be done so that the person with albinism is **not** staring into sunlight to see the blackboard.
- Repositioning may not work where vision impairment is highly significant. If so, the following note is crucial.
- Teacher's notes on the blackboard, exams, assignments and other printed/photo-copied hand-outs must have large enough print or must be copied from a fellow student and provided to the PWA.
- If needed, extra time must be granted to ALL PWA for exam-writing. (Actual time plus half of actual time is suggested). This is especially important if the exam questions are provided in small or regular print, and if the exams questions are re-used/faded copies.

## **1.6 Albinism as a Disability**

- Due to the visual impairment that accompanies nearly all forms of albinism, PWA are often classified as legally blind – this is mostly the status quo outside Africa and the growing trend globally.

- Being legally blind means that PWA have a physical disability. This in turn means that each PWA should be entitled to reasonable accommodation at school and place of employment.
- Likewise, the high susceptibility of PWA skin to skin cancer has also been a reason to classify PWA as disabled in some parts of Africa such as Tanzania. The harsh tropical sun, acute lack of education around sun protection and absence of affordable sunscreen lotions means that most PWA in the region show signs of extensive sun damage and skin cancer at an early age.<sup>iii</sup> Until adequate provision is made for skin protection, it is important to classify this skin problem as an additional source of disability for PWA on the continent as they frequently die from skin cancer. The importance of understanding and highlighting the disability aspects of albinism is further discussed at Section 8.

## 2. Challenges of Albinism Specific to Africa

### 2.1 Showing that PWA are Human Beings with Rights

PWA in Africa are generally not seen as full humans but incomplete beings or animals. In Tanzania for example, PWA are referred to as “Zeru-Zeru” or ghosts. They are also referred to as a “deal” which means a source of money. In South Africa, they are commonly referred to as apes.

“People just see you on the street [and say] ‘its that albino!’ instead of thinking ‘that is Jayne’...[because] they don’t see us like a person [sic] ; ... I’ve been a victim of discrimination, I have been a victim of not getting resources, and , I’ve been a victim of ignorance ...You are called money or walking bank notes<sup>1</sup>

Jayne's experience is not inconsistent with the recent findings of the African Union (AU) Committee of Experts on the Rights and Welfare of the Child.<sup>iv</sup> In 2011 the Committee concluded that children with disabilities on the continent generally face "social attitudes, stigma and discrimination" with harmful impact that "can be profound."

## 2.2 Fatal Discrimination

Discrimination that often results in the murder of PWA is driven by the belief (in some countries like Tanzania) that the body parts of PWA possess magical powers capable of bringing riches if used in potions produced by local witchdoctors. To date in Tanzania, reports indicate that 71 PWA have been murdered while 29 have survived murder attempts with most mutilated. Leaders in the albinism community including UTSS believe that the actual number of attacks – killings and mutilation – are well over the recorded numbers.

## 2.3 Chronic Social and Cultural Discrimination

In sub-Saharan Africa, there has been long-standing and widespread lack of public awareness about albinism. Powerful myths surround albinism, including these:

- PWA never die - They simply vanish - They are not human - They are ghosts.
- Other myths are detailed in Table 1 at Section 3.

As a result of these active myths, many families do not bother to educate their children with albinism. Also, employers avoid hiring a PWA due to fears that their customers and staff will "catch" the condition, or that food would be contaminated. In addition, in some social settings, many PWA are not offered the same kind of social & physical contact, due to this kind of misinformation.

## 2.3 Low Education Levels Due to Legal Blindness

There is considerable lack of accessible low vision devices to help PWA in their learning processes. These include glasses, magnifiers and specialized vision-sensitive computer equipment. For a PWA, this results in tremendous difficulty completing



educational programs, increases the likelihood of dropping out and subsequent unemployment. It also fuels the active myth that PWA are ignorant and unable to learn.

### **2.3 Age 30 to 40 is Life Expectancy**

The lack or reduced levels of melanin in the skin of a PWA and the lack of information about sun protection creates high risk for skin cancer in PWA across the continent. In Tanzania for example, the average life expectancy for a PWA is 30 years, with only 2% living beyond 40 years. In countries and circumstances where adequate care is provided for PWA skin, PWA generally have the same life expectancy as the general population.<sup>v</sup>

## **3. Some Causes of the Killings of PWA in Africa**

There appear two key trends that have culminated in killings of PWA. These are namely (1) cultural beliefs and (2) cultural practices – both traditional and contemporary.

### **3.1 Cultural Beliefs**

- Cultural beliefs regarding albinism are generally myths that have outlasted the (often inadequate and inaccessible) levels of science education in the country. Some of these myths are age-old beliefs while others are crafted relatively recently such as the myth that sexual intercourse with a female PWA can cure HIV/AIDS.
- UTSS is working hard to counter these myths by presenting the truth about albinism through the dissemination of public awareness materials, presentations in newspapers, TV and radio; and through frequent “Understanding Albinism” Seminars provided across the country to students, educators and health service providers.

- Yet, more advocacy efforts such as these are needed because the cultural beliefs and myths surrounding albinism are deeply etched and are wide-spread.

**Table 1 – Myths and Truths about albinism**

<b>PREVAILING MYTHS AND TRUTHS ADVOCATED BY UTSS</b>
<b>MYTH: Albinism is a curse from the gods or from dead ancestors. As a result, contact with a PWA will bring bad luck, sickness or even death</b>
<b>TRUTH:</b> Albinism is no more or less than a genetic condition of the human body. As such, there is nothing magical or supernatural about it. You cannot “catch” albinism – it is not a disease and it is not contagious
<b>MYTH: People with albinism never die. They are not human - they are ghosts</b>
<b>TRUTH:</b> The on-going killings in Tanzania demonstrate that PWA do die. They are NOT ghosts. Their pale skin and hair results from having very little of the substance responsible for colour known as melanin
<b>MYTH: It is the mother’s fault if a child has albinism</b>
<b>TRUTH:</b> Both the mother and father must carry the gene in order for their child to have albinism
<b>MYTH: Having sex with a woman with albinism will cure AIDS</b>
<b>TRUTH:</b> No one can or has ever been cured of AIDS by having sex with a woman with albinism. Belief in this myth will only further spread the virus to others including PWA
<b>MYTH: PWA have normal vision</b>
<b>TRUTH:</b> All PWA are visually impaired to various degrees AND have a very high sensitivity to light (due to the lack of melanin). When outdoors, PWA need to wear sunglasses to protect their eyes from the sun. Many PWA are legally blind and all require special glasses or magnifiers to aid in reading and daily functioning
<b>MYTH: A charm or potion made from the body parts of PWA has magical powers – bringing its owners wealth, success and good luck</b>
<b>TRUTH:</b> No one can or has ever become rich, successful or lucky from having or using body parts of PWA
<b>MYTH: PWA come from and live only in Tanzania</b>
<b>TRUTH:</b> Albinism occurs in every race and nationality of planet earth



**Figure 2a: A young girl from Malawi (Name Withheld). She was raped by a neighbor with AIDS due to the myth that sexual relations with a PWA can cure the disease.<sup>vi</sup>**

“My teacher always told us that when albinos die, they vanish – right there and then. So I was really amazed when I saw that nothing happened here. We buried Mariam normally, just like anyone else. Her body did not vanish. It was a normal burial.” -- Uncle of Mariam Emmanuel, murdered on January 21, 2008

**Figure 2b: The Myth that PWA do not die.<sup>vii</sup>**

### **3.2. Cultural Practices (Traditional)**

Cultural practices that lead to attacks against PWA can be divided into two types: (i) traditional and long-standing rituals that have been regularly practiced by a community – some examples are presented below, and (ii) contemporary practices that are arguably relatively recent reactions to cultural beliefs and myths about albinism. These are discussed in turn below.

## **Samples of Traditional and Long-Standing Cultural Practices**

### **Tanzania (Sukuma Tribe):**

**Current Location: Northwestern Tanzania**

The Sukuma tribe is one of the largest tribes in Tanzania. Sukuma traditionally killed their babies with albinism as soon as they were born. Once killed, the baby's remains were used for witchcraft rituals. Over time, upon the advice of witchdoctors, the child with albinism was spared from the infanticide and allowed to grow to adulthood so that they may be buried alive with the Sukuma Chief when he died.<sup>viii</sup> The intent of preserving PWA in this manner, was to use them as supernatural escorts of the Chief into the afterlife. As chiefs die only occasionally, the need to bury PWA was also an occasional one. As a result, the numbers of PWA among the Sukuma increased. To date, the Sukuma still have a relatively higher number of PWA when compared to other tribes in the region.<sup>ix</sup>

### **Tanzania (Chagga tribe)**

**Current Location: Northeastern Tanzania**

The Chagga traditionally left a new born PWA in the bushes or forests to die. This practice was upheld on the belief that the child was a being but not a human being.

### **Tanzania (Digo tribe)**

**Current Location: Northeastern Tanzania**

The Digo traditionally killed their babies born with albinism. They performed this infanticide using a trial by ordeal. The ordeal consisted of dropping a newly born child with albinism into a lake that ran through the famous Amboni caves. Once dropped into the lake, the parents of the child and their supporters waited to see if the child would emerge on the right side of the lake in which case it is believed that the baby would emerge alive. If the child emerged on the left side of the lake, it was believed that it would emerge dead. UTSS has no evidence that any baby with albinism survived this ordeal.<sup>x</sup>

### **Kenya and Tanzania (The Maasai tribe):**

Like the Digo tribe, the Maasai traditionally committed the new-born child with albinism to a trial by ordeal.<sup>xi</sup> As soon as the child with albinism was born, the child was placed on the floor of the exit gate of a cattle barn. When it was time to release the cattle for grazing, the barn gate was opened and the hungry cattle hurriedly exited the gate, trampling on the baby with albinism. If the baby survived the trampling, it was thereby proven to be the child of the father and allowed to survive. Otherwise, the death of the child proved the opposite.

### **These Practices may still be alive**

While these are generally described as events from the past, there is the possibility that they still occur especially in rural villages where local customs and age-old practices are still alive; records are not kept, and infrastructure is weak. It is possible that any tribe in east Africa that has a low or non-existent PWA population, such as the Maasai, may still be practicing traditional infanticide.<sup>xii</sup>

## **3.3 Cultural Practices (Contemporary): Witchcraft**

At the centre of contemporary cultural practices towards PWA, is the belief that the body parts of PWA will bring wealth, win political elections, and bring success at mining and fishing. This belief has directly led to the murder of PWA by people desperate for success in the form of good luck and money. At the core of this practice are witchdoctors. Witchdoctors as they are known today, are community leaders deemed to have supernatural powers, and are practitioners of what is popularly termed “black magic” or witchcraft.

### **3.3.1 What is Witchcraft?**

- Witchcraft may be described as a system of belief in the supernatural. At its core is the belief that when the supernatural world is evoked by specific

people, namely a witchdoctor or his or her delegates, harm or good may be caused upon person(s) or situation(s) to which it is directed.

- The delegates of the witchdoctor are often his or her clientele who are given specific power for specific purposes in the form of potions, incantations, amulets, and other paraphernalia purported to cause various desired effects. This delegation to a lay man or woman can be described as the service rendered by the witchdoctor who can subsequently charge them fees in cash, in kind or both.
- Witchdoctors also charge for other services such as the provision of explanation for an individual's misfortune or fortune and are able to allegedly identify both the human and supernatural causes for virtually any circumstance or conundrum.<sup>xiii</sup>
- An important effect of the witchcraft system is reverence for the witchdoctor who is seen as very powerful. He or she can dictate outcomes and allocate liability at will, without due process or a public standard of fairness and accountability.

### **The Use of Human body parts of PWA in Witchcraft**

- Human body parts are used in witchcraft to support the belief that regular witchcraft will be more powerful if human body parts are involved. In southern Africa, this type of witchcraft is commonly referred to as "muti". In western Africa, it is commonly referred to as "juju."
- Muti and juju victims are mostly vulnerable people particularly children, young women and vulnerable adults such as persons with a physical abnormality including albinism.<sup>xiv</sup>
- In carrying out muti and juju which involve body parts, the body parts are often taken from live victims. This is because it is believed that the screams of victims being hacked enhances the potency of the medicine.<sup>xv</sup> Body parts of muti victims are not only used and traded locally, but are also often transported across borders of various countries where there is demand.

- The use of PWA body parts in muti and juju is a difficult system to break in the region because it is an attractive economy. PWA limbs can be sold on the witchcraft (muti and juju) market for thousands of US dollars. In Tanzania where the annual income per person is \$1,500 USD, the price of PWA body parts creates a strong incentive for the poor to participate in this economy.

### **The Prevailing Power of Witchcraft**

- Beliefs in witchcraft appear to be stronger than belief in morals and ethics available through human rights discourse or mainstream religious philosophies. Even when these witchcraft beliefs contradict their religion, ethics and/or morals, most still find the need to associate with them rather than dissociate.
- For example, while the major religions in Tanzania – Christianity and Islam – ban consultation with witchdoctors and prescribe that a PWA is a person, a majority of those who profess these major religions still believe in witchcraft. In the year 2010, 93% of people surveyed in Tanzania by the PEW Forum on Religion & Public Life (PEW Forum) stated that religion is very important in their lives. Yet over 60% of the same population believes in witchcraft<sup>xvi</sup>.

**Figure 3: Witchcraft Beliefs in Tanzania**

Even though other African countries are also deeply religious in ways similar to Tanzania, Tanzania has one of the highest percentages of people that believe in *muti* or *juju*.

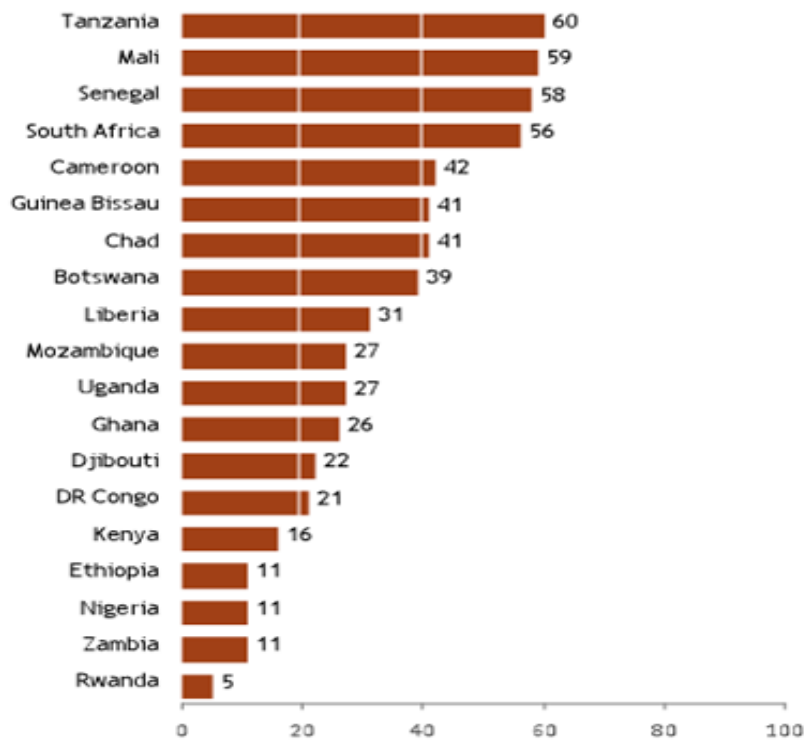
**Belief in the Protective Power of Sacrifices to Spirits or Ancestors**

*% who believe sacrifices to spirits or ancestors can protect them from bad things happening*

*Median results:*



*Among general population in...*



*Q51i. Which, if any, of the following do you believe in? That sacrifices to spirits or ancestors can protect you from bad things happening.*

From "Tolerance and Tension: Islam and Christianity in Sub-Saharan Africa," a 19-country survey by the PEW Forum on Religion & Public Life, February 17, 2011. Pewforum.org



## 4. Record of Documented Killings and Attacks of PWA including Children

### 4.1 Documented Killings, Attempted Killings and Grave Robberies by Country (2006 - 2012)

Country	Murder	Attacks*	Grave Robberies
Tanzania	71	29	17
Burundi	17	0	0
Kenya	7	2	0
Swaziland	3	1	0
Guinea	2	0	0
Nigeria	2	0	0
South Africa	2	0	0
DR Congo	1	0	0
Zambia	0	1	0

**Table 2** – Documented Killings, Attacks and Grave Robberies by Country

\*Attacks include mutilation, rape and attempted murder

## 4.2 Documented Killings and Attempted killings since 2011 : Nearly all are Children

AGE	NAME & COUNTRY	EFFECT OF ATTACK	DATE OF ATTACK OR REPORT	STATUS
2	Juma Kapela <b>Tanzania</b>	Sustained Injury	February 9, 2011	Escaped with minor cuts
4	Meriki Astoliko <b>Tanzania</b>	Mutilated	January 2011	Hair shaved and stolen
15	Kulwa Lusana <b>Tanzania</b>	Mutilated	October 2011	Arm hacked off
5	Mawazo Simon <b>Tanzania</b>	Mutilated	Reported in 2011	attempted face removal
1.2	Doto Mbiti <b>Tanzania</b>	Killed	May 13, 2011	
13	Adam Roberts <b>Tanzania</b>	Mutilated	October 14, 2011	3 fingers hacked off. Other arm wounded
5	Unknown <b>Zambia</b>	Killed	December 2011	Hair missing on side of head
19	Chantal Ngendakumana <b>Burundi</b>	Killed	May 6, 2012	Arms and legs hacked off
16	n.a. <b>Namibia</b>	Raped	May 12, 2012	
1.75	Agneta Dionizi <b>Tanzania</b>	Escaped attempt	May 17, 2012	
25 – 30 (est.)	Unknown <b>Tanzania</b>	Killed	May 22 – 24, 2012	Skinned and several body parts removed
n.a.	Harubu Nuru <b>Tanzania</b>	Escaped attempt	June 12, 2012	

**Table 3 – Most recent attacks against PWA – Nearly all are Children**

### 4.3 Why Mostly Children?

The use of children in muti and juju by witchdoctors is likely for the reasons that they are

- (1) 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.
- (2) 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.<sup>xvii</sup>

### 4.4 Selected Reports of Attacks (Mostly Children):

#### **CHANTAL NGENDAKUMANA– Burundi – AGE: 19**

**Murder: May 6, 2012**

**Death Recorded by: Burundi Albino Association (BAA) and confirmed by Burundi Police**

**Anecdotal Evidence: provided to UTSS in 2012**

19 year old Chantal Ngendakumana was murdered early in the morning of Sunday May 6, 2012 between 0030am and 0100am. Her legs and arms were chopped off. The murder was committed in Bujumbura Rural, Kabezi Ward. A group of armed men with guns, machetes and spears broke into the girl's parents' house. They gagged everyone and abducted Chantal. Chantal's body was later found two kilometers away from her home mutilated. Her legs were chopped off from the ankle and her arms were severed below the shoulder. The incident was reported to UTSS by Kassim Kazungu, the Secretary General of Burundi Albino Association as he was taking Chantal's mutilated body in his car to Bujumbura Hospital morgue.

**ADAM ROBERT – Tanzania – AGE: 12****Attempted Murder: October 14, 2011****Attack Recorded by: UTSS and Tanzania Police****Anecdotal Evidence: provided to UTSS in 2011**

On October 14, 2011 in Nyaruguguna Village, Nyanhwale District in Geita Region, Tanzania, Adam Robert, a 12 year old boy with albinism was attacked with a machete. One of his arms was wounded and three fingers from the other was hacked off and stolen. Adam survived the brutal attack by biting into the private part of his attacker. He later told police that his father, stepmother, older brother, and another male relative were involved in this criminal act. His testimony was confirmed by neighbours and the perpetrators were arrested the following day. Adam continues to suffer from severe wounds and trauma. He says he can never go home to his family.

**UNKWNOWN GIRL - Zambia – AGE: 5****Murdered: 2011****Death Recorded by: Zambia Watchdog.com, December 7, 2011**

The girl's remains were found with hair missing from one side of her head. The leader of the Albino Association of Zambia, John Chiti, termed it an incident of ritual killing.

**DOTO MBITI – Tanzania – AGE: 14 months****Murdered: May 13, 2011****Death Recorded by: UTSS****Anecdotal Evidence: provided to UTSS in August 2011**

Doto was poisoned by a relative who did not want a child with albinism in the family. Two hospitals were unable to treat the poisoning and he passed away. The news of Doto's murder was delivered to UTSS by his parents in August of 2011. The parents did not report the alleged homicide to the police because his grandfather had warned them that if they did, they would never survive the Sukuma tribe's traditional revenge. Sukumas cannot stand relatives who reveal family secrets to the authorities. Since the burial of Doto, there have been two failed attempts to rob his grave.

**WINFRIDA OLUOCH - Kenya – AGE: 22 years****Murdered: March 03, 2008****Death Recorded by: Tanzania Police****Anecdotal Evidence: provided to UTSS in October 2011**

Winfrida who was murdered has a twin sister with albinism by the name of Edna Kemunto Oluoch. A UTSS representative met Edna at a film screening in Kisumu in Kenya's lake region. Edna explained that her sister, Winfrida, had been lured by a cousin and a business partner to Tanzania where she was brutally killed and all her organs taken. The cousin who had lured her there went back to Kenya and during a church service, the point at which everybody was confessing, broke down and told the pastor everything. She was sent to Tanzania for trial, but the trial has yet to take place. Meanwhile she was set free. Since then, her sister Edna, has forsaken all friends and family ties for fear that she might be next.

**ESTHER MORAA - Kenya – AGE: 4 months****Murdered: August 2, 2010****Death Recorded by: The Standard Media and Kenya Police**

A mother, Sara Kemunto Nyabuto of Bokimweri sub location in Nyamache district, killed her 4 month old baby because she had albinism. She explained that her husband had convinced her to do it because the baby's albinism was a disgrace and an omen.

**MATHAYO CHILDREN- Tanzania****(ROSEMARY MATHAYO - AGE: 16)****(PRACSEDA MATHAYO – AGE: 14)****(FOCUS MATHAYO – AGE: 12)****Murdered: 2000****Death Recorded by: UTSS****Anecdotal Evidence: provided to UTSS in April 2011**

All 3 children from the same family were poisoned and died on the same day in Kagera Region in 2000. The deaths were reported to police at the time of their occurrence but it appears that the Tanzanian police department did not begin to document the attacks and killing of PWA until 2006. After the burial of the 3 children, unknown people exhumed the graves of the children and stole all their bodies.

## 4.5 Un-Documented Killings

The killing of PWA across the sub-continent of Africa largely goes unreported for several reasons including

- (1) **The silence around traditional infanticide and familial murder.** Killings of children with albinism perpetrated by traditional leaders and family members often go un-reported as they tend to occur in the home – the place where most children in rural areas are born, and where family bonds often demand loyalty over any apparent civic duty to report crime.
- (2) **The absence of adequate birth and death registration processes in rural areas – where most of the killings occur (See figure 4).** Since the killings came to international attention in 2007/2008, no government in the region has conducted an adequate census of PWA to enable better tracking of their whereabouts.

It is important to note however, that building such data from a census has certain risks. It is essentially a one-stop-shop for killers seeking information on the whereabouts of PWA. This danger is aggravated by police corruption (see Section 5 for details). For such a census, the government of Tanzania will likely need international support and capacity building to ensure that it is carried out adequately and that data gathered from it is secure.



**Figure 4: Top four locations of most documented killings of PWA in Tanzania. *Most of the killings and attacks have occurred in the rural parts of Mwanza, Shinyanga, Geita and Kagera***

- (3) **Fear of international disgrace and loss of revenue.** There is a general fear by national authorities that the more reports about PWA killings are released, the further the country's image would be put into disrepute. This fear is particularly evident in countries such as Tanzania that rely heavily on income from tourism
- (4) **Fear of being held accountable.** Local authorities in Tanzania are often held accountable by higher authority for killing(s) in their region. For this reason, most local authorities fear reporting any attack in their jurisdiction.
- (5) **Fear of reprisal attacks.** Persons who may have witnessed murders or who have been privy to information about the murder of a PWA loathe being forced to testify in court. This is because they fear that witchdoctors and other authorities in the community will attack them for doing so.
- (6) **The absence of healthy press freedoms in the region.** Tanzania was recently ranked as having one of the best freedoms of the press in Africa. It is therefore unlikely that it is merely a co-incidence that Tanzania has one of the most recorded and reported deaths of PWA. Other countries in the region have significantly lower press freedoms when compared to Tanzania such that it is likely that they have a higher number of killings of PWA, than the numbers that have been reported or recorded to date.

	Ranking – Out of 179	Reported Deaths
<b>Tanzania</b>	<b>34 of 179</b>	<b>71</b>
Kenya	84	7
Burundi	130	16
Guinea	86	2
Nigeria	126	2
South Africa	42	2
Zambia	86	1
DRC	145	1
Swaziland	144	3
Somalia	164	0
Rwanda	156	0

TANZANIA - Highest number of documented PWA deaths and 4<sup>th</sup> best freedom of press in Africa.



**Table 4: Freedom of Press Rankings (2012) of Some African Countries 2011/2012 Comparing Tanzania with countries that have reported PWA deaths and those that have reported no PWA deaths. (From Reporters Without Borders)**

## 5. Key Players in the Killings of PWA

### 5.1 Government

As international attention was drawn to the killings of PWA, the government took some notable actions:

- It set up secret ballot stations across the northwestern regions of Tanzania to encourage the submission of information about the killings of PWA.
- The government moved PWA under threat in their community into temporary shelters or centres. These are mostly boarding schools for children with special needs.
- President Jakaya Kikwete publicly condemned the killings on several occasions and ordered that witchdoctors connected to PWA killings be arrested. In 2008, President Kikwete appointed a person with albinism as a Member of Parliament, Ms. Al Shaymaar Kweygir, as a way of showing solidarity with PWA.<sup>xviii</sup>
- Also in 2009, President Kikwete set up a Task Force to investigate the killings of PWA in the country. The Task Force neither released the result of their findings to the public, nor publicly comment that their work was completed.
- In 2009, Prime Minister Mizengo Peter Pinda banned witchdoctor licenses in existence and put a hold on issuance of new ones. The ban also applied to traditional healers who often claim to be different from witchdoctors because they practice alternative medicine such as herbal healing; but in reality, are often are difficult to distinguish from witchdoctors.
- The Ministry of Home Affairs was also instructed by the President to register PWA to be able track them. However, the process was incomplete and there

are no known records produced. The only other known register of PWA is the database of the Tanzania Albino Society (TAS) which has over 8,000 PWA registered despite the fact that there are an estimated 150 thousand PWA in the country.<sup>xix</sup>

All of these attempts have been heavily criticized for being inadequate because killings have continued. The attempts have also been criticized because follow-up mechanisms, such as reporting and maintenance systems were not put in place. For example, nothing came out of the secret ballot stations; the Task Force produced no results to the public and the security of PWA at schools and other centres was rarely enhanced.

On the one hand, government should be commended for taking these actions. While inadequate, they raised awareness on the issue and created an appearance of willingness to curb the problem.

On the other hand, the government of Tanzania can do more to improve the security of PWA. Adequate follow-up on their original initiatives will be a starting point. Other recommendations are listed at Section 9.

## 5.2 Witchdoctors

Witchdoctors are at the centre of the trade in human body parts. As discussed in Section 3, they wield great power in Tanzania. They promise remedies to human needs especially in the area of financial wealth and political gains. Their cultural and historical root generally means that they are still revered by most of society especially in rural areas where traditions are still alive and poverty is rife. While not all witchdoctors practice witchcraft involving PWA body parts, no other profession has been so interlinked with PWA killings as witchdoctors.

## 5.3 Police

Tanzania Police should be commended for those instances where their efforts have protected and led to justice for PWA. For example, police investigation in the murder

of Matatizo Dunia (2008) is what led to the successful prosecution and sentencing of the accused in that case. Another example of effective police intervention is the under-cover operations that prevented the murder of a Kenya PWA who had been deceived by a friend to travel to Tanzania where he was to be killed.<sup>xx</sup>

Yet Tanzania police face steep challenges in playing their crucial role of securing their fellow citizens with albinism. Police corruption which is commonplace in the country remains a hindrance to bringing justice especially carrying out a successful investigation. For example, in 2009, police officers were among suspects arrested on suspicion of killing PWA and trading their body parts.<sup>xxi</sup>

Police investigation is also challenged by fear of political and economic elites, fear of witchdoctors, and lack of adequate human and infrastructural resources especially in the rural areas where most killings occur.

## 5.4 Wealthy Elites

This is the group that are most commonly suspected of spurring the trade in body parts. With PWA body parts ranging in thousands of dollars, locals are generally unable to afford such prices unless they were financially wealthy.

Wealthy elites in Tanzania pose a dilemma in the fight to end the killings of PWA. On the one hand, they are likely the demand side to this macabre economy of PWA body parts. On the other hand, they are potentially strong partners in terms of influence and resources for steering the public away from dangerous beliefs about albinism that spur PWA killings.

UTSS has created and fostered relationships with members of the public who are financially prosperous. These include media elites as well as local businessmen. It has collaborated with these people on a wide range of issues including public awareness in the media and paying hospital bills of victims of attacks. Yet, it is challenging to know the truth about each member of this group so that one might safely collaborate with its members who have “clean hands.”

## 5.5 Some Local Entrepreneurs

Fishermen and miners of precious metals in Tanzania, especially in the northwestern regions of Mwanza and Shinyanga, are key players in the killings. They too, like wealthy elites are on the demand side of the macabre trade in body parts of PWA.

Hair and bones of PWA are mixed in potions that are smeared on to fishing nets for good luck in catching fish – a valuable yet depleting resource in Tanzania. Miners also use PWA blood to advance their luck in finding precious metals. For example, bones from the legs of PWA are used by miners who believe that these bones are supernatural detectors of precious metals and stones.

## 5.6 Family Members of PWA

It is not un-common that family – immediate biological relatives - “sell” their fellow member(s) with albinism to outsiders. The following anecdotes illustrate this

### 5.6.1 Anecdotal Evidence of Attacks Involving Immediate Family

**EUNICE BAHATI – Tanzania - Age: 12**

#### **Anecdotal Evidence: produced by Tanzania Police**

On February 17, 2009, 12 year old Eunice was murdered and her legs severed in front of her siblings including 2 sisters with albinism who fled. Their father was taken into custody as an accused because the youngest sibling of the deceased – a girl without albinism - had recognized him as one of the attackers.

**DOTO MBITI – Tanzania - Age: 14 months****Anecdotal Evidence: provided to UTSS**

On May 13, 2011, a 14 month old boy with albinism died. Doto was poisoned by a relative who did not want a child with albinism in the family. See full story at Section 4.

**MAWAZO SIMON – Tanzania - Age: 5****ELISHA SIMON – Tanzania – Age: 3****Anecdotal Evidence: provided to UTSS**

Since birth, the father of both Mawazo and Elisha had been shaving their hair against the will of his wife, Angelina. When he did not stop, Angelina decided to move out of the home at which point Mr. Simon started sending people (most of them work in the mines) to his wife's home to shave the hair of Mawazo. Many times she had to flee her home. When she complained to the authorities about her husband's behaviour and intentions, her family disowned her.

## 6. Legal Response to killings

### 6.1 Prosecution Reveals Facts of PWA killings

Across the continent, legal response to the killings of PWA, specifically prosecution and punishment, have been slow and in some cases non-existent. In Tanzania for example, to date, only 5 of 71 killings have been brought to prosecution.

Yet, prosecution remains important to deter future crime through punishment. Prosecution is also necessary for fact-finding about the killings because in the few cases that do reach trial, much information has been revealed including confirmation that killings of PWA for body parts do exist and that they are based on cultural beliefs and practices.

For example in the trial of Matatizo Dunia, the 10 year old boy of Shinyanga region killed in 2008, the Tanzania High Court revealed that he was murdered for his body part under the supervision of a witchdoctor [”medicine man”].

Chief Justice Ramadhani writing for the court in *Masumbuko et al v. Republic of Tanzania*<sup>xxii</sup> confirmed the fact by stating that

Then the cops combed the surrounding area and they stumbled over a bundle which they asked PW 2 to unravel. The bundle contained a semi-nylon bag with two albino legs freshly cut at the knees, two machetes, a bush knife, a trouser, a shirt and a pair of shoes. PW 2 told the cops that the bush in which the bundle was found is appellant 1’s place of medicinal rituals. Appellant 1 is a local medicine man.<sup>xxiii</sup>

....

... whoever killed him did so with malice afterthought because the motive was to get the deceased’s body parts, in this case, the two legs, because of the most stupid and barbaric misconception that albinos’ parts are charms.<sup>xxiv</sup>

A similar case from Nigeria, *The State v. Sunday Onwochei et al*<sup>xxv</sup> excerpted below, also confirmed a similar truth about the killings. One of the accused testified as follows:

I went to Kingsley to barb my hair. As Kingsley... was barbing me he told me that Benco, a musician, told him that there is a deal. I asked him what type of deal, He said that Benco said that an Alhaji asked them to bring somebody's head to make medicine for money. I asked him how did Benco come to know of such a thing? He said that it was Papa who informed Benco. He said specifically that it was an albino (Anyari) that is needed. It was then I told him that there is an albino (Anyari) in my compound which they also know.<sup>xxvi</sup>

....

Sunday entered and carry [sic] the child...the child started to cry so Sunday started to run with the child. The mother of the child came out and pursued us and I ran towards another direction while Sunday ran to another direction, but when I later joined Sunday at Azungwu, he had already cut off the head of the child.<sup>xxvii</sup>

## 6.2 Some Challenges to Effective Legal Responses

### Sentences often appear un-enforced

Sentencing records of persons found guilty in the killing of PWA are often not publicly available. This means that it is often unknown whether they are carried out or will be carried out. This uncertainty of information waters-down the ordinary effect of punishment and related deterrence. For example in the case of Matatizo Dunia, excerpted above, all three accused were found guilty and sentenced to death. To date, that penalty has not been carried out. In fact, Tanzania has not carried out the death sentence on any one in the last 17 years. Thus it is doubtful whether it will be carried out in this case.

Death was also the sentence handed down to three accused in the case from Nigeria. UTSS does not know whether that sentence was carried out.

Also in Burundi, a 2009 judgment against the accused persons in the killing of a several PWA for witchcraft resulted in one person being sentenced to life in prison and eight others jailed between 1 and 15 years. In 2009, there was a jail break and all of these accused escaped.<sup>xxviii</sup>

### **The legal system is an inadequate tool against witchcraft Beliefs and Practices**

Tanzanian witchcraft specialist, Dr. Simeon Mesaki, points out that the law is a blunt instrument in dealing with witchcraft.<sup>xxix</sup> This is especially the case where, as in Tanzania, the people have relied on witchcraft beliefs for centuries and continue to rely on it. Moreover, the law in Tanzania – largely colonially inherited, archaic and under-developed is foreign to most and has not evolved to properly match the true and evolving nature of witchcraft.<sup>xxx</sup>

### **Fear of Witchdoctors impedes Investigation**

The belief that witchdoctors truly have supernatural powers means that witnesses are generally too scared to come forward to testify in court because they fear reprisal attacks.

### **Lack of Funding**

In 2009, UTSS was informed by senior representatives of the Tanzania legal system that generally, there is inadequate funding to prosecute accused criminals. This lack of funds is obvious in the fact that to date, only 7% of documented PWA murders have been taken to trial. While other factors contribute to this slow progress, the absence of financial resource remains a major challenge.

Proper funding in the legal system remains crucial to ending the killings because it will not only deter crime but will also expedite trials especially in the area of investigation and evidence gathering; for example, offsetting the cost of DNA forensics which is expensive but relatively accurate and appropriate for these types of crimes. Proper funding will also help to protect informants by creating witness protection schemes, and also encourage them to come forward by providing rewards for correct and helpful leads.



## 7. PWA as Internally Displaced Persons (IDPs) and Refugees

### 7.1 Centres for Internal Displaced Persons Who are PWA

Internally Displaced Persons (IDP) are “persons forcibly uprooted from their homes by violent conflicts, gross violations of human rights and other traumatic events but who remain within the borders of their own countries.”

*Definition from IDP Guiding Principles*

[www.idpguidingprinciples.org](http://www.idpguidingprinciples.org)

The above definition<sup>xxxi</sup> of IDPs, as accepted in international practice, adequately describes the status of PWA, who since the killings increased in 2007 and 2008, have had to flee their homes to places with better security – both real and perceived.

Some of these movements are individual initiatives while others have been government-led. The individual initiatives include relocation to more urban centres where killings are less. They also include the use of a ring of protection made up of trustworthy relatives and friends who act as an informal entourage when PWA are travelling distances that they would otherwise travel alone.

There has also been government-led effort in Tanzania to move PWA, especially children, to safer communities. This movement involves the removal of children from their homes either by family or by government officials to schools and centres. These schools and centres ordinarily care for children with special needs and disabilities. A sampling of Centres Holding Internally Displaced Children with albinism is provided at Appendix C.

The result of moving PWA children to these centres is chronic over-crowding at these centres which were already full and were never designed to accommodate a sharp increase in residents. Other results include poor sanitary conditions, staff that are not sensitized to the needs of PWA, the breeding of chronic abuse and the absence of

adequate security and shade in most centres in a manner that does not guarantee safety for PWA residents.<sup>xxxii</sup>

There is a need for a concerted effort to either relocate IDPs at these centres to better locations or to improve current conditions at these centres. There is also a need to reduce the reality of abandonment that most PWA children at these IDP centres face. A majority are visited only occasionally by family while others are never visited after they have been dropped off at the centres. While affordability of travel costs is an oft-cited reason why family stay away from their members with albinism at these centres, it is also apparent that some families have used the centres to off-load the “burden” that a PWA is perceived to be to them.

## 7.2 PWA as Refugees

In other African countries, there are no known formal IDP schemes as large as that of Tanzania. Yet, from these countries, PWA have, in the last few years, filed for refugee protection and asylum in countries of Europe, North America and Israel.

A refugee is someone who "owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality, and is unable to, or owing to such fear, is unwilling to avail himself of the protection of that country."

UN High Commission for Refugees

<http://www.unhcr.org/pages/49c3646c125.html>

In each case filed, the PWA pleaded against being returned or deported to their home country for fear of persecution due to their albinism.

UTSS provided expert evidence in most of these cases and in each case, asylum was granted.

### Spain, 2009

- **The Case of Moszy, a PWA from Benin**<sup>xxxiii</sup>

Moszy, an 18 year old from the country of Benin in West Africa was granted asylum in Spain after testifying that his life was often endangered in his home country where the skin of PWA was frequently sought after for ritualistic purposes.<sup>xxxiv</sup>

### Florida, USA 2011

- **The Case of Franklin Ibeabuchi, a PWA from Nigeria**

Franklin's removal order was withheld after he testified that he had been brought to the U.S. for a safer life shortly after he survived an attempted kidnapping in his native Nigeria. The judge prevented his removal after he was satisfied from UTSS' evidence that (1) Persecution of PWA was common place all over Nigeria (2) government response to this persecution was weak and inadequate (3) in the absence of government protection, a ring of protection by family and loved ones was of utmost importance and Franklin was lacking in this area (4) to return Franklin to Nigeria would be to subject him to persecution due to his albinism.

### Israel, 2011

- **The Case of Maiken Keita, a PWA from Ivory Coast**

4 year old Maiken and her parents were granted asylum in 2011 by Israeli authorities after the country accepted evidence from UTSS and the family that if Maiken was returned to the Ivory Coast, her life would be at risk due to her albinism. Her father testified that "We've never had an albino in the family before ...Rich people in Africa come with a lot of money, looking for these children, like my daughter. Witch doctors use their parts and blood."<sup>xxxv</sup> Israeli authorities reportedly went out of their way to grant asylum to Maiken's parents as well for the sake of their child.<sup>xxxvi</sup>

### United States, 2012 (Upcoming)

- **Case of \*Name Withheld,\* a PWA from Zimbabwe**

UTSS will be providing expert evidence at this hearing scheduled for November 2012. The client is applying for asylum and withholding of removal from the U.S. in light of abuse she suffered due to having albinism including abuse from law enforcement officers in Zimbabwe and sexual abuse namely rape, while attempting to seek asylum in South Africa.

## 8. Disability as a Ground for Protection

### 8.1 Albinism as a Disability

The disabling aspects of albinism is rarely known, and understood. Yet, such knowledge is crucial not only because it would contribute to the end of fatal beliefs, but also because it would grant PWA in Africa a strong basis for advancing their rights including the right to reasonable accommodation at place of employment, school and other similar environments of productivity.

#### Disabling Aspects of Albinism

##### Skin Cancer

In North America and Europe, where temperatures are cooler, sunscreen lotion are more affordable and education levels on skin protection is generally high, the skin of PWA is generally not a disabling aspect of albinism. The opposite is the case in most of sub-Saharan Africa where the harsh tropical sun, the absence of sunscreen lotion and the lack of public education on PWA skin form a highly fatal equation for most PWA.

Aside from witchcraft-related killings, scores of PWA in the region die from skin cancer due to prolonged exposure to equatorial sun. In Tanzania for example, almost every PWA shows the presence of pre-cancerous lesions before the age of 20.<sup>xxxvii</sup> The result is a shortened life span for most PWA in the region with the average person dying between ages 30 to 40.<sup>xxxviii</sup>

To highlight the connection between PWA skin and the fatal consequences of the sun, PWA in Tanzania sometimes call themselves “*walemavu wa ngozi*” meaning person with skin disability. *Walemavu wa ngozi* serves as a strong educational opportunity for the public while giving PWA a disability status which becomes an avenue to access accommodative rights.

## Eyes

PWA are born with several eye conditions that are a result of little or no pigment or melanin in the eyes. (See [table 5 below for a listing of conditions](#)). Most PWA have all of these conditions listed. Collectively, these conditions result in high levels of near-sightedness and inability to resist light which the average person without albinism could easily resist.

It is because of these visual conditions that PWA in North America are classified as legally blind. For example, in Canada, the average person is said to have 20/20 vision. A person is defined as legally blind if they have 20/200 vision which means that if the average person can see a particular object from 200 feet away, the legally blind person can only see the same object from 20 feet away. Due to this significant vision impairment most PWA are hindered from normal activities. Most cannot read from the blackboard in a normal classroom set-up. Most do not drive because their legal blindness bars them by law from doing so.

NAME OF CONDITION	CONDITION	TREATMENT or REHABILITATION (where available)
<b><i>Nystagmus</i></b>	regular movement of the eyes, side to side or in circular motion	Surgical intervention today <b>minimizes</b> but cannot completely cure nystagmus
<b><i>Strabismus</i></b> includes “crossed eyes” ( <i>esotropia</i> ), “lazy eye” or an eye that deviates out ( <i>exotropia</i> )	Muscle imbalance in eyes	For <i>strabismus</i> , surgery may improve the appearance of the eyes. In the case of esotropia or “crossed eyes,” surgery may help vision by expanding the visual field (the area that the eyes can see while looking at one point).
<b><i>Photophobia</i></b>	Sensitivity to bright light and glare	PWAs need light to see just like anyone else. Sunglasses or tinted contact lenses help outdoors. Indoors, it is important to place lights for reading over a shoulder rather than in front.

<b><i>Near or far sightedness</i></b> Usually with <i>astigmatism</i> or some blurriness	far-sightedness or near-sightedness	Various optical aids are helpful to people with albinism including bifocals, strong prescription reading glasses and bioptics* (glasses which have small telescopes mounted on)
<b><i>Foveal hypoplasia</i></b>	No normal development of the inside surface of the eye that receives light- known as the retina	See photophobia
<b><i>Optic nerve misrouting</i></b>	nerve signals from the retina to the brain do not follow the usual nerve routes	None

**Table 5: Aspects of PWA vision resulting in overall legal blindness (from [www.albinism.org](http://www.albinism.org))**

### **Legal protection of PWA as Persons With Disability**

Tanzania law on disability is currently broad enough to recognize PWA as a group of persons with disability. The primary legal instrument in this regard, *The Persons with Disability Act* (2010) defines disability to include “the loss or limitation of opportunities to take part in normal life...due to physical, mental or social factors.”<sup>xxix</sup> PWA have a physical limitation, namely visual and skin impairments that hampers their opportunities to participate in a normal life. This is especially true in sub-Saharan Africa where poverty and lack of information exacerbates the limitations of albinism. It is thus evident that the definition in the *Act* easily spans PWA. That said, despite the potential of the *Act* to protect PWA, the reality is that the purported protection is rarely applied or materialized.

The same can be said in every other country of the region.<sup>xi</sup> PWA in sub-saharan Africa for the most part are still struggling to be recognized as a group of persons with disabilities. A chronic lack of understanding of the condition and an unwillingness of disability service providers to accept PWA as a part of the community of persons with disabilities are major hindrances to PWA benefitting from disability law.<sup>xii</sup>

## 9. Conclusions and Recommendations

The historic ill-treatment of PWA as sub-human and supernatural – for use in witchcraft – has resulted in widespread neglect in Tanzania and sub-Saharan Africa. While most African countries have signed the *UN Convention on the Rights of the Child (UN CRC)*, the *UN Convention on the Rights of Persons with Disabilities*, the *African Charter on the Rights and Welfare of the Child*, these normative structures are limited until immediate actions are taken nationally and internationally in the following key areas

### 9.1 Recommendations for Tanzania

#### Census of PWA

- This is one of the greatest strengths of any government in tackling murder. Knowing basic information of each PWA such as name, date of birth, name of parents, residential information etc, forms the basis for an effective tracking system. The danger of such a system is that, it is essentially a one-stop-shop for potential killers of PWA.
- One way to overcome this danger is to conduct the census with an independent but internationally trustworthy group that will not only do the work efficiently but also securely. This trusted administrator of the census should also be a group that can store the data safely and serve as a secure bank from which permitted groups, organizations and government may securely access the data while being held accountable for having such access. The UN could be the described administrator in this regard

#### Improve IDP Strategy and Security at Centres

- Tanzania needs to improve on the current IDP process of relocating children with albinism to schools for children with special needs. These centres need immediate attention in the following areas:-
  - secure fencing and the hiring of trustworthy armed guards

- internal tracking system for monitoring the whereabouts of each PWA
- over-crowding
- additional personnel who with current personnel ought to be trained to understand albinism
- sun-protective clothing and sunscreen lotion for PWA
- shaded outdoor spaces for protection from the sun
- end to abuse – physical, psychological and sexual
- separating adult IDP residences from children residences

### Legal

- Add albinism to interpretive instruments and commentaries to legal Acts including the Constitution, *The Persons With Disabilities Act* of Tanzania (2010) and other similar legal instruments. The mention of the condition of albinism as a disability in court cases would also be useful here.
- Quickly, thoroughly and lawfully investigate, prosecute and where applicable, punish crimes against PWA.
- Encourage and protect informants and witnesses.
- Use other justice-related systems that are more culturally-sensitive to prosecute and prevent witchcraft-related crimes.

### Fund social programs aimed at supporting PWA

- Fund and encourage pre-existing as well as new disability serving groups to extend their efforts to PWA. Funding is needed not only to provide disability support services for PWA but also for programs that will educate the general population on the disabling aspects of albinism and to entrench acceptance of PWA in the community of persons with disabilities.

### Health

- A scheme to provide or supply sunscreen at little or no cost to PWA is urgently needed especially in rural areas. This can be achieved in the following ways:
  - Support groups that locally produce sunscreen. For example, cancel import duty on raw materials
  - Also cancel import duty on sunscreen lotion made abroad so that delivery to end-users may be expedited.



- Use of itinerant nurse and other health practitioners to educate new mothers of PWA, especially in rural areas, on albinism and how to care for themselves including how to use sunscreen lotions.
- Normalize the accommodation necessary for the full participation of PWA in the classroom. This includes permitting long sleeved uniforms, and wide-brimmed hats, the use of visual aids in the classroom and exemption from outdoor activities in the sun.
- Train local doctors on visual rehabilitation and skin cancer treatment. It is strongly recommended that this be included in the curricula of medical professionals during their training.

### Education

- Humanize PWA by the inclusion of albinism education in teacher-training colleges. This is important not only as part of specialized programs in disability studies but in the general teacher-training program. The relatively higher frequency of albinism in Tanzania should be indication that training of educators on both the science and social aspects of albinism is necessary. We suggest that the re-teaching of society on the issue will undermine killings and discrimination.
- Supply low vision gadgets and aids for PWA in schools. Magnifiers and monoculars as well as books and exams with large fonts are crucial for the success of PWA in a general learning environment.

### Advocacy of intense and extensive quality

- Intense and extensive public campaigns using public media including TV, radio, bill boards, religious leaders and other similar community leaders especially in rural areas will be helpful in explaining the scientific basis of albinism and to end fatal and dangerous myths.
- Place more PWA in high profile positions so that society may see human dignity in albinism and children with albinism may see a role model.

## 9.2 Recommendations for UN

### We propose the UN to

#### **Pressurize Tanzania and Other Countries with Reported Killings**

- Raise the issue with the government of Tanzania on all possible occasions: From visit of UN delegates to the country, to Tanzania's Universal Periodic Review of at the UN Human Rights Council.

#### **Mobilize strategic alliances with NGOs such as UTSS and the National Government of Tanzania especially in these areas**

#### **Census Support**

- Assist Tanzania and other African countries with census on PWA. Provide support in the safekeeping of the information so that it is not used against the persons it was designed to protect.

#### **Legal**

- Adding albinism to interpretive instruments and commentaries to UN Conventions such as the UN CRPD.

#### **Thematic Studies**

- Assist Tanzania on thematic studies such as research on how best to prevent the targeting of children and how to end the belief in dangerous myths all together.

#### **Internally Displaced Persons**

- Help the country to create an adequate and comprehensive system of prevention of violence against children while developing an equally effective system of response to emergencies including the logistics and planning for safe IDP centres.

#### **Advocacy**

- Use all appropriate mechanisms for advocacy including the production of statements and discussion papers on the killings. A statement that effectively speaks on-behalf of PWA will send a strong message to various leaders of Africa, that the UN recognizes the issue.

- Set aside a day in the year to mark *International Day of Albinism* to bring wide awareness to the unique issues of persons with the genetic condition.



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## Resources

Albino Killings are Muti Killings, from <http://www.underthesamesun.com/sites/default/files/Albino-Killings-are-Muti-Killings.pdf>, (June 16, 2012).

Basic map of Tanzania adapted from <http://www.msh.org/news-bureau/accredited-drug-dispensing-outlets-in-tanzania-13-09-2009.cfm>, (June 16, 2012).

“Myth Busting: The Truth About People with Albinism,”  
<http://www.underthesamesun.com/sites/default/files/UTSS-Brochure-Myth-Busting.pdf>, (June 16, 2012).

National Organization of Albinism and Hypopigmentation, <http://www.albinism.org/>

Photo: Albinism Worldwide, Courtesy of Rick Guidotti of Positive Exposure, [www.positiveexposure.org](http://www.positiveexposure.org)

Photo of children on page 2 , Courtesy of Mafalda Soto, in 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].

Reporters Without Borders: <http://en.rsf.org/press-freedom-index-2011-2012,1043.html>

Further details for teachers and educators of PWA are available in a small easy-to-read handbook: QUICK GUIDE for TEACHERS available at <http://www.underthesamesun.com/resources> (June 16, 2012).

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<sup>i</sup> NOAH, “Hermansky Pudlak Syndrome,” at <http://www.albinism.org/publications/HPS.html>, (June 10, 2012).

<sup>ii</sup> Hermansky-Pudlak Network Inc., <http://www.hpsnetwork.org/en/hps-information/characteristics>, (June 10, 2012).

<sup>iii</sup> 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].

<sup>iv</sup> African Committee of Experts on the Rights and Welfare of the Child (ACERWC), “Concept Note on the Commemoration of the Day of the African Child on 16 June 2012 under the theme “The Rights of Children with Disabilities: The Duty to Protect, Respect, Promote and Fulfil,” at p.5. Available at <http://www.scribd.com/doc/89298837/Concept-Note-Day-of-the-African-Child-2012> (June 16, 2012).

<sup>v</sup> Cruz-Inigo, A, Ladizinski, B, & Sethi, A. “Albinism in Africa: Stigma, Slaughter and Awareness Campaigns,” *Dermatol Clin* 29 (2011) at 81.

<sup>vi</sup> See RDTC at note 3

<sup>vii</sup> Quote is from, *White and Black: Crimes of Colour*, A UTSS Documentary, at 00.25.30 to 00.26.08 , see <http://www.underthesamesun.com/node/193>, (June 10, 2012).

<sup>viii</sup> UTSS Interview in 2009 with Dr. Sandu, an anthropologist and Caretaker of the Bujora Museum in Mwanza who also serves as Priest at Bujora Cathedral.

<sup>ix</sup> Interview with Dr. Sandu at note viii.

<sup>x</sup> UTSS “Albino Killings are Muti Killings,” UTSS, <http://www.underthesamesun.com/sites/default/files/Albino-Killings-are-Muti-Killings.pdf> (June 10, 2012).

<sup>xi</sup> UTSS Interview with Alex Munyere, Chairman, Albino Association of Kenya. Video recorded by UTSS in Kenya, 2011.

<sup>xii</sup> See for example “Scapegoating the most vulnerable in the Central African Republic,” In UNICEF, “Witchcraft Accusations Hurt the Most Vulnerable Children in West, Central Africa,” Voice of America,

<http://www.voanews.com/content/witchcraft-accusations-harmful-to-children-in-west-and-central-africa-98835474/161594.html>, (June 10, 2012)

<sup>xiii</sup> A Paraphrase from Simeon Mesaki, "Witchcraft and the Law in Tanzania," *International Journal of Sociology and Anthropology* Vol.1(8) pp 132-138, December 2009.at p.132. Full quote is as follows:

Witchcraft may be described as the medium "through which life is experienced and acted upon, as manifested in everyday conversation, gossip or a way of speaking and means of handling day-to-day ambiguities or means of allocating responsibility, branding scapegoats for misfortunes, eliminating rivals and competitors. It also explains, rationalizes and makes plausible accusations out of envy, jealousy, greed, hatred, rivalry, vengeance or misunderstanding or misinformation, strained relations, political and economic frustrations"

<sup>xiv</sup> IRIN, "Child Witchcraft Allegations on the Rise," <http://www.irinnews.org/Report/89858/RIGHTS-Child-witchcraft-allegations-on-the-rise>(March 26, 2012).

<sup>xv</sup> See UTSS at note x.

<sup>xvi</sup> Pew Forum, "Importance of Religion," <http://www.pewforum.org/executive-summary-islam-and-christianity-in-sub-saharan-africa.aspx>, (March 26, 2012).

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

<sup>xviii</sup> Three years later, the Constituency of Lindi in southwest Tanzania elected their Member of Parliament with albinism, Bharwani Khalfan.

<sup>xix</sup> Under The Same Sun, "Why did Brutal Albino Killings Happen in Tanzania?," In *Understanding Albinism, Issue No.1, April 2012 at p.4.*

<sup>xx</sup> Will Ross, "Kenyan Arrested for Attempting to 'Sell' Albino Man in Tanzania," BBC News, (August 17, 2010), [http://www.bbc.co.uk/worldservice/news/2010/08/100817\\_albino\\_xn\\_sl.shtml](http://www.bbc.co.uk/worldservice/news/2010/08/100817_albino_xn_sl.shtml) (June 16, 2012)

<sup>xxi</sup> *Republic v. Mboje Mawe and 3 others*, CAT Crim. Appeal No. 86 Of 2010, at Tabora, cited in Speech of Judge John Utamwa, President of President of the Judges and Magistrates Association of Tanzania (JMAT), Speech at the Seminar on "Understanding Albinism" held at Kilimanjaro Hyatt Hotel on 30<sup>th</sup> November, 2011.

<sup>xxii</sup> *Masumbuko et al v. Republic of Tanzania*, In the Court of Appeal of Tanzania, at Tabora, June 8 & 11, 2010 per *Ramadhani, C.J.*

<sup>xxiii</sup> *Masumbuko et al*, at note xxii, p. 4.

<sup>xxiv</sup> *Masumbuko et al*, at note xxii, p. 36.

<sup>xxv</sup> *The State v. Sunday Onwochei et al* at the High Court of Justice, Delta State, Nigeria – Ogwashi-Uku Judicial Division, February 16, 2005 per Justice I.E. Ogbodu

<sup>xxvi</sup> *The State v. Sunday Onwochei et al*, at note xxv, p.12.

<sup>xxvii</sup> *The State v. Sunday Onwochei et al*, at note xxv, p.14.

<sup>xxviii</sup> See "Albino Girl Kidnapped and Killed in Burundi" GhanaNation,

[http://news1.ghananation.com/vivvo\\_general/253709-albino-girl-kidnapped-and-killed-in-burundi.html](http://news1.ghananation.com/vivvo_general/253709-albino-girl-kidnapped-and-killed-in-burundi.html), (June 16, 2012);

Also see "2009 Human Rights Report: Burundi" at Section: "Respect for Human Rights: Arbitrary or Unlawful Deprivation of Life," US State Department, <http://www.state.gov/j/drl/rls/hrrpt/2009/af/135941.htm>, (June 16, 2012)

<sup>xxix</sup> Simeon Mesaki, at note xiii.

<sup>xxx</sup> Simeon Mesaki at note xiii

<sup>xxxi</sup> "Introductory Note by the Representative of the Secretary-General on Internally Displaced Persons, Mr. Francis M. Deng," Global Database, <http://www.idpguidingprinciples.org/> at p. 5, (June 16, 2012).

<sup>xxxii</sup> UNICEF and UTSS, "Sexual Abuse Cases Reported in Assessed Schools and Centres Hosting Internally Displaced Children with Albinism and Other Children with Disabilities," A Report to the Ministry of Education and Vocational Training (MoEVT), May 26, 2011.

<sup>xxxiii</sup> This is the only case in which UTSS was not directly involved

<sup>xxxiv</sup> "Spain Saves Albino African from Sure Death," <http://dalje.com/en-world/spain-saves-albino-african-from-sure-death/249734> (June 16, 2012).

<sup>xxxv</sup> Tomer Zarchin, "Hunted in Ivory Coast, Albino Child and Parents Granted Asylum in Israel,"

<http://www.haaretz.com/print-edition/news/hunted-in-ivory-coast-albino-child-and-parents-granted-asylum-in-israel-1.384727>, (June 10, 2012).

<sup>xxxvi</sup> See "Hunted in Ivory Coast..." at note xxxv.

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<sup>xxxvii</sup> See “RDTC” at note 2.

<sup>xxxviii</sup> The range often reported is between 30 and 40.

<sup>xxxix</sup> s.3 of the *Persons With Disabilities Act of Tanzania* (2010), From the Parliament of Tanzania, <http://www.parliament.go.tz/index.php/documents/acts/year/2010/5> (June 10, 2012).

<sup>xl</sup> See Ghana News Link, “Albinos Call for Special Attention,” April 15, 2010

[http://www.ghananewslink.com/index.php?option=com\\_content&view=article&id=2544:-albinos-call-for-special-attention-&catid=13:headlines&Itemid=34](http://www.ghananewslink.com/index.php?option=com_content&view=article&id=2544:-albinos-call-for-special-attention-&catid=13:headlines&Itemid=34), (August 5, 2010).

<sup>xli</sup> Madinah Tebajjukirah, “Albinos Want Own Member of Parliament,” February 24, 2010 , <http://www.newvision.co.ug/D/8/13/711020>, (March 15, 2012).