

MYTHS, DISCRIMINATION, AND THE CALL FOR SPECIAL RIGHTS FOR PERSONS WITH ALBINISM IN SUB-SAHARAN AFRICA.

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Abstract:

The murders, amputations and trafficking in body parts of persons with albinism in parts of East and southern Africa is an affront to the dignity and sanctity of the human body as guaranteed under international human rights law. Those laws assert and presume that human beings are born free and equal in dignity. Myths surrounding the genetic condition of albinism persist in many parts of sub-Saharan Africa. Superstition in some communities has led to the belief that persons with albinism either possess some special powers or are incomplete. Lack of sound knowledge on the condition has led to discrimination and stigma. States and communities have consistently neglected and shunned persons with albinism in employment and education. Their health status is largely overlooked by the healthcare systems. Persons with albinism deserve the same dignity as pigmented persons and states have the obligations to respect, protect and fulfill their rights. They also have the duty to extend some special rights to persons with albinism in the form of affirmative action in order to integrate them into mainstream society and to ensure that they live their lives in dignity. This paper looks at the myths surrounding albinism and the resulting discrimination. In response to these vices, it proposes some special rights that states in Africa should implement with regards to health, education, livelihood, safety and security of the person and the general welfare of persons with albinism. References have been made to various papers and articles published online. The paper is intended to be a resource for persons/organizations defending the rights of persons with albinism in sub-Saharan Africa.

1.0 Albinism as a Genetic Condition:

Albinism is a genetic condition in which a person lacks the gene for producing melanin - the pigment that protects the skin from ultraviolet light from the sun. Persons with albinism (PWAs)¹ may lack pigmentation in the skin, eyes and hair.

The exact prevalence of albinism in the human race is not clear but estimates say that the ratio is about 1 in 17,000². It is, however, more prevalent in some parts of the world than in others. In Denmark, the prevalence is estimated at a ratio of 1:60,000. In parts of Nigeria, the prevalence is put at 1: 1100 while in South Africa it is estimated at 1:3900. In Tanzania it is estimated that the prevalence stands at around 1:3,000. Estimates for Tanzania quote the total population of persons with albinism at about 170,000³. Statistically, Africa seems to have a high prevalence of people born with albinism. That said, it is important to understand that albinism is found in all races and not just among the people of the black race.

The gene that carries albinism is a recessive gene or a gene that it is not dominant. The recessive gene for albinism becomes expressed only when two parents carrying the recessive genes pass them to the child.⁴ The albinism gene may 'hibernate' for generations only to spring back when a child who carries the recessive genes is born. There are several classes, types and sub-types of albinism defined by level of lack of melanin and body parts affected.⁵

2.0 The Visible Minority: Myths and Misconceptions:

In most communities across the world, albinism is hardly (or not) understood. Myths and misconceptions surround the condition. However this is amplified in the sub-Saharan Africa largely because the light skin tone of PWAs stands out sharply in communities whose members are predominantly dark skinned. In some parts of sub-Saharan Africa, the condition was traditionally thought of as 'a curse' or as some form of 'punishment' from the gods or the ancestors for something wrong done by the parents. In some communities, it was thought that there was something wrong with the mother. For centuries, children born with albinism have been routinely killed immediately after birth by parents and mid-wives. Myths about albinism continue to persist in many parts of Africa.

¹ This paper uses the term 'Persons With Albinism (PWAs)' rather than the term 'Albino(s)' which has been labeled as demeaning and offensive by various quarters of the community of PWAs for failing to appreciate their humanity first before the condition. Also, while there could be an urge to describe them as 'Persons Living With Albinism,' this description includes even those who are carriers of the recessive gene of albinism but are pigmented and it is therefore not appropriate.

² *Albinism Incidence, Causes and Types*, <http://www.medindia.net/patients/patientinfo/Albinism-Incidence-Causes-Types.htm>

³ Color foundation/Wiete Westerhof, *Life of Albinos in East Africa Threatened: A most Bizarre and Dramatic Consequence of having a Skin Color Disease*, <http://colorfoundation.org/>

⁴ Sometimes a person can be born with albinism due to one parent, usually the father, having a dominant X-linked albinism gene.

⁵ For more information, please visit: NOAH - http://www.albinism.org/publications/what_is_albinism.html

Without enough information on the condition, parents, families and communities have been at pains to explain the condition when a child with albinism is born. Peter Ash, the founder of

Under The Same Sun (UTSS), a charitable organization working towards helping people with albinism, as quoted in The Epoch Times says:

“The idea behind it is that albinos look different, particularly in Africa because it's not a Caucasian country, and 95 per cent of children with albinism are born to parents who are both black. You can imagine if you're black and all of a sudden you have a child who's whiter than most Caucasians and you have no idea that it's a genetic disorder.”⁶

It is this kind of stigma that led to the killing of Esther Moraa, a Kenyan child born with albinism by her mother in August 2010. In court, the mother claimed that her husband had convinced her to kill the baby since she was born with albinism and hence a bad omen and a disgrace to the family. She was jailed for one year but her husband remains at large.⁷

Many women have been divorced by their husbands and shunned by families after giving birth to children with albinism. They have been accused of sleeping with men of other races; of being cursed and unclean; and of being witches. Children with albinism have also been hidden from the public, forbidden from socialising with others and treated as outcasts.

Persons with albinism continue to suffer stigma, prejudice, stereotyping and discrimination in sub-Saharan Africa. It is a condition that cannot be hidden and when a person with albinism is in a group of dark skinned people, he/she stands out as different. They are a visible minority and are in many parts of Africa subjected to open discrimination. Jake Epelle, founder and Chief executive Officer of the Albino Foundation of Nigeria (TAF), as quoted by Kemi Yesufu, says:

“.....from relationships to the workplace, I have come face to face with these problems. I don't know where to start. I have been sent out of a party because I am albino; a woman has rejected me because I am an albino. I have been sacked from the work place because I am an albino.”⁸

Some of the **myths and misconceptions** (sourced from different papers/sites on the web) surrounding albinism in different parts of Africa includes:

- Myth: That the mother slept with a white man.
Fact: This is not true. Children born with albinism may look 'white' due to absent or reduced pigmentation but are not products of cross race relationships.
- Myth: That a child born with albinism is conceived when a woman has intercourse while she is menstruating.

⁶ Joan Delaney, *Albinos under Siege in Tanzania: Witchcraft behind rash of killings* 3 Dec, 2008, Epoch Times, www.theepochtimes.com

⁷ Mars group, *Mother jailed for killing albino baby*, www.marsgroupkenya.org/youth/index.php?option=com

⁸ Kemi Yesufu, *Nigeria: Our Ordeal as Albinos*, <http://allafrica.com/stories/200903190436.html>

Fact: This is biologically impossible.

- Myth: That albinism occurs for people who fail to eat salt.

Fact: Albinism is a genetic condition and has nothing to do with salt.

- Myth: That albinism is a punishment or a curse from the gods or ancestral spirits due to wrongs done in the family

Fact: Albinism is a genetic condition that is passed on from parents to children. Many people are carriers of this recessive gene. Albinism is not a curse.

- Myth: Persons with albinism cannot see during the day but see well at night.

Fact: Persons with albinism have visual impairments due to lack of melanin pigmentation in the retina. They can see during the day and also at night though they may either be short or long sighted and may need sight aids.

- Myth: That people living with albinism are blind

Fact: Persons living with albinism are not necessarily blind but all forms of albinism are associated with some form of vision impairment⁹. However they have enough vision to carry out daily living activities albeit with a variety of challenges.

- Myth: That body parts of persons living with albinism make potent charms that can make people rich and successful

Fact: This is absolutely not true. It is a myth spread by witchdoctors in order to enrich themselves at the expense of others.

- Myth: That drinking the blood of a person with albinism gives extra magical powers

Fact: This is not true. Persons with albinism are just human beings like anyone else and do not possess any magical powers.

- Myth: That having sex with a person with albinism can cure HIV/AIDS

Fact: This is not true. Persons with albinism do not possess any healing powers and any ritual rape or unprotected sex with them will only lead to further HIV/AIDS infections.

- Myth: That albinism is a contagious condition

Fact: Albinism is a genetic condition and is not contagious even with blood transfusion.

- Myth: That a person with albinism cannot have normal pigmented children

Fact: A person with albinism can give birth to normally pigmented children if his/her partner is not a carrier of a similar recessive gene for albinism. The children may be carriers of the recessive gene but it will not be expressed in them.

- Myth: That persons with albinism are sterile.

Fact: This is not true. Persons with albinism are fertile and can have children like other people.

- Myth: That persons with albinism don't die, they simply vanish

Fact: Persons with albinism die like all other normally pigmented people.

- Myth: That persons with albinism are only found within people of black race.

Fact: This is not true as albinism is found in all races. However some parts of Africa seem to have higher prevalence rates than other parts of the world.

- Myth: That persons with albinism normally have a short lifespan.

⁹ In some countries persons with albinism are classified as being 'legally blind'.

http://www.albinism.org/publications/what_is_albinism.html

Fact: This is not true. If enough medical care is given to protect the skin from ultra violet rays of the sun, a person with albinism can attain a normal and productive lifespan.

- Myth: That persons with albinism are mentally retarded and are not intelligent.

Fact: This is not true. Persons with albinism are intelligent and gifted in many different ways. They also perform well academically like other normally pigmented persons. There are teachers, lawyers, politicians and musicians¹⁰ who are living with albinism. However many persons with albinism in Africa do not realize their potential due to discrimination in the education systems.

- Myth: Those children born with albinism are products of incest.

Fact: This is not true. The parents just happen to carry recessive genes for albinism which become expressed in the children. There are many people with recessive genes but they are pigmented.

Myths such as the ones above lead to discrimination which in turn spurs abuses and violations against the rights of persons with albinism

¹⁰ Stephen Brookes, *Salif Keita: From Outcast to Icon*, June 15, 2009, Washington Post, <http://www.stephenbrookes.com/new-writing/?currentPage=6>

3.0 Discrimination, Violations and Abuses against Persons With Albinism in sub-Saharan Africa: An Overview:

Due to misconceptions and myths, persons with albinism in many parts of Africa face stigma and discrimination right from birth and in their day to day lives. Discrimination infringes on their fundamental human rights and basic freedoms. Various forms of discrimination and abuses/violations include:

i) Social stigma and derogatory name-calling leading to prejudice and discrimination:

In many parts of the world, persons with albinism are largely seen as being incomplete. Virginia L. Small, in her paper *Sociological Studies of People of Color with Albinism* (1998) writes:

“Among the few papers being written specifically about the social and psychological status of people with albinism in dark-skinned families and communities was a study published in 1993 in the Dominican Republic. This study and others like it concluded that there was indeed a negative stigma attached to albinism as well as other "special populations". It states that in general, albinism is equated with, and categorized as a blemish, mark, stain, even disfigurement. That is, it is a visual stigma that makes society look at it with suspicion and fear. Unlike any other stigma albinism is the only condition of any type mistaken for mixed race. People with albinism are also perceived to be inscrutable, sinister, less capable or having a character flaw. In the study done the respondents stated that the community basically finds reasons to criticize and reject them. An earlier study was published in 1989 on people with albinism in Nigeria. As in the latter study this concluded that people with albinism may suffer socially and psychologically due to family and society's negative attitudes.”¹¹

The use of derogatory names for persons with albinism has led to prejudice and stereotypes which lead communities to condemn them based on the condition rather than appreciate their humanity first. In East Africa, most of the descriptive terms used to refer to persons with the condition are derogatory and demeaning. They seem to suggest a lesser being. In Kiswahili, a language spoken by millions in East Africa, the name for persons with albinism is *Zeru Zeru* meaning 'ghost like creature' while others refer to them as '*mzungu*' meaning 'white man'.

Jake Epelle the Chief Executive Officer of the Albino Foundation of Nigeria (TAF), in an interview with Yekeen Nurudeen on challenges facing persons with albinism in Nigeria, says:

“If you go into the names we are called you will just know that albinos have suffered untold derogatory insults. Let us take the Yoruba that call us Afin. Afin is not complimentary; it is

¹¹ Virginia L. Small, *Sociological Studies of People of Color with Albinism*, 1998, <http://www.goldenalbinism.com/My%20report.htm>

derogatory. The Igbo call us Ayarin, the Edo people call us Ebo. Akwa Ibom people call us Bakara while the Hausa call us Bature Ntuda. That means fake white man."¹²

Virginia L. Small (1998) writes:

"In the Dictionary of Jamaican English blacks with albinism are specifically targeted by a term known as a "dundus". The dictionary states that a dundus is "an albino Negro; a freak. Someone who is not up to the mark of normality."¹³

Even within the English language, the correctness of the term albino(s) for persons with the condition is currently being questioned.¹⁴ While in some parts of the world the term is accepted, the term is increasingly seen as derogatory because it puts the condition ahead of the person.

Ero I. K. of Under The Same Sun, commenting on this paper, wrote

Even though the term "albino" remains in use today as a valid word, it is important to mention that it is a high point of contention in the community of persons with albinism (PWAs). Some PWAs have argued that it is an offensive label as it characterizes a human with his condition instead of putting him first as one who is more than the condition.

In her comments on this paper, Virginia Small wrote:

Old ways of describing people who are different have almost always been derogatory. That is true of the word 'albino.' It describes the condition without mentioning the person. Therefore it is better to use 'person with albinism' rather than 'albino'. Also, people, even medical professionals use the term "suffers from." This is also incorrect. I do not suffer from my albinism."

Mumbi Ngugi of Albinism Foundation of East Africa, in her article, *They Call Us 'Albinos' – The Right to Mock and Kill Fellow Humans*, writes,

"We have to deal with a society that is largely silent about our plight, and media that refuse to find a way of referring to us in ways that can bring to the fore our humanity, rather than our genetic condition. For that is the only thing "wrong" with us. In a world where colour has defined so much of people's fate, from slavery to colonialism, we are in the unfortunate

¹² Yekeen Nurudeen, *All Nigerian tribes hold albinos in Derision*, 23 April 2010, www.compassnewspaper.com/.../index.php?.

¹³ Virginia L Small, *Sociological Studies of People of Color with Albinism*, 1998, <http://www.goldenalbinism.com/My%20report.htm>

¹⁴ *Is The Word Albino Derogatory?* www.suite101.com/content/is-the-word-albino-derogatory-a91274 and NOAH: <http://community.albinism.org/forums/p/8494/39175.aspx>

position of not having been born with any, or with very little, and thus remain eternal outsiders”¹⁵

In order to shun out any prejudice against persons with the condition, it is agreeable that they should generally be referred to as **Persons With Albinism (PWAs)**.

The demeaning and derogatory names and terms against persons with albinism leads to discrimination based on color which is against the rights guaranteed in the *Universal Declaration of Human Rights (UDHR)* and all other major international and regional human rights instruments which variously state that no one shall be discriminated against on the basis of color, birth, health, or other status.

With regard to marriage and the right to found a family, persons with albinism have been treated with stigma for generations. Whereas people who are pigmented find it relatively easy to find partners, those with albinism are routinely forced to lead their lives single because no one wants them or families refuse to sanction relationships. They suffer rejection by the community. Jake Epelle of Nigerian Albinism Foundation is quoted:

“Are you talking about relationships? Most albinos who are men struggle to get wives while those who are women struggle to get husbands. When you go to some people they will say I can marry an albino and I used to advice such people that you better be careful because the pressure may not be from you. You may just see him light in skin and you are in love but when you get home your parents will reject him. Your friends will reject him.”¹⁶

The denial of the right to found a family goes against the spirit of the Universal Declaration of Human Rights and other international human rights instruments that guarantee the right of consenting adult persons to marry and found a family. The situation of PWAs is complicated by the fact that they are advised against marrying persons with the same condition due to the fact that they will eventually have children who have the condition due to the recessive genes they carry.

The stigma suffered by people with albinism has spread further with modern day media. As Virginia L. Small (1998) writes:

“The mystique of albinism still intrigues people who exploit the condition in many genres. Modern movies, novels, television programs, etc. still insist on using albinism for its shock value. Rather than present the facts about the condition since these do not lend themselves

¹⁵ Mumbi Ngugi, *They call us ‘Albinos’ – The Right to Mock and Kill Fellow Humans*, <http://allafrica.com/stories/201008210123.html>

¹⁶ Yekeen Nurudeen, *All Nigerian tribes hold albinos in Derision*, 23 April 2010, www.compassnewspaper.com/.../index.php?..

to an interesting story. Instead, storytellers choose to use the physical appearance of albinism to invent their own fantasies, and expose their own superstitions and fears.”¹⁷

This is an abuse of the rights of persons with albinism. Their dignity as human beings does not diminish just because they have the condition of albinism.

ii) **Gender-based sexual violence:**

In southern Africa countries, ritual defilement and rape of girls and women with albinism has been reported. Cases are known from Zimbabwe, Swaziland, and South Africa¹⁸. The myth that having sex with a woman with albinism can cure HIV/AIDS has fueled this form of violence. The shocking trend has left the victims contracting HIV which complicates their health and psychosocial condition. For women and girls with albinism, sexual violence makes theirs a case of multiple tragedies. Firstly, women rights are yet to be realized in largely patriarchal traditional communities. Secondly, being born with albinism means stigma from birth which is normally accompanied by skin and sight problems and poverty. Being targeted for ritual rape as a cure for HIV/AIDS, and the infections that follow, only aggravates the situation of the victims and this calls for urgent action from governments, communities and international actors. Defilement and rape are infringements on the dignity of a woman and an abuse of the rights to safety and security of the person.

iii) **Killings and harvesting of body organs:**

Recently, killings of persons with albinism in East Africa and southern Africa, especially in Tanzania, has woken up the world to the threats facing people with the condition¹⁹. Reports from various sources indicate that about 100 persons with albinism may have been killed in Tanzania and Burundi in the past few years. The killings are done in order to harvest body parts which are used in making of charms by traditional witch doctors. It is believed that charms made with body parts of persons with albinism, especially hair, genitals, limbs, breasts, fingers, the tongue and blood make strong magic portions which sell for more²⁰. In Tanzania, organs can go for a high price. Mr Ash of UTSS says, “a leg or an arm can fetch between US\$1,000 and US\$3,000 — big money in a country where the annual average income is just \$800”²¹. The killings are known to peak during election times as

¹⁷ Virginia L Small, *Sociological Studies of People of Color with Albinism*, 1998, <http://www.goldenalbinism.com/My%20report.htm>

¹⁸ Color foundation, *Life of Albinos in East Africa threatened: A most bizarre and dramatic consequence of having a skin color disease*, <http://www.colorfoundation.org/>

¹⁹ UTSS, *Persons with albinism in Tanzania face several major challenges*: <http://www.underthesamesun.com/home.php>

²⁰ Rachael Pollock, *Albino Killings in Tanzania related to Ancient Tribal Beliefs* www.mediaglobal.org/.../albino-killings-in-tanzania-related-to-ancient-tribal-beliefs

²¹ Joan Delaney, *Albinos under Siege in Tanzania: Witchcraft behind rash of killings*, 3 Dec 2008, Epoch Times, www.theepochtimes.com

demand increases for magical portions by politicians seeking election or re-election²². Killings have been reported in Kenya, Uganda, Congo and Burundi possibly to sell the organs in Tanzania. The trend has now hit southern African countries with killings reported in Swaziland and Zimbabwe. Similar cases have been reported in Mali, West Africa. Also, people in Benin believe that blood of persons with albinism has magical properties and that it brings prosperity and luck. The fingers of persons with albinism are worn on necklaces around people's necks as amulets.²³

The demand for body parts of persons with albinism has also spurred inhumane attacks. Victims have been attacked and their limbs hacked off and left to die. Those who have survived have undergone trauma as they contemplate their safety. Mariam, a 28-year-old Tanzanian woman with albinism who was pregnant, miraculously survived an attack in October 2008 in which both her arms were hacked off. The attackers left her for dead. She later had a miscarriage²⁴. A certain Abdallah was tilling in his farm when he was attacked by men who hacked off one of his hands and disappeared. He can no longer till the land for himself and he lives in fear that the attackers would come back for his other limbs. In Burundi, families with PWAs have been attacked with guns and grenades and their body parts chopped off²⁵.

Trade in organs of persons with albinism has also lead to human trafficking across East African countries. The case of the attempted 'sale' of a person with albinism, Robinson Mkwama, 20, by his Kenyan friend, Nathan Mutei, brought this illegal trade to world attention. Mutei tried to 'sell' Mkwama for US\$250,000 to a witch doctor in Tanzania²⁶. When he was caught in a sting operation by Tanzanian Police, he admitted that he was selling him so that his body parts could be harvested for making charms. Mutei was jailed for a total of 17 years by a Tanzanian court. Human rights groups protested and called for stiffer sentences since the sale would have resulted in the murder of a human being. This case brought to light the inhumane trade in persons with albinism in East Africa and perhaps other regions of Africa. Others may have been killed or mutilated in neighboring countries and their body parts smuggled into Tanzania.

Human trafficking of persons with albinism is an affront on the sanctity and dignity of the human body as guaranteed under international human rights law.

Even in death, persons with albinism cannot rest in peace in some parts of Tanzania. Organ hunters often desecrate their graves and rob off the body parts. Joan Delaney writes:

²² Makulilo, Earnest Boniface, *Albino Killings in Tanzania Illogical and Racism*
<http://sandiego.academia.edu/makulilo/Papers/155503/ALBINO-KILLINGS-IN-TANZANIA> .

²³ Lajla Mlinarić Blake, *Spain Saves Albino African from Sure Death*
<http://dalje.com/en-world/spain-saves-albino-african-from-sure-death/249734>

²⁴ UTSS Honor Roll, <http://www.underthesamesun.com/docs/survivor-honour-roll.pdf>

²⁵ BlogSpot, UTSS Press Release, *Appetite for albino body parts continues unabated in Tanzania and Burundi: 7 more slaughtered in just weeks*, albinos-in-tanzania.blogspot.com/.../appetite-for-albino-body-parts.html

²⁶ Daily nation, *Man in plot to sell albino imprisoned*, 18 August 2010, www.nation.co.ke/

“To add insult to injury, after the torso of the victim is buried the attackers will often return and raid the grave for the bones and additional body parts. To prevent this, the graves have to be cemented over or the victims buried inside the home.”²⁷

Persons with albinism deserve the same rights to safety and security as any other people. The savage attacks and killings have greatly curtailed their freedom of movement and residence as they hide in fear. This has serious impacts on their psychological status as well as on their economic status since they cannot attend to their daily activities in peace. Pupils with albinism have been withdrawn from schools or are put under police escort. This affects their education since they cannot concentrate on education due to fear of attacks.

iv) Lack of appropriate medical attention:

Because of lack of melanin pigment, persons with albinism are pre-disposed to health problems of the skin and vision. Skin cancer cases are higher in persons with albinism due to the effect of ultra violet rays from the sun which causes lesions. To lessen the effects of the sun, persons with albinism need to apply sunscreens, wear hats and use special sunglasses which are costly and in most rural areas, unavailable. Many governments have failed to ensure access and affordability of these vital items. The national health systems have failed to factor in the needs of persons with albinism adequately.

As Virginia L. Small (1998) writes:

“Aside from the sociological problems faced by people with albinism in underdeveloped and developing countries, health care is poor because the condition may not be seen as a true health concern. In these areas of the world, governments and the health structure may sometimes provide persons with albinism with glasses, but not sunscreen, special low vision aids, or sunglasses making it almost impossible for a person living with albinism to spend much time outdoors. The health and employment structure may not help with getting an indoor job.”²⁸

The right to health is a basic human right and persons with albinism should be factored in the national health systems as a special category.

v) Discrimination in employment:

Persons with albinism are routinely shunned from employment by both private employers and governments due to their condition. They are thought of as being incapable or as being a burden. Sometimes, they are employed but assigned tasks that require them to work for a long time in the sun which exposes them to the risk of developing skin cancer. The condition also causes sight

²⁷ Joan Delaney, *Albinos under Siege in Tanzania: Witchcraft behind rash of killings* 3 Dec, 2008, Epoch Times, www.theepochtimes.com

²⁸ Virginia L. Small, *Sociological Studies of People of Color with Albinism*, 1998, <http://www.goldenalbinism.com/My%20report.htm>

impairments which mean that most PWAs can not pass the vision component of a driving test yet some employers invariably request drivers licenses even when such a criterion might not be necessary to fulfil the post. Also PWAs, even when qualified, are routinely discriminated against. Jake Epelle of TAF, Nigeria, is quoted:

“From our last courtesy visit in Lagos, one of us was the second best student in the Nigerian Defence Academy (NDA) examination nationwide and they told him to his face that “yes you passed well but you are an albino we can’t take you”. The person in question is my coordinator in Calabar, his name is Bassey. I’ve several (*such*) complaints”²⁹

These factors make it hard for persons with the condition to find an employment as they are shunned by employers including governmental bodies. This is against international human rights law that guarantees non-discrimination based on color and the rights to equal treatment for all and to a safe, meaningful employment.

vi) **Discrimination in education systems:**

For years, learning institutions in Africa have put students with albinism under the same conditions as other students without taking into account the visual impairment associated with the condition. In other instances, students with albinism are taken to schools for the blind while they are not blind. Poor vision may cause students with albinism to be slow learners either due to inability to see the black board clearly or inability to read books and other learning materials.³⁰

The colours used in writing also matter because students with albinism have a problem with contrast. The text books and exam papers are mostly printed in normal fonts which may be hard for students with albinism to read quickly. Persons with albinism have a medical condition known as nystagmus or pendulous nystagmus. It sometimes makes the words wiggle on the page and makes it hard to focus on small narrow print.

Students with albinism have also been required to finish exams at the same time as other pigmented students whose sight is normal. These conditions have led to poor academic performances and low education levels for persons with albinism. This in turn denies them livelihood options hence the abject poverty that many live in. Lack of education and life skills also limits their active participation in local, national and international affairs. Mumbi Ngugi of Albinism Foundation of East Africa writes:

²⁹ Yekeen Nurudeen, *All Nigerian tribes hold albinos in Derision*, 23 April 2010, www.compassnewspaper.com/.../index.php?..

³⁰ Please see UTSS, *Albinism Guide for Teachers and Educators of Persons with Albinism*, www.underthesamesun.com/documents/Media-Pack-2010.pdf

'We have to battle skin cancer because we do not have melanin, yet most of us cannot get adequate education, and even if we do, getting employment is a major challenge. So we end up working in the sun, as farmers or hawkers, and die before our 30th birthday.'³¹

Some families, out of ignorance and due to stigma have also failed to take children with albinism to school in order to hide them from the public or thinking that they are not intelligent enough.

Education is a basic right for all and persons with albinism should not suffer exclusion. Any State/government that fails to ensure the fulfillment of this right for persons with albinism is violating international human rights law.

vii) Attacks on persons protecting/defending persons with albinism:

Many persons, especially family members have been harmed or even been killed while trying to stop attacks on persons with albinism. Cases have been recorded from Tanzania and Burundi where attackers brutalized family members of persons with albinism.³²

A Tanzanian journalist, Vicky Ntetema, (also the current Executive Director of Under The Same Sun), was threatened for working to unravel the killing of persons with albinism in Tanzania. She was working on a sting operation to unravel the use of organs from persons with albinism by witchdoctors in Tanzania when she started receiving threats on her life. In her reports to the BBC, she reported that the slaughter of persons with albinism in Tanzania was for ritual purposes and that clients included some police officers, rich people and politicians. She had to flee the country for her life twice. For her investigations, the International Women's Media Foundation gave her the 'Courage in Journalism' Award of 2010.³³

³¹ Mumbi Ngugi, *They call us 'Albinos' – The Right to Mock and Kill Fellow Humans*, <http://allafrica.com/stories/201008210123.html>

³² UTSS Honor Roll, <http://www.underthesamesun.com/docs/survivor-honour-roll.pdf>

³³ BBC News, *Vicky Ntetema Wins Bravery Award for BBC Albino Report*, <http://news.bbc.co.uk/2/hi/africa/8428688.stm>

4.0 The Call for Special Rights:

Article 1 of the Universal Declaration on Human Rights (UDHR)³⁴ clearly states that 'all human beings are born free and equal in dignity'. **Article 2** states that everyone is entitled to the rights and freedoms set therein, 'without distinction of any kind, such as, race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.' These guarantees are also found in the *International Covenant on Civil and Political Rights (ICCPR)* and the *International Covenant on Economic, Social and Cultural Rights (ICESCR)*. Most of African State-Members of the United Nations have ratified these two Covenants. The regional international human rights instrument, the *African Charter on Peoples and Human Rights (ACPHR)* clearly states in **Article 2** that "Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, color, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status."³⁵

The *UN Convention on Elimination of All Forms of Racial Discrimination (CERD)* defines racial discrimination as 'any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and

fundamental freedoms in the political, economic, social, cultural or any other field of public life.' Based on this definition, persons with albinism can contest the discrimination they face on the grounds of skin color due to the reduction or absence of pigmentation.

The *UN Convention on the Rights of Persons with Disabilities (CRPD)* defines persons with disabilities as 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. Persons with albinism qualify to be considered as a special category of persons with disabilities and affirmative actions instituted by States towards their welfare and health.

States have the obligations to respect, protect and fulfill the rights of all persons under their jurisdiction³⁶. Failure to ensure that rights and fundamental freedoms are realized even for minorities such as persons with albinism amounts to violation of their civil rights. Failure to take action against perpetrators who discriminate, kill or harm persons with albinism also amounts to failing the concept of due diligence and is an abdication of duty. Normally pigmented persons

³⁴ www.un.org/en/documents/udhr

³⁵ www.hrcr.org/docs/Banjul/afrhr.html

³⁶ Amnesty International, Special Programme on Africa, *Haki Zetu: ESC rights in Practice, Main Book*, http://www.amnesty.nl/in_actie_vervolg/spa

should not be allowed to abuse the rights of persons with albinism on basis of discriminatory cultural beliefs and stigma.

The guarantee of rights for all human beings should be activated in the call for special protection of persons with albinism. They should enjoy all rights guaranteed in domestic constitutions as well as international and regional human rights instruments. These rights include: right to safety and security of person; freedom from non-discrimination; right to life; freedom of movement and residence; right to employment; right to family; right to health; and right to education. Beyond those basic rights, people living with albinism should be accorded special treatment and consideration as happens to those with physical disabilities and other minorities. These 'sub-rights' are affirmative action aimed at according full dignity to persons living with albinism in any human rights compliant State.

TABLE 1

DEFENDING RIGHTS OF PERSONS WITH ALBINISM – A CASE EXAMPLE OF THE NEW CONSTITUTION OF KENYA (2010):

Persons with albinism in Kenya now have constitutional backing when claiming or defending their rights. **Article 260** of the new Constitution of Kenya (2010), defines disability as “any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have, a substantial or long-term effect on an individual’s ability to carry out ordinary day-to-day activities’. Persons with albinism perfectly fit in this definition.

Under **Article 27 (4), (5) (Equality and freedom from discrimination)**, it is stipulated that: ‘**4)** The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth. **5)** A person shall not discriminate directly or indirectly against another person on any of the grounds specified or contemplated in clause (4).’ The same Article obliges the State to take legislative and other measures including affirmative action programmes and policies designed to redress any disadvantage suffered by individuals or groups because of past discrimination.

Under **Special Application of Rights, Article 54** gives special recognition to persons with disabilities in order to preserve their dignity. It guarantees the rights to be treated with respect, and in particular, demands that they be referred to in a manner that is not demeaning. It also stipulates that persons with disabilities are entitled to rights such as : access to education; that facilities for persons with disabilities be integrated into society to the extent compatible with the interests of the person; reasonable access to all places, public transport and information; to use sign language, Braille, or other appropriate means of communication; to access materials and devices to overcome constraints arising from the person’s disability; and that the State should ensure the progressive implementation of the principle that at least five per cent of members of the public in elective and appointive bodies are persons with disabilities.

Persons with albinism in Kenya could use these constitutional provisions, alongside several other Articles in the new Constitution that guarantee rights of persons with disabilities, to defend their rights and dignity, fight stigma and discrimination, and push for more participation in local and national affairs.

4.1 Proposed Special Rights and Treatment:

This paper proposes that African States/governments ensure affirmative action for persons with albinism by according special rights in the following areas:

1. Special rights in education systems:

- Special considerations in schools and colleges – This includes allowing students with albinism to sit at strategic positions in the classroom, the use of readable writings and fonts, allowing extra time for students with albinism to complete tasks and increased attention on such students from teachers. Students with albinism should be given extra time to complete exams.³⁷
- Exemption from paying fees or offering of subsidies in costs of education and training for skills for persons with albinism, especially those from poor rural areas as an affirmative action.
- Development of special courses for life skills tailored for persons with albinism in order to deal with poverty associated with the condition.
- States to ensure the provision of reading aids such as handheld magnifiers and monoculars for students with albinism.

2. Special rights to health:

- States to ensure free or subsidized provision of sunscreens, low vision aids and sunglasses for persons with albinism especially for the poor in the rural areas.
- Removing all customs duty for all provisions associated with albinism including sunscreens, sun-protective clothing and sight aids.
- States to provide free treatment for skin cancer cases and free anti-retroviral therapy for women with albinism who are infected with HIV/AIDS.
- States to ensure free provision of prosthetics for persons with albinism who have had their limbs amputated by organ harvesters
- States to ensure the development of counseling and trauma healing centers for persons with albinism who have undergone traumatic experiences such as defilement, rape, amputations of limbs or who have been infected with HIV/AIDS especially after ritual rape.

3. Special rights to safety and security:

- Development of rescue centers in hotspots where persons with albinism are threatened. This includes timely and coordinated rescue for persons with albinism who are threatened by organ hunters.
- Sustained security in hotspot areas where persons with albinism are threatened especially for students with albinism.

³⁷ For more on this please see: UTSS, *Albinism Guide for Teachers and Educators of Persons with Albinism*, www.underthesamesun.com/documents/Media-Pack-2010.pdf

- Strict enforcement of laws protecting life including formation of special law enforcement teams to deal with cases of murders and mutilations of persons with albinism in hotspots especially in eastern and southern African countries.
- Enacting strict laws to deal with perpetrators who traffic in persons or organs of persons with albinism. States should pass laws to counter trafficking in persons to deter cross border trade in persons with albinism
- States to ensure effective redress for victims (and families) who have been traded or have suffered harm, death or discrimination due to the condition of albinism.

4. **Special social-economic rights:**

- States to ensure sustained education of the general population, including those in the medical profession, through all media on the genetic condition of albinism and how to integrate persons with albinism in mainstream society so as well as to deal with stigma and myths that lead to prejudice and discrimination.
- States to actively ensure that persons with albinism are not discriminated against during employment by both governmental agencies and private employers. This includes the affirmative action of employing persons with albinism in their respective civil service structures. States should undertake affirmative action in order to mainstream persons with albinism in the local and national structures including promoting the active participation of people living with albinism in socio-political and cultural processes.
- State authorities to ensure special protection of labour rights of persons with albinism in places of employment so that they are not unduly exposed to the sun by virtue of their employment which exposes them to the development of skin cancer.
- States to undertake periodic census of persons with albinism in order to ensure availability of data on their population, location and their welfare. This will facilitate timely action and coordinated assistance for both the government and for non-governmental organizations.
- States to undertake sustained education for persons with albinism and their families in order to make them aware of best practices regarding their condition and empower them to make informed life choices
- States to avail and ensure accessibility of grants and collateral-free loans to persons with albinism in order to enable them initiate income generating micro-enterprises that help alleviate poverty.

States, regional political federations and the African Union should formulate guiding principles on the special rights category for persons with albinism stating such rights and defining the obligations of governments in ensuring the respect, protection and fulfillment of those rights. In particular, the East African Parliament, which has condemned the slaughter and trafficking of persons with albinism in Tanzania, Kenya and Burundi, should work together with member states, albinism organizations and other civil society actors to come up with guiding principles which member states should use to develop mechanisms for the protection of special rights for persons with albinism.

All States should also domesticate or constitutionalise the various international human rights instruments that guarantee rights to special categories of persons, in particular, the *Convention on the Rights of Persons with Disabilities (CRPD)*, the *Convention on Elimination of All forms of Discrimination Against Women (CEDAW)*, the *Convention on the Rights of the Child (CRC)* and the *Convention on the Elimination of All Forms of Racial Discrimination (CERD)*. Domestication of such international human rights instruments will facilitate persons with albinism to defend and claim their rights and fundamental freedoms using domestic law and mechanisms.

In order to enhance policy and practice changes, donor agencies should also use, as a yard stick, the criterion of how a state treats its population of persons with albinism when determining the level and possibility of funding of various initiatives. This will lead to increased attention to this particular minority by governments.

States with strong mechanisms of protection of rights also have an obligation to offer asylum to persons who face discrimination and killings due to the condition. Recently, Spain has granted persons living with albinism from Mali and Benin asylum based on grounds of discrimination at home due to the condition³⁸.

4.2 Roles of Individuals, Media and Non-Governmental Organizations and Agencies:

Individuals, international human rights organizations and aid agencies should also come in to help persons with albinism in Africa. They have the obligation to help in funding, lobbying, advocacy and influencing policy and practice changes. This will ensure increased and sustained civic education on albinism so as to do away with myths surrounding the condition.

Increased funding from international agencies should also be geared towards the welfare, education and health of persons with albinism. The provision of sun screen lotions, special sunglasses, magnifiers and other aids should be the concerted effort of all actors. This also includes availing micro enterprise funds for persons with albinism to assist them to start income generating activities in order to alleviate extreme poverty associated with the condition.

Non-state actors should also assist persons with albinism to establish their own organizations at local, national and regional levels in order to make their voices heard. With facilitation and capacity building, these organizations run by persons with albinism will become strong instruments in the process of lobbying and advocating for policy and practice change. Where legal redress is sought by federations of persons with albinism, for instance to pursue cases of violations of rights at the *African Commission on Human and Peoples' Rights* against governments, international actors should readily offer technical, material and financial assistance.

³⁸ Lajla Mlinarić Blake, *Spain Saves Albino African from Sure Death* <http://dalje.com/en-world/spain-saves-albino-african-from-sure-death/249734> and *Spain grants asylum to albino African*, http://www.typicallyspanish.com/news/publish/article_24439.shtml

The mass media (print and electronic) should educate their readers on the condition of albinism and on the need to integrate and embrace persons with albinism as part of society. This should also include promoting of favorable names and shunning the use of derogatory or demeaning terms used to refer to persons with albinism. The mass media can also be a powerful tool to lobby governments in Africa to ensure respect, protection and fulfillment of special rights for persons with the condition.

Those in the medical profession should also help in demystifying the condition. They should explain the cause and the best practices to parents and families with children born with albinism. They should also be trained in the area of counseling and trauma healing for persons with the condition who have suffered attacks. This is especially needed and should also be included in the healthcare systems of regions where attacks have routinely occurred. Medical terminologies should also be tailored to reflect the person first rather than the condition.

5.0 Conclusion:

All persons are born free and equal in rights and dignity. Persons with albinism are human beings and they deserve all rights and freedoms enjoyed by normally pigmented persons. They are part of the human society and the diversities that make it. When they suffer discrimination, violations, and abuses, the human race suffers too. Their genetic condition requires that the society treats them as a special minority. Special sub-rights to safety, health, education, meaningful employment and non-discrimination should be ensured. Governments, medical profession and organizations, civil society groups, the media and individuals of good will should help PWAs achieve their aspirations in consideration of their challenges in terms of health – skin and vision – as well as the general stigma that they experience.

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Glossary:

Human Rights – These are universal entitlements attained at birth, and which guarantee dignity and fundamental freedoms for every person in order to live like a human being. They are inherent and are not granted by the State.

Violations – These are breaches of international human rights law by state actors e.g. police officers or government officials.

Abuses – These are breaches of international human rights law by non-state actors e.g. civilians, militia groups or multi-national companies.

Due diligence – This is the concept that the State/government has the duty to protect individuals from abuses by non-state actors by providing the degree of care that a prudent person would exercise. This is achieved through: formulating laws that prohibit the abuses; informing the public about them; setting up monitoring systems; and ensuring that victims have access to courts and free legal aid if needed.³⁹

Stigma – This is an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one.

Prejudice - An opinion or judgment formed without due examination; without just grounds, or before sufficient knowledge.

Stereotypes - A stereotype is a commonly held public belief about specific social groups or types of individuals based on some prior assumptions that are unfounded.

Discrimination-This is treatment/action taken toward or against a person of a certain group in consideration based solely on class or category. It is the *actual behavior* towards another group. It involves excluding or restricting members of one group from opportunities that are available to other groups. It involves exclusion or rejection.

Nystagmus – This is an optical condition affecting persons with albinism that makes the eyes either rock slowly or jerk back and forth.

Photosensitivity – This is a natural reaction to sunlight that causes inflammation of the skin. It is sometimes referred to as ‘sun allergy’ or ‘sun sensitivity’. Persons with albinism have photosensitivity due to lack of melanin which protects the skin from the effects of ultra violet rays from the sun.

³⁹ Amnesty International, Special Programme on Africa, *Haki Zetu: ESC rights in Practice, Main Book*
www.huridocs.org/resource/2132/

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Links:

The following are important links on organisations/subject of Albinism:

Albinism Foundation of East Africa - www.albinismfoundationea.com/

Albinism Incidence, Causes and Types,
www.medindia.net/patients/patientinfo/Albinism-Incidence-Causes-Types.htm

Color Foundation - <http://www.colorfoundation.org/>

The National Organization for Albinism and Hypopigmentation (NOAH) -
www.albinism.org/

The Vision for Tomorrow Foundation - www.visionfortomorrow.org/

Salif Keita Global Foundation – www.salifkeita.us/

Under The Same Sun (UTSS) – www.underthesamesun.com/

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