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Promotion and protection of all human rights, civil,  
political, economic, social and cultural rights,  
including the right to development

## Report of the Office of the High Commissioner for Human Rights on persons with albinism\*

### *Summary*

This preliminary report of the Office of the High Commissioner for Human Rights on the attacks and discrimination against persons with albinism is submitted pursuant to Human Rights Council Resolution 23/13 of 13 June 2013.

In some communities, erroneous beliefs and myths influenced by superstition put the security and life of persons with albinism at risk.

OHCHR has received information from various countries on cases of killings and dismembering of persons with albinism for ritual purposes. It has also collected information on the multiple and intersecting forms of discrimination persons with albinism face worldwide.

States should adopt specific measures to protect and preserve the rights to life, and to security of persons with albinism, as well as their right not to be subject to torture and ill-treatment, and ensure their access to adequate health care, employment, education and justice.

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\* Late submission.

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## I. Introduction

1. In its resolution 23/13, the Human Rights Council expressed concern about attacks against persons with albinism<sup>1</sup> and the widespread discrimination, stigma and social exclusion they suffer. The Council requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to submit a preliminary report to its twenty-fourth session.

2. This report provides an overview of the most serious human rights violations faced by persons with albinism, primarily focussing on ritual killings and attacks they are subjected to. It also highlights the multiple forms of discrimination, stigma and social exclusion faced by persons with albinism, which is of widespread occurrence across the globe.

3. The report generates some preliminary conclusions to guide further work and address attacks and discrimination against persons with albinism. It also contains a number of recommendations to Member States and the international community aimed at ensuring the protection of the rights of persons with albinism.

4. OHCHR welcomes the adoption of resolution 23/13 by the Human Rights Council, which constitutes the first global decision on this matter.

## II. Methodology

5. On 17 June 2013, for the purpose of preparing this preliminary report, OHCHR addressed a *note verbale* to all Permanent Missions to the United Nations Office at Geneva and to all United Nations Agencies, Funds and Programmes to solicit information on: (a) detailed data disaggregated by sex and age of persons with albinism; (b) information on attacks against persons with albinism and on measures taken to ensure their effective protection as well as that of their family members; and (c) information on any type of discrimination against persons with albinism and measures taken to combat it.

6. In addition, OHCHR sent requests for inputs to the report to Special Procedures Mandate-Holders, national human rights institutions, human rights mechanisms of the African Union, and various non-governmental organizations, including associations of persons with albinism.

7. OHCHR is grateful for the 38 replies received, which have informed this preliminary report.<sup>2</sup> Written submissions were received from seven States,<sup>3</sup> four United Nations entities,<sup>4</sup> three Special Procedures Mandate-Holders,<sup>5</sup> the African Commission of

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<sup>1</sup> The term “persons with albinism” refers to person before it mentions its condition and is preferred to the term “albino”, which is often use in a derogatory way.

<sup>2</sup> The original replies are available for consultation from the Secretariat.

<sup>3</sup> Colombia, Ecuador, Guatemala, Irak, Mauritius, Mexico and Thailand.

<sup>4</sup> The Special Representative of the Secretary General on Violence against Children, the United Nations Interregional Crime and Justice Research Institute (UNICRI), the Food and Agriculture Organization of the United Nations (FAO) and the International Seabed Authority to the United Nations.

<sup>5</sup> The Special Rapporteur on trafficking in persons, especially in women and children; the Special Rapporteur on extrajudicial, summary or arbitrary execution; and the Special Rapporteur on the situation of human rights in Eritrea.

Human and Peoples' Rights, three national human rights institutions<sup>6</sup> and 20 civil society organizations.<sup>7</sup>

8. The content of this report is a compilation and review of information from different sources, including those mentioned above, as well as information received from OHCHR field presences. The particular focus on Africa is explained by the fact that according to the information received, all cases of ritual attacks against persons with albinism have occurred in African countries. The written submissions and information gathered, including from United Nations sources, refer mainly to this region.

9. The collection and verification of cases of ritual attacks is a challenge due to the secret nature of witchcraft rituals, the inability and/or fear of victims' relatives to report such incidents, as well as the limited capacity of associations of persons with albinism to monitor human rights violations.

### III. Definition

10. Albinism is a rare, non-contagious, genetically inherited condition present at birth. In almost all types of albinism,<sup>8</sup> both parents must carry the gene for it to be passed on, even if they do not have albinism themselves. The condition is found in both genders, regardless of ethnicity and in all countries of the world.

11. Albinism results in lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to sun exposure and bright light. As a result, almost all people with albinism are visually impaired and may develop skin cancer. There is no cure for the absence of melanin.

12. Many types of albinism exist; the most common form is known as Oculocutaneous albinism (OCA) and is affecting the skin, the hair and the eyes. There are different types and sub-types of OCA, with varying degrees of lack of melanin. The main ones are tyrosinase negative (OCA1) and tyrosinase positive (OCA2). In OCA1, there is little or no melanin production. In the more prevalent OCA2 type, particularly in African countries, there is some level of melanin giving rise to sandy coloured hair and light brown irises.

13. Another less common form of albinism is called Ocular albinism (OA) and is only affecting the eyes. A more rare form of albinism is known as Hermansky-Pudlak Syndrome (HPS) and is accompanied by bleeding disorders and large bowel (colitis) and lung diseases.

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<sup>6</sup> The National Human Rights Commission of Mexico, the Ombudsman of Panama and the National Human Rights Commission of Togo.

<sup>7</sup> Albinism Empowerment Network, Albinism Fellowship of Australia, Albinos Sans Frontières (Burundi), Bien-Etre des Albinos de Côte d'Ivoire, Confédération nationale des Albinos de Guinée, Ecran Total (Cameroon), Foundation Mwimba Texas (RDC), L' Association Burkinabè pour l'intégration des personnes Albinos, L' Association des femmes Albinos Espoir (Burundi), L' Association nationale des Albinos de Côte d'Ivoire, L' Association nationale des Albinos du Sénégal, L' Association nationale des Albinos du Togo, L' Association pour la promotion des Albinos au Cameroun, L' Organisation mauritanienne pour l'appui et l'insertion des Albinos, RCN Justice & Démocratie (Belgium), The Association of Gambia Albinos, Witchcraft and Human Rights Information Network (WHRIN), Rotary International, Somali-Canadian Cultural Society of Edmonton and Under The Same Sun (Canada). The Salif Keita Global Foundation made an oral submission in a meeting with OHCHR.

<sup>8</sup> The exception is one type of ocular albinism, which is passed on from mother to son.

14. The prevalence of albinism varies across the world. Reports suggest that in North America<sup>9</sup> and Europe it is estimated that 1 in every 20,000 people have some form of albinism.<sup>10</sup> Epidemiologic data on albinism from a public survey in African countries, published by the World Health Organization (WHO) in 2006, mentions that “Epidemiologic data on albinism, such as prevalence, were available for South Africa, Zimbabwe, Tanzania and Nigeria. Prevalence as high as 1 in 1,000 were reported for selected populations in Zimbabwe and other specific ethnic groups in Southern Africa. An overall estimate of albinism prevalence ranges from 1/5,000 – 1/15,000”.<sup>11</sup> According to WHO, the estimated prevalence of albinism suggests the existence of tens of thousands of people living with albinism in Africa. OHCHR did not receive detailed data on prevalence of albinism from any country or region.

#### IV. Attacks against persons with albinism

15. In some communities, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of persons with albinism at a constant risk. These beliefs and myths are centuries-old<sup>12</sup> and are present in cultural attitudes and practices around the world.

16. As mentioned by six Special Procedures Mandate-Holders: “They are regarded as ghosts and not human beings who can be wiped off the global map. They are people living with albinism, the target of many false and harmful myths in several countries, especially in the African region”.<sup>13</sup> In some countries persons with albinism are considered persons that simply vanish. In other countries, they are referred to as apes and a source of money. They are seen as sorcerers, devils or persons suffering from a curse and in some communities, it is believed that contact with them will bring bad luck, sickness or death.<sup>14</sup>

17. Some other frequent myths which threaten the life and physical integrity of persons with albinism are the following: that sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS, that the sacrifice of persons with albinism can appease “the god of the mountain” when a volcano starts to erupt, or that pulling out the hair of a person with albinism brings good luck. It has been reported that miners use bones of persons with albinism as amulets or buried them at the site of drumming gold,<sup>15</sup> and that fishermen weave hair of persons with albinism into their nets to improve their catches.<sup>16</sup> Civil society

<sup>9</sup> The National Organization for Albinism and Hypopigmentation (NOHA) refers to 1 person in 17,000 having some type of albinism in the U.S.A.

[http://www.albinism.org/publications/what\\_is\\_albinism.html](http://www.albinism.org/publications/what_is_albinism.html)

<sup>10</sup> Estimates from UTSS submission.

<sup>11</sup> Esther S Hong, Hajo Zabeed, Michael H Repacholi. “Albinism in Africa as public health issue”, WHO, 17 August 2006. <http://www.biomedcentral.com/1471-2458/6/212>

<sup>12</sup> UNICEF refers to the human sacrifice of a person with albinism believed to strengthen the power of the king in the Dogon cosmology and in the Bambara Kingdom. Aleksandra Cimpric, “Children Accused of Witchcraft. An anthropological study of contemporary practices in Africa,” UNICEF, Dakar, April 2010, pg.28. [http://www.unicef.org/wcaro/wcaro\\_children-accused-of-witchcraft-in-Africa.pdf](http://www.unicef.org/wcaro/wcaro_children-accused-of-witchcraft-in-Africa.pdf)

<sup>13</sup> See joint press statement issued on 4 May 2013.

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E>

<sup>14</sup> Written submissions from civil society describe the various beliefs and provide examples of derogatory terms used towards persons with albinism.

<sup>15</sup> Deborah Fahy Bryceson, Jesper Bossee Jonsson and Richard Sherrington, “Miner’s magic: artisanal mining, the albino fetish and murder in Tanzania,” *Journal of Modern African Studies*, 48,3 (2010): 369, cited in UTSS submission.

<sup>16</sup> This phenomenon was reported to occur in Lake Victoria in Tanzania (UTSS submission). Similar

organizations denounce the role the film industry plays in promoting and entertaining superstitious beliefs.<sup>17</sup>

18. These various beliefs and superstition lead to various forms of attacks against persons with albinism in many communities. These include ritual attacks, which usually result in death and which involve in some cases trade of organs, trafficking in persons and sale of children; as well as infanticide and abandonment of children.

## A. Ritual attacks

19. This report considers as ritual attacks those attacks reportedly aiming at the use of body parts of persons with albinism for witchcraft purposes.

20. There are beliefs according to which the body parts of persons with albinism would possess magical powers capable of bringing riches and power if used in potions produced by local witchdoctors. As noted in a recent report by the Special Representative of the Secretary-General on Violence against Children: “[persons with albinism] are perceived as a curse from the gods and a charm made from their body parts is considered to have magical powers that bring wealth, success and good luck”.<sup>18</sup>

21. Some even believe that the witchcraft is more powerful if the victim screams during the amputation, so body parts are often cut from live victims, especially children. The use of children is likely linked to the pursuit of innocence which, it is believed, enhances the potency of the witchcraft ritual. Moreover, children are more vulnerable to attacks as they are easy to find and capture and do not have the strength to physically defend off attackers.

22. To date, OHCHR has received information about more than 200 cases of ritual attacks against persons with albinism in 15 countries, from 2000 to 2013. Due to the secret nature of witchcraft related rituals and the vulnerability and stigmatization of the target population, it is believed that many attacks remain undocumented and unreported.

23. The attacks are committed in particularly horrifying circumstances, severely traumatizing survivors and families of the victims. The following examples provide an idea of the nature of these attacks.

24. On 11 February 2013, a 38-year-old woman with albinism was attacked with machetes by her husband and four other men while she was sleeping, and had her left arm chopped off. Her 8-year-old daughter witnessed the attack and saw her father coming out of the bedroom carrying the arm of her mother. The woman survived the attack.

25. On 31 January 2013, a 7-year-old boy with albinism was attacked while he was asleep. The attackers slashed his forehead, right arm, left shoulder and chopped off his left arm above the elbow, using machetes. The child did not survive the attack. His grandfather, a 95-year-old man, was killed while trying to protect his grandson. The child’s father and grandmother were also attacked and survived with serious injuries.

26. In most of the cases documented, attacks involve dismembering the victim’s limbs and result in death. In few other cases the victims are beheaded; genitals, ears, and bits of

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practices were reported in the submission from *L’Association pour la Promotion des Albino au Cameroun* and WHRIN.

<sup>17</sup> Reference is made to the portrayal of albinism in Hollywood and Nollywood (Nigeria) movies. (Submissions from UTSS and WHRIN).

<sup>18</sup> “Protecting children from harmful practices in plural legal systems with a special emphasis on Africa”, joint publication by the SRSG on Violence against children and Plan International, 2012. (SRSG submission).

skin are removed; the tongues are cut out and the eyes and the heart gouged out. Other types of attacks reported include rape for healing purposes.

27. The information on the various cases collected by OHCHR was received from multiple sources, but the level of verification varies in each case. In most cases, the information was received by national and international non-governmental organizations working for the promotion and protection of the rights of persons with albinism, gathered through field work and contacts with family members. Some cases could be confirmed through police records and court verdicts, and few were verified by some OHCHR field presences.

28. According to civil society organizations working on the subject, in countries where witchcraft is practiced, the demand for human body parts tends to increase in the lead up to and during elections, thereby generating higher risks for persons with albinism during these periods.<sup>19</sup>

29. As the body parts of persons with albinism are traded for high prices, it is reported that business people and wealthy members of society foment these ritual attacks.<sup>20</sup> It is also reported that law enforcement authorities fail to properly investigate and prosecute and sometimes cover such crimes. In one of the cases reported to OHCHR, four high and middle-rank police officers were arrested on suspicion of accepting bribery from witchdoctors in order to escape prosecution.<sup>21</sup>

30. The killing of, and attacks –including mutilation– against persons with albinism violate the right to life, the right to security of person and the prohibition of torture and ill-treatment,<sup>22</sup> enshrined in various international human rights treaties.<sup>23</sup> While attacks against persons with albinism are “manifestations of the worst forms of cruel, inhuman or degrading treatment and can never be justified”,<sup>24</sup> they also could qualify as torture, both physical and mental, if the authorities fail to provide the necessary preventive and protection measures.

31. Whether any particular ritual killing or attack against persons with albinism is attributable to a State agent needs to be determined on a case-by-case basis. In addition to cases of direct liability, the State violates its obligation to ensure the right to life and the prohibition of torture and ill-treatment by failing to take appropriate measures to prevent, investigate, prosecute, punish or redress<sup>25</sup> the harm caused by the attacks on persons with albinism committed by non-state actors.<sup>26</sup> The responsibility to protect and prevent is

<sup>19</sup> Submissions from Bien-Etre des Albinos de Côte d’Ivoire, L’Association nationale des Albinos de Côte d’Ivoire, L’Association nationale des Albinos du Sénégal and UTSS. Some cases reported in the media refer to ritual attacks during electoral periods. As an example, see “Swazi Albinos Plead for Protection Ahead of Vote,” Daily Nation, 24 May 2013.<http://www.nation.co.ke/News/world/Swazi-albinos-plead-for-protection-ahead-of-vote/-/1068/1861356/-/item/1/-/blp9q0z/-/index.html>

<sup>20</sup> SRSG on Violence against Children and UTSS submissions.

<sup>21</sup> UTSS submission.

<sup>22</sup> The generic term “ill-treatment” refers to any form of cruel, inhuman or degrading treatment or punishment in accordance with article 16 of the Convention against Torture.

<sup>23</sup> Article 6 (1) of the ICCPR and article 6 (1) of the CRC consecrate the right to life. Article 9 of the ICCPR provides for the right of every person to the security of person. Article 7 of ICCPR and article 37 (a) of CRC prohibit torture and ill-treatment. See also the Convention against Torture.

<sup>24</sup> Supra note 13.

<sup>25</sup> The Committee against Torture considers that the term “redress” in article 14 of the Convention encompasses the concepts of “effective remedy” and “reparation”, entailing the full scope of measures of restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition. See Committee against Torture, General Comment No. 3, paragraph 2.

<sup>26</sup> See Human Rights Committee, General Comment No. 6 (paragraphs 3 and 5) and General Comment

particularly relevant in cases of persons in vulnerable situations, such as persons with albinism, and in circumstances where authorities are aware of the real and imminent danger faced by such persons and communities.

32. Measures taken by some States to address the issue of attacks and discrimination against persons with albinism are analyzed in section D of this chapter.

## **B. Trade of organs, trafficking in persons and sale of children**

33. The killing of, and attacks against persons with albinism with a view to using their body parts for ritual purposes is often related to a trade of organs and, in some cases, linked to trafficking in persons and the sale of children.

34. The secrecy surrounding witchcraft and the underground nature of its associated market make it difficult to find evidence about trafficking of persons and organs. However, the issue has been reported by organizations working with persons with albinism, as well as by United Nations agencies and bodies.

35. A 2010 UNICEF anthropological study of contemporary practices in Africa mentioned that body parts of persons with albinism were commercially traded.<sup>27</sup> In November 2009, in its concluding observations on the Democratic Republic of the Congo, the Committee on Economic, Social and Cultural Rights expressed deep concern that persons with albinism had been killed and their organs used or trafficked for witchcraft ceremonies.<sup>28</sup>

36. The demand for body parts of persons with albinism appeared to be sustained by the high prices that some are willing to pay to obtain them. A 2009 report of the International Federation of Red Cross and Red Crescent Societies (IFRC) mentioned that the market for body parts of persons with albinism was “generated by big-money buyers who use them as talismans to bring luck and above all wealth.” The report added that, according to “senior police officers in Dar es Salaam, a complete set of albino body parts – including all four limbs, genitals, ears, tongue and nose – was fetching the equivalent of 75,000 USD”.<sup>29</sup>

37. There are concerns that the existing market is an incentive for desecration of graves and subsequent robbery of body parts. To date, OHCHR has received reliable information on 19 cases of grave robberies in two countries. The cases were reported by organizations working with persons with albinism, through contacts with family members. Some cases were confirmed by police records.

38. Associations of persons with albinism have alleged that body parts of persons with albinism are traded across borders among some countries in Africa and that, in some cases, the trade of organs is linked to trafficking in persons. However, data is scarce on the subject and difficult to verify.

39. In the review of the third periodic report of Kenya, in 2012, the United Nations Human Rights Committee expressed concern at continuing reports of trafficking in persons for labour, sexual exploitation and for body parts, particularly of persons with albinism.<sup>30</sup> In 2010, a court in Tanzania sentenced a national from another country for kidnapping and

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No. 7 (paragraph 1)

<sup>27</sup> Cimpric, *supra* note 12, p.28.

<sup>28</sup> E/C.12/COD/CO/4 of 16 December 2009, paragraph 19

<sup>29</sup> See IFRC, “Through Albino Eyes”, September 2009.

<http://www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf>

<sup>30</sup> CCPR/C/KEN/CO/3, paragraph 17



trafficking in persons, for trying to sell the man with albinism for \$250,000<sup>31</sup>. The arrest of a man crossing the border with the Democratic Republic of the Congo, carrying the head of a child with albinism in his suitcase, was mentioned in a UNICEF report<sup>32</sup>. Few other cases of cross-border trade and trafficking in persons were reported to OHCHR by multiple sources.

40. In relation with the sale of children, the Special Representative of the Secretary-General on Violence against Children has noted that “In some cases, acts of violence and killings have been committed by members of the family, and children have been known to have been “sold” by their families to outsiders. The absence of adequate registration of vital statistics, such as information on birth and death, further enhances the likelihood of cases going unreported and failing to be investigated”.<sup>33</sup>

41. In its review of Tanzania under the Optional Protocol to the Convention on the Rights of the Child on the Sale of Children, Child Prostitution and Child Pornography, the Committee on the Rights of the Child expressed its deep concern about reports of sale of children for ritual purposes, including ritual killings of children with albinism.<sup>34</sup>

42. While article 3 (a) of the UN Protocol to Prevent, Suppress and Punish Trafficking in Persons refers to trafficking in person for the purposes of exploitation, including removal of organs, it does not apply to cases of trade of organs.

### C. Infanticide and abandonment of children

43. As mentioned by the Special Representative of the Secretary-General on Violence against Children, “Children with albinism are at high risk of abandonment, discrimination and exclusion as a result of the appearance of their skin, and due to disability factors such as impaired eyesight and high susceptibility to skin cancer and other health risks associated with albinism”.<sup>35</sup>

44. Harmful traditional practices of infanticide of children with albinism have been reported in a few East-African tribes.<sup>36</sup> Written submissions received by OHCHR from civil society organizations in African countries, refer to persistent beliefs that children with albinism are a potential source of misfortune and/or the proof of unfaithful wives. As a result, sporadic instances of infanticide still occur and abandonment of children seems to be a common practice.<sup>37</sup>

<sup>31</sup> UTSS submission and court verdict.

<sup>32</sup> Cimpric, *supra* note 12, p.28.

<sup>33</sup> SRSG on Violence against Children submission.

<sup>34</sup> Committee on the Rights of the Child, Concluding Observations, CRC/C/OPSC/TZA/CO/1, 10 October 2008, paragraphs 20 and 21.

<sup>35</sup> SRSG on Violence against Children submission

<sup>36</sup> The Sukuma tribe traditionally killed their babies with albinism as soon as they were born. Over time, the child with albinism was spared from the infanticide and allowed to grow to adulthood but would be buried alive with the Sukuma Chief when the latter died. In the Chagga tribe the new born with albinism were traditionally left in the forests to die. In the Digo and Maasai tribes, new-born children with albinism were killed after a trial by ordeal. See “Children with Albinism in Africa: Murder, Mutilation and Violence”, report submitted to the SRSG on Violence against Children by UTSS. June 2012.

<sup>37</sup> Most of the submissions from civil society refer to the abandonment of children. Submissions from Albinos Sans Frontières, Bien-Etre des Albinos de Côte d’Ivoire, L’Association nationale des Albino du Sénégal and L’Association pour la promotion des Albinos au Cameroun, refer to infanticide.

45. The documentation of these cases is difficult as like in other births considered as “abnormal,” the death of a child considered a curse is perceived as a beneficial act for the family and the community. Thus, the killing is often done in secret and the birth is often unreported.<sup>38</sup> In some cases, a mid-wife would assist in killing the child, announcing that the child was stillborn and burying the child immediately, without the parents seeing it.<sup>39</sup>

46. As mentioned earlier, the general absence of adequate registration of birth and death of persons with albinism hinders the report and investigation of cases of infanticide. A few such cases have been reported to OHCHR by different sources.

47. Article 6 of the Convention of the Rights of the Child consecrates as an inherent right of the child the right to “life, survival and development”, requesting States Parties to take all positive steps towards ensuring its enjoyment. States Parties are obliged to protect all children from infanticide and abandonment, and should take steps towards the abolition of practices which put the life of children under threat, including through the adoption of appropriate criminal legislation.<sup>40</sup>

## **D. Measures taken by States concerned**

48. The State’s obligations to take the necessary measures to prevent attacks and discrimination against persons with albinism are particularly critical due to the vulnerable situation of this group. These measures include the appropriate criminalization of such acts, their investigation, and the prosecution of perpetrators. They also include preventive measures to protect persons with albinism; and measures to ensure the access of survivors and their families to effective remedies, redress and rehabilitation, including health care, shelters and other services.

### **1. Legal response and impunity**

49. In its resolution 23/13, the Human Rights Council expressed concern about the impunity associated with attacks on and killings of persons with albinism.

50. From the cases of ritual attacks received by OHCHR, very little information was available as to the legal status of the cases. While some level of investigation and prosecution seems to take place, sentencing appears to be extremely rare: out of the 72 murders of people with albinism documented in Tanzania since 2000, only five cases are known to have resulted in successful prosecution.<sup>41</sup> While noting the State-party’s commitment to prevent, investigate and prosecute cases of mutilation and killing of persons with albinism, the Human Rights Committee expressed concern about the high number of reported incidents in Tanzania and the limited number of court cases and slow proceedings in this regard.<sup>42</sup> In relation with four reported cases in 2013, in Tanzania, the Attorney General’s Chambers informed OHCHR that a significant number of suspects had been apprehended and charged and that a Special Task Force was assisting law enforcement authorities in the investigation and prosecution of these cases.<sup>43</sup>

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<sup>38</sup> Cimpric, *supra* note 12, p.26.

<sup>39</sup> UTSS submission.

<sup>40</sup> Article 6 of the ICCPR and Human Rights Committee, general comment No. 6.

<sup>41</sup> See press release issued by the High Commissioner for Human Rights on 5 March 2013.

<http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=13074&LangID=E>

<sup>42</sup> CCPR/C/TZA/CO/4, 6 August 2009, 10 October 2008, paragraph 15.

<sup>43</sup> Correspondence received from the Permanent Mission of Tanzania, 21 March 2013.

51. From the information gathered from OHCHR, in Burundi, since 2008, 11 people have been arrested in relation with attacks against persons with albinism, out of whom six escaped and one was convicted. In 2010, in the DRC, two persons were sentenced for the murder of a person with albinism. According to available information from Côte d'Ivoire and Nigeria, two cases have resulted in conviction in each country.

52. Monitoring of court proceedings by civil society actors concerning these crimes is very rare, and associations of persons with persons with albinism often lack the financial means and expertise to conduct legal monitoring activities.

53. According to information received by OHCHR, persons with albinism face significant difficulties in having their cases brought to justice, for the following reasons: the fear of further attacks, reprisals or further stigmatization; difficulties in finding witnesses, due to the ostracism they face within their community and, frequently, the involvement of family and community members in the attacks; lack of awareness of legal rights; lack of financial resources; inadequate capacity of the judicial system to address such cases, and lack of legal aid and adequate legal representation, as well as lack of knowledge of or confidence in the law enforcement and justice systems.

54. As noted by the SRSR on Violence against Children, "The human rights violations committed against children with albinism are of the highest severity. Discrimination, harassment and violence, including cases of mutilation and murder are often met with passivity and are rarely reported, as they take place in remote areas and because such children are perceived as bringing bad luck and being a source of shame to even their own families and communities (...) Mutilation and murders of children with albinism are mostly met by social silence and indifference".<sup>44</sup>

55. The information available to OHCHR indicates that access of persons with albinism to justice, remedies and redress is extremely limited. The right of victims of human right violations to claim redress and reparation is enshrined in most universal<sup>45</sup> and regional human rights instruments.<sup>46</sup> Under this right, States not only have the duty to provide redress for the harm suffered but also need to guarantee equal and effective access to justice.<sup>47</sup> Reparations should be proportional to the gravity of the violation and the harm suffered and could take the form of restitution, compensation, rehabilitation, satisfaction, and guarantees of non-repetition.<sup>48</sup>

56. Further work is required in collecting legal data, including the analysis of criminal laws in the countries concerned. This should be done in close cooperation with Member States.

## 2. Preventive measures

57. OHCHR received examples of a number of preventive measures taken by those States in which the highest number of attacks on and killings of persons with albinism have been reported. These measures include the public condemnation of attacks and killings; the

<sup>44</sup> SRSR on Violence against Children submission.

<sup>45</sup> UDHR, article.8; ICCPR, article. 2; CERD, article. 6 ;Convention against Torture, article 14 ; CRC, article 39.

<sup>46</sup> Article 7 of the African Charter on Human and Peoples' Rights (ACHPR); Art. 25 of the American Convention on Human Rights (ACHR); Article. 13 of the Convention for the Protection of Human Rights and Fundamental Freedoms.

<sup>47</sup> See Committee against Torture, General Comment No. 3 paragraph 5.

<sup>48</sup> See Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of the International Humanitarian Law, A/RES/69/147/, 16 December 2005, paragraphs 18 to 23.

appointment of a person with albinism as Member of Parliament or Cabinet; the banning of witchdoctors licenses; public awareness-raising campaigns and the provision of temporary shelter to persons under threat of attacks.

58. While the effectiveness of these measures is to be evaluated, concerns were expressed in relation to poor living conditions in temporary shelters, particularly the hygienic conditions, overcrowding and food.<sup>49</sup> There is also concern that these shelters reinforce the marginalization of persons with albinism and keep children separated from their families.

59. It was reported that important initiatives, such as the instruction to register disaggregated data on persons with albinism in Tanzania, and the elaboration of a national policy to promote and protect the rights of persons with albinism in Burundi, are underway.

## **E. Action by international and regional human rights mechanisms**

60. Overall, the situation of human rights of persons with albinism has received little attention from Member States, the international community and human rights advocates. International and regional human right mechanisms have only sporadically raised the issue.

61. Specific mention of the situation of persons with albinism has been made in a few concluding observations from the Human Rights Committee,<sup>50</sup> the Committee on Economic, Social and Cultural Rights,<sup>51</sup> the Committee of the Rights of the Child<sup>52</sup> and the Committee on the Elimination of Discrimination against Women.<sup>53</sup>

62. On 4 May 2013, a joint press statement was issued by six United Nations Special Procedures Mandate-Holders, highlighting the gravity of attacks against persons with albinism and the profound discrimination they face.<sup>54</sup> The Special Rapporteur on extrajudicial, summary or arbitrary executions included a brief reference to the killings of persons with albinism in his 2009 report<sup>55</sup> and in his oral statement to the 24th session of the Human Rights Council.<sup>56</sup> The Universal Periodic Review recommended to the Governments of Burundi<sup>57</sup>, Tanzania<sup>58</sup> and Uganda<sup>59</sup> preventive and protection actions to address attacks and discrimination against persons with albinism.

63. In its 34th activity report submitted to the Assembly of Heads of State and Government of the African Union, the African Commission on Human and Peoples' Rights identified the situation of persons with albinism in Kenya and Tanzania as a matter of

<sup>49</sup> According to information gathered by OHCHR, in Burundi, persons with albinism used to be accommodated in police stations and houses near the communes. In Tanzania, they are sheltered in boarding schools for children with special needs.

<sup>50</sup> CCPR/C/TZ/CO/4 of 6 August 2009, paragraph 15 and CCPR/C/KEN/CO/3 of 31 August 2012, paragraph 17.

<sup>51</sup> E/C.12/COD/CO/4 of 16 December 2009, paragraph 19 and E/C.12/TZA/CO/1-3 of 13 December 2012, paragraph 5.

<sup>52</sup> CRC/C/OPSC/TZA/CO/1 of 10 October 2008, paragraphs 20-21; CRC/C/BDI/CO/2 of 20 October 2010, paragraphs 33-34; and CRC/C/GNB/CO/2-4 of 14 June 2013, paragraphs 28-29.

<sup>53</sup> CEDAW/C/TZA/CO/6 of 16 July 2008, paragraph 45.

<sup>54</sup> *Supra* note 13.

<sup>55</sup> A/HRC/11/2 chapter on "Human Rights, extrajudicial executions and witchcraft" by Philip Alston.

<sup>56</sup> Opening Remarks by Christoph Heyns, 30 May 2013.

<sup>57</sup> A/HRC/10/71, paragraph 80.5 and A/HRC/23/9 paragraphs 126.31 and 126.84

<sup>58</sup> A/HRC/19/4 paragraphs 85.33-34-35-39-40-41-42.

<sup>59</sup> A/HRC/19/16 paragraph 111.35

concern, highlighting some initiatives taken by the concerned States, such as the provision of free sunscreen and education campaigns.<sup>60</sup>

## V Discrimination against persons with albinism

64. The right to equality and non-discrimination is enshrined in the Universal Declaration of Human Rights (article 2) and is at the core of the main international human rights treaties<sup>61</sup> and regional human rights instruments.<sup>62</sup> The UDHR, the ICCPR and the ICESCR, include discrimination on the basis of “colour” as well as the open-ended category: “other status”.

### A. Main forms of discrimination

65. Structural discrimination against, and marginalization and social exclusion of persons with albinism have been reported as a global phenomenon. According to submissions received by OHCHR, persons with albinism have difficulties getting the health care they require, and in accessing education, employment, legal protection and redress. This situation is compounded by deeply entrenched societal prejudices against and stereotypes of persons with albinism.

66. The following testimony illustrates the nature and scope of discrimination suffered by persons with albinism throughout their lifetime:

67. “I have never known happiness in my life, and every time I think about my future tears flow in my eyes, I wonder if I would be happy one day? I still remember my difficult childhood, my father has always rejected me because I am an “albino”. One day he told my brothers that I represented the devil, that I was not his daughter. He refused to send me to school. My maternal uncle enrolled me in a public school where I studied until third grade. Teachers and students made fun of me because I could not see the class-board. I could not endure all these insults, so I dropped out of school. This is how I found myself on the street, helpless. When I tried to sell some goods on the market nobody wanted to buy what I was selling. I was raped by a man and have a 15-month-old child. I feel desperate and lost”<sup>63</sup>.

68. As noted by the United Nations Independent Expert on minority issues “One of the major challenges for people living with albinism is that they are often rejected and abandoned by their own families under the societies’ pressure”.<sup>64</sup>

69. As noted earlier, children with albinism are at high risk of abandonment, and women giving birth to children with albinism are often repudiated by their husband and families. Families frequently neglect the education of children with albinism as they believe their education is a waste of resources. Those who attend school often suffer from teasing and bullying from classmates. In some cases, the inability to see the blackboard, due to significant vision impairment, force them to drop out of school.<sup>65</sup> As a result, many have

<sup>60</sup> ACHPR submission.

<sup>61</sup> ICCPR, article 2; ICESCR, article 2; CRC, article 2; Convention of Migrant Workers, article 7; and CRPD, article.5. CERD prohibits discrimination on the ground of race, and CEDAW on the ground of gender.

<sup>62</sup> ACHPR (article 2 and 3) and ACHR (article 24).

<sup>63</sup> Albinos Sans Frontières submission.

<sup>64</sup> Supra note 13.

<sup>65</sup> The United Nations Special Rapporteur on the right to education has referred to drop-out rates of children with albinism and ways to reduce them (supra note 13). All the written submissions received

low education levels and do not have the full social or economic tools to live productive lives. This marginalization can be a contributing factor to a shorter life expectancy than for other members of the same society.

70. The United Nations Special Rapporteur on the right to health noted that “People living with albinism often do not receive the necessary special attention, health care or treatment that corresponds to their health needs”.<sup>66</sup> Many cannot, for example, afford simple remedies, such as sun cream, that would protect them from the elevated risk of developing skin cancer.

71. Without effective and affordable access to justice, persons with albinism are denied the possibility to claim their rights and contest abuses or human rights violations they are exposed to.<sup>67</sup>

72. All these forms of discrimination are interrelated, and the principle of the indivisibility and interdependence of human rights should be highlighted.<sup>68</sup> The right to education of persons with albinism, for instance, is adversely affected due to the vision impairment they suffer. A poor education, in turn, affects the right to an adequate standard of living, consigning many persons with albinism to poverty.

73. The right to work is provided for in article 6 of the ICESCR, prohibiting discrimination in access to and maintenance of employment, including on the basis of colour and on the ground of “other status”. It also prohibits, denying or limiting equal access to decent work to all persons, especially disadvantaged and marginalized individuals and groups.<sup>69</sup> In addition, the 1958 ILO Convention 111 concerns Discrimination in Respect of Employment and Occupation. The right to everyone to the enjoyment of the highest attainable standard of physical and mental health is recognized by article 12 (1) of the ICESCR. According to the Committee on Economic, Social and Cultural Rights, “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds”.<sup>70</sup> Article 26 of the ICCPR, Article 5 of CERD, and article 15 of CEDAW similarly enshrine the right of everyone to equality before the law.

74. The right to freedom from discrimination would require that States ensure that persons with albinism are afforded equal protection under the law and in practice.<sup>71</sup> States are obliged to ensure that their laws, policies and practices address the specific needs of persons with albinism.

## **B. Discrimination against women and children**

75. Women and children with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination. In addition, children are particularly

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from civil society referred to discrimination in education and/or incessant bullying and name calling.

<sup>66</sup> See supra note 13.

<sup>67</sup> See chapter 4.1. of this report describing challenges persons with albinism face in accessing justice.

<sup>68</sup> See for instance, paragraph 3 of the general comment no. 14 of the CESCR referring on how the right to health is closely related to and dependent upon the realization of other human rights, including the rights to food, work, education, human dignity, life, non-discrimination and the prohibition against torture, among others. E/C.12/2000/4.

<sup>69</sup> Committee on Economic, Social and Cultural Rights General comment No. 18, paragraphs 12 (b)(i) and 23.

<sup>70</sup> General comment No. 14, paragraph 12b.

<sup>71</sup> Human Rights Committee, General comment No. 18, paragraphs 1,5 and 10.

targeted for ritual killings<sup>72</sup> and women with albinism are sometimes victims of sexual violence.<sup>73</sup>

76. The Committee on the Elimination of All Forms of Discrimination Against Women has referred to women with albinism as a group of women in a vulnerable situation, meaning that they are at risk of being victims of multiple discrimination.<sup>74</sup> According to the Special Rapporteur on Violence against Women, its Causes and Consequences, violence against women is deeply rooted in multiple layers of discrimination and inequality. As these layers of discrimination intersect, violence against women intensifies. Addressing systematic discrimination and marginalization is crucial to end violence against women.<sup>75</sup> In her 2012 report to the Human Rights Council, the Special Rapporteur included witchcraft-related killings as gender-related killings.<sup>76</sup>

77. The Committee on the Rights of the Child has also expressed serious concerns at reports of killings of and attacks against children with albinism, addressing this issue under the right to equality and non-discrimination (article 2 of the Convention), among other rights. In the case of Burundi, the Committee expressed concern that ‘*de facto* discrimination of children prevails [in the country] and is tolerated in the State-party’ vis-à-vis albino children”. The Committee encouraged the State-party to review legislative instruments and to adopt a comprehensive strategy, including awareness-raising, to eliminate discrimination on any grounds and against all vulnerable groups, particularly children with albinism.<sup>77</sup>

### C. Areas requiring further study

78. Further analysis and consultations are required to determine the category in which persons with albinism could fall and the basis for discrimination against them. Some of the written submissions received from associations working with persons with albinism, consider them as persons with disabilities.<sup>78</sup> Others refer to discrimination on the ground of colour of the skin.<sup>79</sup>

79. Under the Convention on the Rights of Persons with Disabilities, persons with albinism could be considered as persons with disabilities. According to article 1 of the Convention, persons with disabilities include 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. However, the Committee on the Rights of Persons with Disabilities has not dealt with the issue so far.

<sup>72</sup> See paragraph 21 of this report.

<sup>73</sup> Submissions from Albinos Sans Frontières, Bien-Etre des Albinos de Côte d’Ivoire, Confédération nationale des Albinos en Guinée, L’Association des Femmes Albino Espoir, Ecran Totale and UTSS.

<sup>74</sup> In its concluding observation in Tanzania, the Committee expressed concern at reports that women and girls with albinism had been targeted in ritual killings, recommending the State-party to protect them. CEDAW/C/TZA/CO/6 of 16 July 2008, paragraphs 142-143. See as well CEDAW General comments No. 12, 19 and 28.

<sup>75</sup> A/HRC/17/26 of 2 May 2011.

<sup>76</sup> A/HRC/20/16 of 23 May 2012 paragraphs 14 and 16.

<sup>77</sup> Committee on the Rights of the Child, Concluding Observations, CRC/C/BDI/CO/2, 20 October 2010, paragraphs 29- 30.

<sup>78</sup> Albinism Fellowship of Australia, L’Association nationale des Albinos du Sénégal, The Association of Gambia Albinos and UTSS.

<sup>79</sup> Confédération nationale des Albinos en Guinée, L’Association des Femmes Albinos Espoir, L’Association nationale des Albinos du Sénégal, L’Organisation mauritanienne pour l’appui et l’insertion des Albinos and UTSS.

According to the information received, some national legislation recognizes albinism and the associated visual impairment as a disability.<sup>80</sup> Additional review of national legislations on disability needs to be conducted. Moreover, consultations with persons with albinism are required on the issue of self-identification.

80. With regards to disabilities, the Durban Declaration and Programme of Action urges States and international and regional organizations to address the situation of persons with disabilities who are also subject to racism, racial discrimination, xenophobia and related intolerance; and to take necessary measures to ensure their full enjoyment of all human rights.

81. Similarly, the Committee on the Elimination of Racial Discrimination has not yet examined the issue of discrimination on the basis of colour with respect to persons with albinism.

82. The United Nations Special Rapporteur on racism, referring to people living with albinism, has noted that: “Regardless of whether one has a lighter or a darker skin compared to the majority population in a country or a community, everyone is entitled to the same rights, dignity and treatment (...) and has the same opportunities as anyone else.” On the other hand, the United Nations Independent Expert on minority issues has stated that “People living with albinism do not fall under the internationally accepted definition of minorities (...). However, their stigma, the lifelong social exclusion and general discrimination they face is a similar experience to those vulnerable racial minorities because of their different skin colour”.<sup>81</sup>

83. The Durban Declaration and Programme of Action, while not addressing specifically the situation faced by persons with albinism, recognizes that racism, racial discrimination, xenophobia and related intolerance occur on the grounds of race, colour, descent or national or ethnic origin, and that victims can suffer multiple or aggravated forms of discrimination based on other related grounds (including “other status”). It notes that these practices may be aggravated by inequitable distribution of wealth, marginalization and social exclusion.

84. Organizations working with persons with albinism advocate for considering them as a group requiring special attention, as the discrimination and attacks they are exposed to are mainly rooted in erroneous beliefs and myths that must be addressed.<sup>82</sup>

## VI. Preliminary conclusion and recommendations

**85. OHCHR expresses its grave concern at the severity of the human rights violations committed against persons with albinism in many countries, including at the multiple and intersecting forms of discrimination they face, particular children**

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<sup>80</sup> For instance, the amended version of the Persons with Disabilities Act in Kenya recognized albinism as a disability. Discrimination laws in Australia protect the rights of people with disabilities, including albinism (Albinism Fellowship of Australia submission). In Canada and the USA, persons with albinism are considered “legally blind”, thus classifying as persons with disabilities according to domestic legislation (UTSS submission).

<sup>81</sup> Supra note 13. The list of types of minorities included in the 1992 UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities is not open-ended.

<sup>82</sup> Albinos Sans Frontières and UTSS submissions. According to UNICEF, in order to understand the particular character of ritual killings of person with albinism, it is essential to analyse the types of representations associated with these harmful practices and which are linked to the belief that persons with albinism possess magical characteristics. Cimpric, supra note 12, p.28.



and women. Persons with albinism have the right to start living without fear of being killed or dismembered and without being discriminated<sup>83</sup>.

86. OHCHR recommends the following actions:<sup>84</sup>

**1. To States**

(a) To address the root causes of attacks and discrimination against persons with albinism, notably by proactively combating superstition and stigma vis-à-vis albinism, including through education and awareness-raising campaigns.

(b) To adopt positive and specific measures to protect and preserve the rights to life, to security of person, and the right not to be subject to torture or ill-treatment.

(c) To take the necessary legislative measures to criminalise harmful practices.\*

(d) To evaluate and address the needs of persons with albinism, including through a census of the population and the mandatory registration of birth and death of persons with albinism.\*

(e) To increase efforts in putting an end to the various forms of crimes affecting persons with albinism, strengthening the legal response to such crimes and bringing perpetrators to justice, through prompt and impartial investigations.

(f) To guarantee the victims' right to justice and redress, and provide medical, psychosocial and legal support to victims of attacks.

(g) To adopt firm measures and policies to address the multiple and intersecting forms of discrimination affecting persons with albinism, including by ensuring they have adequate access to health care, social services, employment and education.

(h) To adopt a comprehensive strategy to eradicate violence and discriminatory practices affecting persons with albinism.

(i) To develop national institutional mechanisms for the protection and promotion of rights of persons with albinism, including \*by ensuring that national human rights institutions effectively address the human rights situation of persons with albinism.

(j) To support civil society organizations working for the promotion and protection of rights of persons with albinism.

(k) To integrate the situation of persons with albinism in human rights national action plans or action plans to combat discrimination.

<sup>83</sup> High Commissioner for Human Rights statement, supra note 41.

<sup>84</sup> The recommendations marked with (\*) are part of a set of recommendations resulting from the international expert's consultation on the protection from harmful practices in plural legal systems (supra note 18).

**2. To international and regional human rights mechanisms**

*(a) To the United Nations Treaty Bodies*

**To conduct a more systematic review of the situation of persons with albinism when assessing compliance of States parties with their international obligations arising from the relevant treaty provisions.**

*(b) To the relevant mechanism of the Human Rights Council*

**To request a follow-up study on the human rights situation of persons with albinism**

*(c) To the Special Procedures of the Human Rights Council - particularly the mandates on extrajudicial, summary or arbitrary executions; on torture and other cruel, inhuman or degrading treatment; on racism; on health; on education; on violence against women and on trafficking in persons, especially women and children*

**To pay greater attention to human rights violations committed against persons with albinism during their country visits, and to consider the submission of thematic report on the situation of persons with albinism, as relevant.**

*(d) To the Durban follow-up mechanism*

**To specifically address the situation of persons with albinism during a relevant session.**

*(e) To African Union mechanisms*

**To pay further attention to human rights violations committed against persons with albinism, including by seeking effective means to combat discrimination and violence against them.**

**3. To the international community**

**(a) To provide financial assistance for the development of technical cooperation activities aimed at supporting measures to prevent and combat discrimination and attacks against persons with albinism, and at providing assistance to the victims and their family members.**

**(b) To strengthen international, regional and bilateral cooperation for the prevention of cross border crimes affecting persons with albinism, notably trafficking in persons, child trafficking and organ trafficking.\***

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