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**Requests addressed to the Advisory Committee stemming from Human Rights Council resolutions:
Technical cooperation for the prevention of attacks against persons with albinism**

**Preliminary study on the situation of human rights of
persons living with albinism¹**

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albinism

¹ This Draft report has benefited from the support of OHCHR, in particular from Ms Alicia Londono.

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I. Background

1. In three recent seminal resolutions,² the Human Rights Council expressed its concern at the situation of human rights of persons living with albinism. The first condemned attacks against persons with albinism. Upon the Council's request, the Office of the United Nations High Commissioner for Human Rights (OHCHR) submitted to its twenty-fourth session in September 2013 a preliminary report on on-going attacks and discrimination against persons with albinism.³

2. In the second resolution, the Human Rights Council requested that its Advisory Committee "prepare a study on the situation of human rights of persons with albinism and to submit a report thereon to the Human Rights Council at its twenty-eighth session".⁴

3. In April 2014 the Advisory Committee sent out a questionnaire to States and other stakeholders requested information on the status and treatment of persons with albinism around the world. A total of 41 answers were received: 15 from States: Azerbaijan, Burundi, Chile, Denmark, Georgia, Germany, Luxemburg, Mexico, Nicaragua, Paraguay, Senegal, Slovenia, Spain, Swaziland, Tunisia; 9 from NHRIs: Bosnia and Herzegovina, Denmark, Malawi, Namibia, the Netherlands, Nicaragua, Romania, Rwanda, South Africa; 10 from NGOs: Amis des Etrangers au Togo, Bien-Etre des Albinos de Côte d'Ivoire, Elgon Foundation for Persons with Albinism (Uganda), Uganda Albinos Association, The Albino Foundation (Nigeria), Chinese Organization for Albinism (China), ALBA – Asociación española de Ayuda a Personas con Albinismo (Spain), Genespoir – France, Albinism Fellowship of Australia, NOAH Albinismus Selbsthilfegruppe (Germany); and 7 from OHCHR/Treaty Bodies/Special Procedures: OHCHR – Palestine, OHCHR Regional Office in South Africa, OHCHR-MONUSCO (DRC), OHCHR-ONUCI (Côte d'Ivoire), OHCHR BINUCA (relating to Burundi), Subcommittee on Prevention of Torture, SR on extrajudicial, summary or arbitrary executions.

4. The first part of this report – relying on some of the findings in the OHCHR preliminary report – presents a summary of the various human rights problems faced by persons with albinism including the type and severity of the human rights violations they face. The second part succinctly presents the actions which have been taken at the international level and by OHCHR in response to the issue. The third and final part recommends further initiatives for addressing some of the key problems identified in the first part.

II. Albinism, special needs and human rights problems

5. Albinism is a rare, non-contagious, genetically inherited difference present at birth. In almost all types of albinism, 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. Albinism results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a

² Res. 23/13 Attacks and discrimination against persons with albinism; Res. 24/33 Technical cooperation for the prevention of attacks against persons with albinism; Res. 26/10 International Albinism Awareness Day.

³ Persons with albinism. Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/24/57, 12 September 2013 (hereinafter OHCHR Report).

⁴ Para. 1 of Res. 24/33.

result, almost all people with albinism are visually impaired and are prone to developing skin cancer. There is no cure for the absence of melanin.⁵

6. While numbers vary in North America and Europe it is estimated that 1 in every 20,000 people have some form of albinism in both continents. In Tanzania, and throughout East Africa, albinism is much more prevalent, with estimates of 1 in 1,400 people being affected.⁶

A. Specific needs

7. Persons with albinism have specific needs. An Advocacy report of the International Federation of the Red Cross and Red Crescent Societies (IFRC) dealing with the situation of persons with albinism categorized these needs into 3 key areas which are discussed in turn:

- (a) Security;
- (b) Displacement from insecurity; and
- (c) Discrimination arising from the lack of:
 - (i) Health education on how to prevent skin cancer;
 - (ii) Protective clothing;
 - (iii) Optician services;
 - (iv) Assistance in participating in mainstream primary and secondary education;
 - (v) Vocational training to maximize the chance of indoor work out of the sun.⁷

8. While the IFRC report on which the above listing is based focused on the Great Lakes region of east Africa, it is proposed that the same list can be correctly applied generally to the collective experience of persons with albinism.

B. Security

9. With respect to **security**, grave concern has been expressed by the Human Rights Council about the “attacks against persons with albinism, including against women and children, which are often committed with impunity”.⁸

10. OHCHR has identified various forms of attacks against persons with albinism. They comprise, inter alia, ritual attacks; the killing of and attacks of persons with albinism with a view to using their body parts for ritual purposes. It is reported that as of July 2014, over 300 attacks against persons with albinism have been recorded in 24 countries (see list at Annex 1). NGOs working in the field also report that the number of on-going attacks is higher than those reported but data-gathering is difficult due to the secretive nature of witchcraft that serves as the context of most ritual attacks against persons with albinism.

⁵ The definition of albinism in this and the next paragraph are adopted from OHCHR Report, A/HRC/24/57, paras 10 & 11(Footnotes omitted).

⁶ Under the same Sun, Children with Albinism and the Right to Health, Summary Report on Tanzania with Implications for other parts of sub-Saharan Africa, p. 2.

⁷ From International Federation of Red Cross and Red Crescent Societies, Through albino eyes. The plight of albino people in Africa’s Great Lakes region and a Red Cross response, 2009, p. 17.

⁸ Res. 24/33, preamble.

11. On 15 May 2014, the High Commissioner issued a press statement in which she called for increased protection for people with albinism after the murder of a 40-year-old woman with albinism in north-western Tanzania three days earlier. On 27 May 2014, the Working Group on the Rights of Older Persons and People with Disabilities in Africa also issued a press statement condemning this specific killing

12. Arising from the attacks and use of body parts of persons with albinism is a trade of organs linked to trafficking in persons and the sale of children; infanticide and abandonment of children.⁹

13. The report adds that “in some communities, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of persons with albinism at constant risk. These beliefs and myths are centuries old and are present in cultural attitudes and practices around the world.”¹⁰

14. Further as mentioned by six special procedures mandate holders, persons with albinism face dehumanization because they “are regarded as ghosts and not human beings who can be wiped off the global map ... [they are] the target of many false and harmful myths in several countries, especially in the African region.”¹¹

15. The situation of persons with albinism who have gone into, or have remained in hiding in the wake of attacks against them, is worrisome. OHCHR has received information on the appalling living conditions in 13 centres for displaced children and adults with albinism in Tanzania.

16. It is reported that hundreds of children with albinism have been living there after being abandoned by their families or having fled their homes due to a spate of killings and attacks against them. Some of these centres are administrated by the Government while others are owned by faith-based organizations.

17. Further, according to the information received, these centres are overcrowded and offer very poor health and hygiene conditions. In addition, due to very limited human and financial resources, teaching and learning materials are almost inexistent. Health-wise, there have been worrisome reports of skin cancer at various stages, which is very visible on most of the children with albinism living in these centres partly due to the lack of awareness amongst staff as well as lack of basic health information on self-care amongst the persons with albinism themselves. Sexual abuse has been reported in some of these centres.

18. Also in Burundi, after the spate of killings and attacks registered from 2008 to 2012, persons with albinism were accommodated in police stations and houses nearby to ensure their security. OHCHR’s field presence in Burundi has recently conducted an assessment of displaced persons with albinism in the Northern Province of Kayanza, in Musongati and in Gitega. The assessment shows the precarious security situation for some of them and its negative impact on the right to an adequate standard of living.

19. In a press release of 15 May 2014, the High Commissioner expressed concern about the situation of children with albinism living in these centres. She called the Tanzanian authorities to take urgent measures to assess and address the situation in these centres, including allegations of sexual harassment and abuse, and the poor living conditions. She added that the staff working with people with albinism should be trained on their special needs, in particular with regard to basic preventive measures to avoid skin cancer.

⁹ OHCHR Report, para. 18 (Footnotes omitted).

¹⁰ Ibid, para. 15 (Footnotes omitted).

¹¹ Ibid, para. 16 (Footnotes omitted).

20. The Committee on the Rights of the Child included reference to these centres in the List of Issues of Tanzania adopted on 27 June 2014.¹²

C. Discrimination

21. In addition to issues of security and associated displacement, the OHCHR expressed “its grave concern at the severity of the human rights violations committed against persons with albinism in many countries, including the multiple and intersecting forms of discrimination they, and particularly children and women, face.”¹³

22. These multiple and intersecting forms of discrimination are evident from a vicious and truncated cycle of life faced by persons with albinism: If they survive infanticide at birth, they face a constant threat of physical attacks. Should they survive these physical threats, they are unlikely to get educated due to the absence of reasonable accommodation for their low vision. A lack of education leads to unemployment or employment outdoors in the sun where they are vulnerable to developing skin cancer. Skin cancer remains a life-threatening condition for most persons with albinism, killing most in the Africa region by the age of 40. For instance an epidemiological study estimated that less than 10% of persons with albinism in Tanzania survive to age 30, and only 2% were expected to reach age 40.¹⁴

23. During a press release in Nigeria, in March 2014, the UN High Commissioner for Human Rights alluded to the specific discrimination faced by persons with albinism and the extra vulnerability faced by children with albinism. She stated “One group at particular risk are the some 800,000 children among the 2 million people living with albinism in Nigeria. Many of them are not in school because of visual impairment, discrimination from other children, and social exclusion as a result of their skin colour.”

24. The preponderance of reported cases of attacks and specific discrimination against persons with albinism is often reported from countries in the Africa region. Yet, it has been reported that persons with albinism globally face discrimination and stigma. As noted in OHCHR’s preliminary report, discrimination and marginalization of persons with albinism have been reported as a global phenomenon compounded by deeply entrenched societal prejudices against and stereotypes of persons with albinism.”¹⁵

25. The discrimination faced by persons with albinism varies by region in the form it takes and in severity. In the western world including North America, Europe and Australia, persons with albinism face the effects of entrenched misconceptions and misunderstanding perpetuated by the media and pop culture particularly caricatures of persons with albinism reported to translate into bullying of children with albinism.¹⁶ Given the rarity of albinism in these regions, media will likely remain the sole source of information on the condition for the majority unless specific steps is taken to raise awareness or support groups currently doing the same.

26. It is also important to restate from the OHCHR preliminary report that a real or apparent focus on Africa on the issue of albinism is explained by the fact that to date, all

¹² CRC/C/TZA/Q3–5.

¹³ OHCHR Report, para. 84 (Footnotes omitted).

¹⁴ Andres E. Cruz-Ingo et al., *Albinism in Africa: Stigma, Slaughter and Awareness Campaigns*, 29 *DERMATOLOGIC CLINICS* 79, 81 (2011) (citing J. Luande et al., *The Tanzanian human albino skin*, 55 *CANCER* 1823 (1985)).

¹⁵ OHCHR Report, para. 65.

¹⁶ See *Under the Same Sun (UTSS)*, <http://www.underthesamesun.com/>

reported cases for ritual attacks have come from African countries. Further, some of the strongest NGO groups on the issue are based in the same region. Beyond anecdotal reports, little is available for other regions such as Asia, South America, and the Pacific, among others. Lack of sufficient knowledge remains a significant barrier to tackling discrimination, stigmatisation and violence.

27. Persons with albinism are disproportionately affected by poverty due to the structural discrimination and marginalization they face. There is an inextricable linkage between discrimination and poverty. Persons with albinism are affected by different manifestations of poverty in the areas of economic and social rights. This situation also negatively impacts access to justice. OHCHR's preliminary report referred to this issue, mentioning that all forms of discrimination are interrelated. The right to education of persons with albinism, for instance, is adversely affected due to the vision impairment they suffer from. A poor education, in turn, affects their right to an adequate standard of living, consigning many persons with albinism to poverty.¹⁷

28. Another issue is the inter-linkage between discrimination and impunity. There are little legal data available on all cases. Where there has been information, it is reported that persons with albinism are discriminated throughout the whole judicial process and that their basic human rights continue to be violated. Corruption and shortcomings in the justice system, compounded with the specific challenges faced by persons with albinism in accessing justice fail to translate initial action of the police into concrete results in the fight against impunity. Moreover, law enforcement authorities and judicial authorities share the same superstitious beliefs entrenched in the communities, sometimes considering persons with albinism as sub-human beings. In addition to the significant difficulties persons with albinism encounter in accessing justice, remedies and redress are extremely limited, even in the form of medical rehabilitation and psychological support.

29. The challenges persons with albinism face in having their cases brought to justice are grounded in the vulnerability of the population and include: the fear of further attacks, reprisals or further stigmatization; difficulties in finding witnesses owing to the ostracism they face within their community and, frequently, the involvement of family and community members in the attacks; the lack of awareness of legal rights; the lack of financial resources; the inadequate capacity of the judicial system to address such cases; the lack of legal aid and adequate legal representation; and the lack of knowledge of or confidence in the law enforcement and justice systems.¹⁸

30. OHCHR's preliminary report also highlighted that without effective and affordable access to justice, persons with albinism cannot claim their rights and contest the human rights violations to which they are subjected.¹⁹

31. The inter-linkage between poverty and witchcraft is also a matter of concern. As mentioned in one of the written submissions received by OHCHR: "As is the case with witchcraft accusations against women, the elderly and children, muti murders of persons with albinism appear to follow patterns of poverty, misfortune, tension and conflict in societies. Attacks may originate from tense social relations, where no effective or social alternative exists to release or explain such tension. Lack of access to basic resources, education and basic health services correlate with such human rights abuses. These spiritual explanations act as a way of justifying life's misfortunes, hence, maintaining social order. It is, predominantly, the most vulnerable and marginalized groups in society who are accused of witchcraft, because they are either least able to defend themselves from attack and are,

¹⁷ OHCHR Report, para. 71.

¹⁸ OHCHR Report, para 53.

¹⁹ OHCHR Report, para. 70.

therefore, easy targets. Furthermore, as they are considered of little value to society, they consequently become a burden to it in times of hardship”.²⁰

32. The severity of the violations against persons with albinism and the particular vulnerability of this population requires States not only to take a more active role in their responsibility to protect but also to take effective measures to prevent poverty and improve access to all rights. As mentioned in OHCHR’s preliminary report, the responsibility to protect and prevent is particularly relevant in cases of persons in vulnerable situations, such as persons with albinism, and in circumstances where the authorities are aware of the real and imminent danger faced by such persons and communities.²¹

33. In its study on unlawful killings in Africa for the UN Special Rapporteur on extrajudicial, summary or arbitrary execution, the Centre of Governance and Human Rights of the University of Cambridge has included a specific chapter on attacks against persons with albinism. The study approaches the issue from a discrimination angle²² and also highlights the vulnerability of the population.²³

34. In order to respond to the severity of attacks and address their root causes, a holistic approach is necessary. Accountability measures should come hand in hand with other measures combatting discrimination, including superstition, misconception and stigma, with a view to diminishing the multiple and intersecting forms of discrimination affecting persons with albinism.

III. Responses: successes and subsisting challenges

A. Advocacy

35. Further to new reports of ritual killings and attacks against persons with albinism documented in early 2013, the OHCHR started to actively promote and advocate for the rights of persons with albinism, resulting in concrete actions at the international and regional levels.

36. The High Commissioner’s voice, through press statements²⁴ and opening remarks at various events, has increased the visibility on violations against this group, which until then had received little attention from the international community. As the High Commissioner said: “It is always with eagerness that I raise my voice to increase awareness on the human rights situation of persons with albinism, for they suffer terrible discrimination, stigma and social exclusion.”²⁵

²⁰ The Witchcraft and Human Rights Information Network, Exploring the role of Nollywood in the Mutilations of Persons with Albinism, 16 August 2013.

²¹ OHCHR Report, para. 31.

²² Unlawful killings in Africa, pp. 153–168.

²³ “The victims of mutilation-related killings can be diverse, but persons with albinism are a particularly vulnerable group, around whom certain protective or promotional measures may be undertaken”, *ibid.* p. 165.

²⁴ Press statement of 5 March 2013 condemning the attacks against persons with albinism in Tanzania; Press statement of 15 November 2013, welcoming the adoption of the resolution by ACHPR on the prevention of attacks and discrimination against persons with albinism; Press statement of 14 March 2014 during her mission to Nigeria; Press statement of 15 May 2015 calling for increased protection for people with albinism.

²⁵ Opening Remarks for the side-event on violence against persons with albinism, Geneva, 11 March 2014.

37. Further, since the presentation of OHCHR's preliminary report on the human rights situation of persons with albinism in September 2013, various major awareness-raising activities were conducted and planned.

38. On December 5, 2013, as part of OHCHR's commemorating activities of its 20th anniversary, Salif Keita, musician and advocate for the rights of people with albinism, performed few songs at Palais des Nations in Geneva.

39. On March 11, 2014, OHCHR, in collaboration with the NGO, UTSS, organised on 11 March 2014 a side-event in the margins of the 25th session of the Human Rights Council. Participants to the side-event included the Special Representative of the Secretary-General on Violence against Children (SRSG) and the UN Special Rapporteur on Torture. The side event focused on violence against children with albinism and was co-sponsored by the Permanent Mission of Canada, the Permanent Mission of Somalia, and the Permanent Mission of the Organisation Internationale de la Francophonie (OIF) to the United Nations in Geneva, as well as UNICEF.

40. On 26 June 2014, the Human Rights Council adopted, without a vote resolution 26/10, recommending to the General Assembly to proclaim 13 June as International Albinism Awareness Day²⁶. 13 June is a symbolic date, as the first global resolution on attacks and discrimination against persons with albinism was adopted by the Human Rights Council on 13 June 2013. This initiative provides a platform on which stakeholders can raise public awareness on this pressing human rights issue. The resolution recognises the importance of increasing awareness and understanding on albinism and fighting against global discrimination and stigma against persons with albinism.

41. In September 2014, OHCHR, in collaboration with the Organisation Internationale de la Francophonie (OIF) will organize an Expert Meeting on persons with albinism. Here, civil society actors are expected to discuss the current situation of persons with albinism in three countries (Tanzania, Burundi and Cote d'Ivoire). Participants will also discuss a framework for dealing with challenges persons with albinism face in terms of categorization (i.e., are persons with albinism facing racial discrimination? If considered as persons with disabilities, would persons with albinism have adequate legal protection? Should persons with albinism be considered as a specific group requiring special attention?). An Outcomes document is expected to be published from this event and distributed as a resource to stakeholders including the Human Rights Council Advisory Committee.

42. Advocacy work at the field level has been conducted to a lesser degree. The Human Rights Component of UN Operation in Ivory Coast (ONUCI) has strengthened the operational and institutional capacities of one of the albinism groups in the country (BEDACI), through a quick impact project, and has conducted training on documentation techniques of human rights violations.²⁷ The Human Rights Component of the UN Office in Burundi (BNUB) has been monitoring the situation of people with albinism in the country.

43. With the recent deployment of Human Rights Advisors in Tanzania and Nigeria, it is expected that OHCHR will have a more active engagement of with PWA stakeholders in these countries.

²⁶ The celebration of international albinism day on 13 June is a proposal put forward by Under The Same Sun (Canada) together with "World Albinism Alliance" (Australia), a consortium of NGOs working for promoting and defending the rights of persons with albinism. Other albinism groups from various countries (Ghana, Burundi, Kenya, Nigeria and South Africa) have welcomed the initiative and has celebrated this day as international albinism day.

²⁷ See ONUCI replies to the Advisory Committee questionnaire.

44. A public information campaign was designed to support OHCHR advocacy efforts. The communications section of OHCHR will soon launch an online campaign to raise awareness, among the general public, of the human rights abuses perpetrated against persons with albinism everywhere on a daily basis. The campaign also aims to support the advocacy work of OHCHR, and more specifically the Africa Branch, to achieve a consensus by African States on the importance of promoting and protecting the rights of persons with albinism generally and in particular by combatting the impunity for violent attacks against them.

45. The campaign has started with a Google+ Hangout in July 2014 with the participation of civil society partners and UN human rights experts.

46. A special campaign website and a visual identity for the campaign are being prepared for September. Fourteen campaign champions, including the Malian musician Salif Keita, have agreed to share their stories through video messages on the website. A Public Service Announcement featuring these celebrities will also be distributed to TV broadcasters.

47. Feature stories have already been posted on the OHCHR website providing information on various human rights issues linked to albinism. Furthermore, media releases and press briefings are issued whenever incidents of grave violations occur. OHCHR also informs international media accredited at the Palais des Nations in Geneva of landmark resolutions or decisions adopted by UN rights bodies. Other media outreach will be undertaken throughout the year.

48. OHCHR intends to publicise this study on the rights of persons with albinism by the HRC Advisory Committee through traditional and social media. During the week of the presentation of the report of the Advisory Committee, OHCHR is looking into the possibility of hosting a photo exhibit in Geneva and New York, showing persons with albinism in their daily lives; or organizing a screening of a documentary on persons with albinism followed by a panel discussion.

49. At the African regional level, OHCHR has also provided support aimed at enhancing the engagement of civil society organizations (CSOs) with human rights mechanisms with a view to stimulate regional responses to key human rights concerns. For instance, OHCHR supported representatives of CSOs conducting advocacy on behalf of persons with albinism to participate during the 53rd and 54th session of the NGO Forum in Banjul. A panel discussion on cooperation with the AU organs was organised in October 2013.

50. On 5 November 2013, the African Commission of Human and People's Rights adopted Resolution 263 on the prevention of attacks and discrimination against persons with albinism. Among other things, this resolution requires Member States to include in their reports to the African Commission, information on the situation of persons with albinism, including good practices in protecting and promoting their rights.

51. In November 2013, at its 22nd ordinary session held in Addis Ababa (4 to 8 November 2013), the African Committee on the Rights and Welfare of the Child (ACERWC) considered the issue of albinism through presentations made by the SRSG on Violence against Children, OHCHR, and UTSS²⁸. On 5 November 2013, ACERWC adopted a Declaration to End Discrimination and Violence against Girls in Africa in which the situation of children with albinism is addressed.

²⁸ ACRWC/RPT (XXII).

B. Direct assistance to victims

52. OHCHR has promoted and facilitated the use of the UN Voluntary Fund for Victims of Torture (UNVFVT) as a way to provide direct assistance to some survivors of attacks and family members. On May 2014, the UNVFVT disbursed USD 40,000 to one NGO, UTSS, for an emergency grant for the provision of medical (prosthetic work) and psychological support for the victims and family members of persons with albinism that were attacked. UTSS has also applied for the regular cycle of the UNVFVT, in order to be able to provide similar assistance to other victims and family members. It has also submitted another project to train associations of persons with albinism on legal monitoring and reporting skills. The UNVFVT Board of Trustees will consider these two latter projects during its next session, starting 29 September 2014.

C. Engagement with human rights mechanisms

53. In order to promote greater engagement with human rights mechanisms and increased understanding of albinism, OHCHR's Field Operations and Technical Cooperation Division (FOTCD) has organised general briefings for OHCHR staff working with treaty bodies, special procedure mandate-holders and members of some Committees.²⁹ The briefings have been organised with the participation of the leading NGO on the issue, UTSS. FOTCD has also informed OHCHR staff on the various resolutions adopted, inviting relevant mechanism to give further attention on this issue. Moreover, as earlier said, there has been regular information-sharing with these groups on the human rights violations of persons with albinism.

54. The input of Special Procedure Mandate Holders³⁰ was also provided, whenever relevant, to the UPR process³¹ and the treaty bodies.³²

55. On 29 April 2014, during the review process of Cote d'Ivoire by the Working Group on the Universal Periodic Review (UPR), Spain expressed concern regarding discrimination of persons with albinism (para. 87) and the following recommendation enjoyed the support of the country: "128.103. Take concrete measures to protect the rights of people with

²⁹ So far, FOTCD has facilitated a meeting with UTSS and the Chairperson of the Committee on the Rights of the Child (CRC) in September 2013. A General Briefing was organised for members of the CRC, on 12 June 2014. A briefing with members of the Committee on the Rights of Persons with Disabilities (CRPD) is scheduled for September 2014. Members of the Human Rights Committee will also be briefed.

³⁰ On cases of killings and attacks in Tanzania, resulting in one joint communication to the Government of Tanzania in 18 March 2013; on the situation in the centres for children/adults with special needs in Tanzania on 3 cases of torture in Tanzania.

³¹ Inputs have been provided for the UPR process in Cote d'Ivoire (29 April 2014); DRC (29 April 2014); and for Kenya and Guinea-Bissau (both countries are to be reviewed on 27 October 2014).

³² Inputs were provided to the Committee on Economic, Social and Cultural Rights (CESCR) for its review of Gabon on November 2013. The issue was raised during the interactive dialogue but was not included in the Concluding Observations (COBs) due to the very little available information specific to persons with albinism. The delegation considered there was no discrimination or violence against persons with albinism in the country. Inputs were provided to the pre-sessional group of the CRC working on the List of Issues (LOIs) for Tanzania, on 18 June 2014. The information was reflected in the LOIs adopted by the CRC on 27 June. Inputs were provided to the Committee on the Elimination of Discrimination Against Women (CEDAW) for its review of Swaziland on 16 July 2014.

albinism, in accordance with the recommendations made by the Office of the High Commissioner, and raise awareness among society about their situation (Spain).”³³

56. On 29 April 2014, during the review process of DRC by the Working Group on the Universal Periodic Review (UPR), Guatemala shared the concern of the Committee on Economic, Social and Cultural Rights (CESCR) about the killing of persons with albinism and the use of their organs for witchcraft ceremonies and acknowledged improvements (para.104). The following recommendation enjoyed the support of the country: “133.47. Combat all forms of discrimination against persons with albinism (Guatemala)”.³⁴

57. Despite the above strides, there remain challenges to a more active engagement with human rights mechanisms. These are detailed below amongst other challenges to an adequate response to the issue.

D. Challenges

58. Limited knowledge of the issue and its human rights consequences.

59. Limited knowledge and capacity of associations of persons with albinism around the world to engage with human rights mechanisms.

60. Little information, scarce data and incomplete reports on case of discrimination on specific grounds.

61. Scarce available data on cases of killings and attacks³⁵ in countries other than Tanzania, Burundi and Côte d’Ivoire, where there is higher prevalence of albinism but also a more active and better skilled civil society. For example, the immediate interest of the mandate on the *Sale of Children and Trafficking in Persons* is simultaneously subdued by the secrecy surrounding witchcraft and the underground nature of its associated market, making it difficult to find evidence about trafficking of persons and organs, relevant to the Special Rapporteurs of Sale of Children and Trafficking in Persons.

62. Narrow definition of some mandates of Special Procedures, which prevent a holistic approach to address this issue. For example, the mandate on *Minorities*. In spite of the immediate interest of the Special Rapporteur, people with albinism do not fall under the internationally accepted definition of minorities and therefore are not properly under her mandate. The definition of “minorities” is currently limited to national, ethnic, religious or linguistic minorities.³⁶

63. Further, the narrow mandates on Health, Education, Racism, Extreme Poverty, and Violence against Women, Summary Executions and Torture could only address certain aspects of the issue; and mandate-holders remain overwhelmed with other pressing situations to deal with an aspect of albinism that incidentally touches their mandate.

³³ A/HRC/WG.6/19/L.3.

³⁴ A/HRC/WG.6/19/L.4.

³⁵ It is worth noting that ritual killings and attacks remain undocumented and unreported, due to the code of silence surrounding these crimes and the vulnerability of the targeted population.

³⁶ See UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, Adopted by General Assembly resolution 47/135 of 18 December 1992.

IV. Actions and recommendations

A. States

64. States are the prime guardians of the human rights of their citizens. States should have guarding measures against practices such as attacks against persons with albinism, and should be up to their international commitments towards human rights which are enshrined in local laws as well as international human rights legal instruments.

65. Laws should be enacted by states that would criminalize attacks on people with albinism. However, such laws are in fact not enough to prevent attacks on them. This is because other measures need to be taken in order to effectively implement these laws. The mere enactment of laws is not enough to protect people with albinism. Such laws should be accompanied by other concrete measures that would help implement them. Law enforcement officers, judicial institutions, and prosecutors should all play a role.

66. Another matter which is important in protecting people with albinism is the publicity of the verdicts of prosecutions. This would serve as deterrence and at the same time would protect the safety and the rights of people with albinism. NGOs can help raise awareness on these issues.

67. Education also plays a role. It can decrease practices that adversely affect the rights of persons with albinism. Educating the community would serve as a protection measure for people with albinism since education will enlighten ordinary people of the rights of people with albinism. Moreover, education would discourage superstition and practices that affect the rights of people with albinism. Therefore, it is important that states include in their educational curricula, courses that would enlighten people of the rights of persons with albinism.

68. Awareness of the problems that face people with albinism through mass media could also contribute positively to protecting people with albinism. The role of mass media is important to tackle core problems of stigmatization and discrimination. The importance of mass media stem from directing the public opinion to the core of the problem, and collectively searching for a solution that would help protect people with albinism. In fact, the more mass media campaigns are launched, the more enlightenment of the rights of people with albinism.

69. It is also important to involve religious authorities to protect people with albinism and discourage any attack against them. The co-operation of different authorities could be beneficial for people with albinism. In fact, religious leaders are usually well-placed to provide followers with guidance which would address the problems faced by people with albinism and could suggest remedial measures for these problems as well as protective measures that would contribute to the promotion and protection of their rights.

70. Resources – both financial and otherwise - are important in the success of any effort to improve the lives of people with albinism. Resources would be helpful for activities designed to decrease prejudice and create an environment conducive for respect of the rights of individuals with albinism.

71. To make the efforts of all the aforesaid sectors succeed, there is a need for implementing a strategy that would protect people with albinism. It is important to have an effective strategy to bring efforts together in the countries concerned. To do that, there is need for coordination and support from all sectors, key stakeholders as well as people with albinism. Such strategy should be based on the cooperation of state authorities, civil society and individuals.

B. A dedicated mechanism for a holistic approach

72. Although the increased engagement of international and regional mechanisms on the issue of persons with albinism is welcome, efforts continue to be fragmented and reflect only partially the complexity of human rights challenges that need to be addressed at the country level. A more sustainable response to bridge protection gaps and to ensure accountability for human rights violations committed against persons with albinism is required.

73. Therefore it is necessary to consider having a specific and dedicated mandate-holder to work on ending violence against persons with albinism and effectuate mechanisms to end the structural and multi-layered discrimination against them.

74. The mandate-holder would initiate and foster a holistic approach on the issue. Further a dedicated mechanism on the issue would have better access to information, and would therefore have a better understanding on albinism both regionally and globally, and could initiate as well as follow-up on concrete measures taken on the ground, through regular field visits and cooperation with authorities, civil society and other key stakeholders.

C. Summary - key points

75. In order to respond to the severity of attacks against persons with albinism and address their root causes, a holistic approach is necessary. Measures combating discrimination, including superstition, misconception and stigma are crucial for diminishing the multiple and intersecting forms of discrimination affecting persons with albinism.

76. Data on cases of killings and attacks are scarcely available.³⁷

77. Although the increased engagement of international and regional mechanisms on the issue of persons with albinism is welcome, efforts continue to be fragmented and reflect only partially the complexity of human rights challenges that need to be addressed at the country level.

78. There is a need for a dedicated mechanism on the issue such as a specific mandate-holder procedure. This would help ending violence against persons with albinism and addressing the structural and multi-layered discrimination against them.

³⁷ See Reported Attacks of Persons with Albinism (PWA) – Summary – from: Under The Same Sun (UTSS), available online at: http://www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page_0.pdf