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

Written statement* submitted by Standing Voice, a non- governmental organization in special consultative status

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

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* Issued as received, in the language(s) of submission only.



Defending the Rights of Persons with Albinism in Africa

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Standing Agenda Item 3: Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

Clustered Interactive Dialogue with the Special Rapporteur on the Rights of Persons with Disabilities and the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism

Standing Voice is an international NGO defending the rights of people with albinism in Africa. In Africa, people born with the genetic condition of albinism face severe discrimination and violence; many are marginalised from services, and hundreds have been mutilated or murdered, their body parts stolen for use in ritual witchcraft. Based in the United Republic of Tanzania and Malawi and delivering programmes in Health, Education, Advocacy and Economic Empowerment, Standing Voice seeks to amplify the voices of people with albinism and equip them with the tools to reclaim their place in society.

On the occasion of the fortieth session of the Human Rights Council—and in conjunction with the latest report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (UN document code: A/HRC/40/62)—Standing Voice provides this written statement as a means of identifying current critical challenges in the realisation of human rights for persons with albinism in Africa, and elucidating best practices in the protection and empowerment of this severely marginalised group.

The first (and perhaps most urgent) challenge facing people with albinism in Africa is skin cancer. Because of their melanin deficiency, people with albinism are uniquely susceptible to ultraviolet radiation from the sun, and face a greatly elevated risk of developing skin cancer. This is particularly the case in the hot climates of sub-Saharan Africa, and is even more likely when people with albinism are marginalised from healthcare, unable to access sunscreen or regular skin examinations. Certainly in the countries where we work, we have seen systemic social exclusion and an equatorial climate combine to exacerbate melanin deficiency and produce a skin cancer crisis among people with albinism. Across Tanzania and Malawi, a lifetime of social ostracism and reduced access to education mean that many people with albinism lack the self-esteem to seek dermatological care or engage with health information, a situation compounded by a medical culture that can position doctors as authority figures never to be questioned. The destructive synchronicity of these elements continues to wreak havoc on the health of people with albinism. One recent study of 73 patients conducted by Standing Voice in Tanzania found fully developed skin cancer in 23% of participants; precancerous lesions in 70%; and sunburn in 92%: sobering documentation of the prevalence of cancerous and precancerous symptoms in populations of people with albinism for whom dermatological healthcare has not historically been accessible.

Since 2013, Standing Voice has intervened to halt this crisis by growing the first international network of skin cancer prevention services for persons with albinism in Africa. The Skin Cancer Prevention Programme functions by activating dormant networks of community dermatologists and training them to deliver an outreach service of health information and treatment to people with albinism and their families across Tanzania and Malawi every six months. The programme currently reaches 5,362 patients at 49 locations across both countries, with each clinic providing skin cancer screening, liquid nitrogen cryotherapy, preventative education, sun-protective clothing, surgery referral where necessary, and a regular supply of sunscreen. In Tanzania, this sunscreen is specifically made for people with albinism and produced locally in Moshi. The national government supports the programme by providing free venue space, covering selected transport costs, assigning supporting personnel, and paying the salaries of programme dermatologists, who are public-sector

employees. The programme has quickly established itself as the leading model of dermatological healthcare for people with albinism in Tanzania, and, after successful replication in Malawi, is ripe for expansion into other African countries, where the skin cancer crisis continues at pace.

The second challenge facing people with albinism in Africa is the trend of witchcraft-related violence that continues to threaten the welfare and security of this population. Across Africa, beliefs persist in the magical properties of the body parts of people with albinism, which are thought to generate wealth and prosperity when used in witchcraft rituals. This myth has caused 207 murders, and hundreds more attacks, across 28 African countries since 2006. Tanzania presents a uniquely severe case—with 76 murders and counting—though the centre of gravity has recently switched to Malawi, where 150 reports of human rights violations have emerged since 2014. The most recent of these came on New Year’s Eve, when a 54-year-old man with albinism in northern Malawi was dragged from his home and murdered in front of his 9-year-old son. Both hands were amputated and his heart was removed.

Ending this violence requires multi-faceted intervention: strengthening prosecution mechanisms to fight impunity; lobbying to generate the political will necessary for thorough investigations; and awareness-raising at the grassroots level, to transform perceptions of albinism and create a climate of vigilance and care, where people with albinism are valued, included and protected. In her most recent report to the Human Rights Council (A/HRC/40/62), the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism highlights the ideological, judicial and logistical barriers currently restricting access to justice for people with albinism, across Africa but particularly in Malawi: she cites the inability of legislation, in many contexts, to adequately address witchcraft, which is highly resistant to definition and therefore hard to regulate; she commends Malawi, Mozambique and Tanzania for initiating a plan to prevent cross-border trafficking in the body parts of people with albinism, but laments a lack of evidence that this plan is being implemented effectively; and she advises including people with albinism in the development and delivery of community education campaigns to generate awareness of their rights and needs.

The situation in Malawi is particularly urgent, given the country’s impending national elections in May 2019. Following the recent murder of one person with albinism and the separate abduction of a one-year-old baby, a coalition of UN experts—including the Independent Expert on Albinism, as well as Special Rapporteurs on the Rights of Persons with Disabilities; Extrajudicial, Summary or Arbitrary Executions; and Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment—issued a statement calling upon the Government of Malawi to take immediate action. The experts warned: “Election periods can be a dangerous time for persons with albinism as this is when killings and attacks often spike, because of false beliefs that their body parts can bring good luck and political power when used in witchcraft-related rituals [...] These two incidents are part of a larger disturbing pattern in Malawi where ritual killings and egregious human rights violations of the worst kind are instigated specifically against persons with albinism. The attacks and violations are astonishing in their brutality.”¹

The rehabilitation and reintegration of people with albinism who have survived these atrocities is an equally pressing concern. In Tanzania, Standing Voice has established a rehabilitation and training facility for persons with albinism who have suffered physical and psychological abuse; named the Umoja Training Centre—with ‘Umoja’, in Swahili, meaning ‘Unity’—this facility provides a space for people with albinism and their families to interact and heal, to undergo group therapy and enrol in skills development programmes that enable their reintegration into the workplace and wider community life. Standing Voice is currently seeking to replicate similar provisions in Malawi, where there are 21 torture survivors who are yet to receive long-term psychosocial or material assistance to facilitate their recovery. Standing Voice works closely on an individual basis with many of these victims, and has built detailed case studies profiling their needs. We will continue strengthening our network

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<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=24149&LangID=E> (accessed 11/02/2019)

of partnerships in Malawi and invite the collaboration of the United Nations Fund for Victims of Torture to establish a robust programme of rehabilitation and care to support people with albinism in Malawi who have survived this horrific violence.

Standing Voice is delighted to participate in the fortieth session of the Human Rights Council and support the findings illuminated by the latest report of the Independent Expert on the Enjoyment of human rights by persons with albinism (A/HRC/40/62). With the mounting support of the United Nations—and the strengthening of collaboration between all stakeholders across affected states—we hope to puncture the cycle of marginalisation and violence that continues to afflict persons with albinism in Africa.

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