



## **Submission in response to a call for input in relation to Human Rights Council resolution 53/6 on human rights and climate change.**

This is a joint submission led by the Africa Albinism Network in collaboration with albinism organizations from Benin Malawi, Mali, Nigeria, Kenya, Tanzania, and Zambia. The submitting organisations include; Divine Connexion Worldwide, Standing Voice Malawi, Association pour la Promotion, la Protection et l’Insertion Sociale des Personnes Atteintes d’Albinisme (SOS ALBINOS), Anambra State Association of Persons with Albinism, Black Albinism, Tanzania Albinism Society, and Albinism Multipurpose Organisation.

### **The Lead Organization**

The [Africa Albinism Network \(AAN\)](https://africanetwork.org) exists to promote the rights, well-being, and inclusivity of people with albinism in Africa through advocacy, capacity development, and collaboration.

Contact: [info@africanetwork.org](mailto:info@africanetwork.org)

Website: [www.africanetwork.org](https://www.africanetwork.org)

### **Summary<sup>1</sup>**

The Intergovernmental Panel on Climate Change (IPCC) states that Africa is warming faster than the rest of the planet and, if not addressed, will result in adverse impacts on African economies as well as the well-being of all. Persons with albinism, who have reduced melanin pigment in their skin, are disproportionately more vulnerable to the dangerous effects of climate change resulting in a higher incidence of skin cancer particularly in Africa. The United Nations Independent Expert on albinism states that in Africa, it is estimated that persons with albinism are up to 1000 times more likely to develop skin cancer and die by 40 years of age. It is important to advocate for an intersectoral and transdisciplinary planetary approach to address how to mitigate the effects of climate change, specifically related to the ongoing lack of access to sunscreen protection, UV protective clothing, and skin cancer prevention and treatment, socio-economic and other human rights-based measures to advance the climate resilience of a person with albinism, particularly in Africa and the tropical climates affected by climate change.

### **Methodology**

---

<sup>1</sup> Credit for this summary: Astle, B. et al, Abstract submitted to Planetary Health: Protecting & Sustaining the Wellbeing of Our Ecosystems, Conference by Trinity Western University, January 21, 2024.



This submission is compiled by the Africa Albinism Network, drawing on inputs received from human rights defenders who serve as leaders of albinism groups and organizations dedicated to promoting the rights and welfare of Persons with Albinism in their respective African countries. These inputs were collected through one-on-one phone interviews and written submissions, utilizing the questionnaire provided by the Office of the High Commissioner for Human Rights (OHCHR) in relation to Human Rights Council Resolution 53/6 on human rights and climate change. Our submission centres on examining the repercussions of climate change specifically on persons with albinism in Africa. We have gathered insights from the organizations above focusing on their country situations. . Additionally, we have considered other pertinent climate crises across the African continent to provide a comprehensive understanding of the challenges faced by individuals with albinism in the context of the broader climate crisis in Africa.

### **Overview of the Impact of Climate change on the full enjoyment of human rights by Persons with albinism in Africa**

Climate change presents a severe threat to persons with albinism in Africa, with an alarming 90% estimated to face a premature death by age 30 due to skin cancer.<sup>2</sup> Without intervention, they are five-times more likely to die from skin cancer and some estimates show that by age 40, most, - and up to 90% would have had a significant degree of sun-related damage, have contracted or have died from skin cancer.<sup>3</sup> Deforestation exacerbates this risk, as the diminishing tree canopy exposes them to harmful sun rays. The United Nations on the Enjoyment of Human Rights by Persons with Albinism notes that persons with albinism often work outdoors, driven by challenges such as early school dropout, lack of accommodation, and bullying. Living predominantly outdoors in a subsistence lifestyle, they are particularly vulnerable to the health consequences of climate change, impacting both their well-being and socio-economic status. The lack of essential health support, including the omission of sunscreen in national essential medicines lists and limited access to skin cancer treatments, further compounds their vulnerability. Amid escalating ultraviolet radiation linked to climate change, it is crucial to recognize people with albinism as a high-risk group in global climate discussions. Their inclusion in platforms like the Conference of Parties (COP) to the UN

---

<sup>2</sup> <https://beyondsuncare.org/en/albinism-in-africa/>

<sup>3</sup> Human Rights Council (HRC), 'Preliminary study on the situation of human rights of persons with albinism' (2014) A/HRC/AC/13/CRP.1 para 22



Convention on Climate Change and national strategies for achieving Sustainable Development Goal 13 is imperative for addressing their unique challenges.

## Responses to the Questionnaire in relation to Human Rights Council resolution 53/6 on human rights and climate change

1. Please describe through concrete examples and stories the impacts of loss and damage from the adverse effects of climate change on the full enjoyment of human rights in your country. Please indicate whether the impact was exceptional or whether an example of many similarly situated cases. Please estimate the number of cases that may be similar in your country.

Climate change has the potential to exacerbate existing inequalities and vulnerabilities, affecting various aspects of the human rights of persons with albinism, including the right to life, health, housing, water, and food. For instance:

- **Right to Life:** Extreme weather events, such as hurricanes, floods, or heatwaves, can result in loss of life, displacement, and community destruction. Vulnerable populations, including persons with albinism, face heightened risks. In Malawi, during cyclone Freddy, a person with albinism was attacked and killed while in a temporary shelter. In Madagascar, persons with albinism were targeted and attacked for their body parts due to prolonged droughts, causing food shortages and famine.
- **Right to Health:** Skin cancer, linked to sun exposure and increasing ultraviolet radiation, poses a significant threat to the survival of persons with albinism in the continent, damaging their skin, appearance, and health, and claiming lives. Estimates put these various damages to health and loss of life as affecting up to 90% of people with albinism in the region, before age 30.<sup>4</sup>
- Changes in climate patterns contribute to the spread of diseases, affect food security, and impact access to clean water, disproportionately affecting marginalized communities. Given that many people with albinism, as a constituent of people with disability are often socio-economically poor, they are more vulnerable to this socio-economic impact of climate change.

<sup>4</sup> <https://beyondsun care.org/en/albinism-in-africa/>



- The slow onset of heat and increasing UV rays leads to lasting damage to the melanin-deficient skin of persons with albinism in Africa, resulting in the development of lesions and eventual skin cancer. Skin cancer stands as the primary cause of morbidity among persons with albinism in Africa, exacerbated by the lack of adequate healthcare infrastructure, including sunscreen and protective gear. These challenges intensify during climate crises, such as flooding, droughts, and temperature hikes.
- **Stigma and Discrimination:** Sun damage on the skin of people with albinism contributes to the disfiguration of their appearance. This is due to sun-induced – often permanent – lesions and visible scarring. In addition to worsening the discrimination they face in society at large, the sun-induced scarring is often a barrier to employment. In addition, sun-induced scarring contributes to myths against people with albinism as seen by the names they are often called – often names of animals such as monkeys, pigs, and other dehumanizing names.<sup>5</sup>

**2. Please describe any relevant quantitative and qualitative data as well as mechanisms and tools to measure, monitor, report on, and evaluate the impacts of loss and damage, including from extreme weather and slow-onset events, on the full enjoyment of human rights. Please take into account, inter alia, the disproportionate effects on women and girls, children, youth, older persons, persons with disabilities, Indigenous Peoples, migrants, persons living in poverty, and others in vulnerable situations.**

In the last 20 years, UVA/UVB rays have increased in Africa by a significant margin. The desertification process across the continent is growing at alarming rates, with deforestation increasing by substantial percentages. Temperatures rise by several degrees, and rainfall has diminished by considerable amounts. These factors contribute to making a hotter, drier Africa in most parts, exposing people with albinism, who are already left out of health measures, to the adverse reality of these conditions.

Given that about 85% of persons with albinism in Africa live in rural areas where subsistent farming and peddling are common, the exposure leaves them highly

<sup>5</sup> [chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.underthesamesun.com/wp-content/uploads/2023/06/Names-used-for-PWA-website-ready.pdf](https://www.underthesamesun.com/wp-content/uploads/2023/06/Names-used-for-PWA-website-ready.pdf)



vulnerable to damage of skin and corresponding fatality. <sup>[6]</sup> The number of persons with albinism suffering and dying from skin cancer is not collected by most governments in the region. However, a sample of 3500 people with albinism in Malawi, showed that 75% had developed skin cancer.<sup>6</sup> in Kenya, over 4,000 persons with albinism are currently benefiting from the monthly allocation of sunscreen products through the National Albinism Sunscreen Support Program (NASSP)<sup>7</sup>

**3. Please describe any specific measures, including public policies, legislation, practices, strategies, or institutional arrangements that your Government has undertaken or plans to undertake at a national, sectoral, or sub-national level, in compliance with applicable international human rights law, to avert, minimize and address loss and damage, including equity-based approaches and solutions. Please also identify any relevant mechanisms for ensuring accountability, including means of implementation.**

- **Climate Change Mitigation and Adaptation Policies:** Governments across Africa implement policies aimed at reducing greenhouse gas emissions (mitigation) and adapting to the impacts of climate change. For instance, in 2021, the Nigerian federal government enacted a Climate Change Act, alongside several other climate change-related policies. Similarly, the Tanzanian government has had a National Climate Change Policy since 2012, among other initiatives including the National Environmental Policy of 2004.
- **National Climate Action Plans:** Many countries develop National Determined Contributions (NDCs) outlining their commitments to climate action under international agreements such as the Paris Agreement. NDCs often include both mitigation and adaptation measures. Nigeria, Tanzania, and Zambia among others updated their NDCs in 2021 while adopting other climate-related strategies to deal with the changing weather patterns
- **National Action Plans on Albinism:** Based on the African Union Plan of Action on albinism, and local advocacy, several countries in Africa have adopted National Action Plans on Albinism and similar policies which include sunscreen on the essential medicines list. These include Kenya, Malawi,

<sup>6</sup> <https://beyondsuncare.org/en/albinism-in-africa/>

<sup>7</sup> National Council on Persons with Disabilities, 'Albinism (Support Program)' <https://ncpwd.go.ke/albinism-support-program>.



Mozambique, Angola and Uganda. Others have invested in local production such as in Tanzania and Malawi as well as in subsidized skin cancer treatment such as in Kenya and Nigeria

**4. Please identify and share examples of promising practices and critical challenges in the promotion, protection, and fulfilment of the full enjoyment of human rights in the context of loss and damage, including examples that highlight multilateral cooperation and approaches, at global and regional levels, including equity-based approaches and solutions.**

**Promising Practices:**

- **Local Production of Sunscreen:** Local production of sunscreen is vital to make the products available and accessible, including economic accessibility. Since 2012, the Kilimanjaro Sunscreen Production Unit under the Regional Dermatology Training Centre (RDTC) has delivered over 21,300 pots of Kilisun to persons with albinism across Tanzania.<sup>8</sup> Similar production units are available in Malawi, Ghana, and Ivory Coast which provide this essential product to persons with albinism.
- **Mobile Clinic to Distribute Sunscreen:** Mobile clinics run by Standing Voice in Malawi and Tanzania distribute sunscreens, wide-brimmed hats and conduct regular skin screenings for persons with albinism with over 5900 beneficiaries since 2017.
- **Annual Purchase of Sunscreen:** The governments of Kenya, South Africa, Namibia, and Zambia procure sunscreen lotions which are distributed among persons with albinism through health facilities and albinism associations. For instance, over 4000 bottles of sunscreen lotions are distributed to persons with albinism annually in Kenya by the National Council for Persons with Disability through the National Albinism Sunscreen Support Program<sup>9</sup>
- **National Essential Medicine List includes sunscreen not as a cosmetic but as a lifesaving and health measure: As mentioned above, South Africa, Kenya, Namibia, and Zambia have sunscreens listed as an essential medicine for**

<sup>8</sup> Standing Voice, 'Skin Cancer Prevention Program Annual Report 2018-2019' (2020)

<sup>9</sup> National Council on Persons with Disabilities, 'Albinism (Support Program)' <<https://ncpwd.go.ke/albinism-support-program/>>





persons with albinism. They therefore are making efforts to make it easily accessible and available by purchasing and distributing it to beneficiaries.

- **Cash Transfers to Mitigate Socio-Economic Shocks:** In Countries such as Namibia, South Africa, and Ghana, Persons with albinism are beneficiaries of disability allowances. For instance, persons with albinism in Namibia receive monthly allowances once qualified and after being assessed and certified by doctors as persons with disabilities.
- **Business Loans to People with Disabilities to Find Alternative Livelihoods:** In countries such as Ghana, Zambia, Kenya, and Tanzania, persons with disabilities including those with albinism are provided with start-up capital in the form of soft loans to establish small businesses. For instance, persons with albinism in Ghana benefit from the 3% District Assemblies Common Fund dedicated to persons with disabilities for various purposes including start-up capital, education, and healthcare.
- **Inclusive Climate Action Planning:** Countries adopting inclusive climate action planning, which involves engaging diverse stakeholders, including civil society, marginalized groups, and indigenous communities. This ensures that policies are equitable and reflect the needs of all populations.

#### **Critical Challenges:**

- **Discrimination and Stigma:** Systemic discrimination often results in the exclusion of persons with albinism from essential conversations about climate change, hindering their ability to contribute to the development and implementation of policies that directly impact them. This exclusion perpetuates a cycle of marginalization, leaving this population disproportionately vulnerable to the adverse effects of climate change.
- **Resource and Capacity Gaps:** In most cases, adaptation and mitigation measures put in place leave out the specific needs of persons with albinism such as the provision sunscreen lotion as an essential medicine with a structure in place to ensure distribution and education around its use as well as accessibility to and quality of the product. This in addition to other reasonable accommodation for students with albinism including adapting uniforms to enhance protection are necessary.

- **Displacement and Migration:** Climate-induced displacement poses a significant challenge, and the lack of a clear framework for protecting the rights of climate migrants remains a global issue. This includes challenges related to citizenship, legal status, and access to basic services. Aside these, persons with albinism are particularly vulnerable when displaced due to attacks and other harmful practices. For instance, in Madagascar where they are housed in police/Gendarmerie quarters without adequate protection in a high UV area of the Country. Also, migrant with albinism from DRC (Democratic Republic of Congo) found in immigration camps under tents in Uganda without proper protection measures

5. **Please provide specific recommendations, if possible, on how to address the critical challenges that have been identified, including actions to be taken at country, regional, and global levels, as well as by different groups of stakeholders, Governments, development agencies, financing institutions, and others.**

- **National Essential Medicine list should include sunscreen:** We strongly advocate for the inclusion of sunscreens on the essential medicine list by the World Health Organization and governments throughout Africa. This crucial addition would serve as a protection measure against the loss and damage to the health and life of people with albinism. They should ensure that such sunscreen is distributed equitably, especially to those in the rural areas, and that there is access facilitated by mobile clinics and social cash transfers as demonstrated in Kenya and Malawi.

To ensure sustainability, affordability, availability, and widespread distribution, countries in Africa should consider local production of sunscreen. This also enables a bespoke product that responds to the particular degree of environmental damage from climate change in the local context. This, in turn, will empower persons with albinism to safeguard their health effectively, fostering a substantial reduction in the adverse health impacts associated with prolonged sun exposure.

- **Integration of Human Rights in Climate Policies:** Governments should ensure that climate policies and adaptation plans explicitly integrate human rights considerations, taking into account the specific vulnerabilities of persons



with albinism. This includes addressing health risks associated with increased UV radiation due to climate change.

- **Inclusive Decision-Making Processes:** Foster inclusive decision-making processes that involve persons with albinism as a key group at risk among other groups with disabilities and other vulnerable groups in shaping climate policies and adaptation strategies at the local and national levels.
- **Community-Based Adaptation Programs:** Implement community-based adaptation programs that consider the unique needs of persons with albinism. This may involve providing resources for sunscreen production, distribution and other sun protection measures such as sun protective clothing, healthcare, and public education.
- **Education and Awareness Programs:** Develop and integrate in public education programs about climate change, awareness programs at the intersection of climate change and the specific challenges faced by persons with albinism. This can include training on adaptive strategies and access to healthcare.
- **Equitable Climate Finance:** Advocate for and ensure equitable access to climate finance, with a focus on supporting adaptation and resilience-building measures for vulnerable communities, including persons with albinism focusing on socio-economic poverty alleviation, support for career shift through loans to move from outdoor work to work indoors.
- **Mainstreaming Human Rights in Projects:** Development agencies and financing institutions should mainstream human rights considerations into climate-related projects, ensuring that the specific needs of persons with albinism are considered in the design and implementation phases.
- **Support for Adaptation Measures:** Allocate funds specifically for adaptation measures that address the intersectionality of climate change impacts and vulnerabilities faced by persons with albinism.
- **Raise Awareness and Advocate for Inclusion:** Civil society organizations and advocacy groups should raise awareness about the challenges faced by persons with albinism in the context of climate change and advocate for their inclusion in climate policies and programs.



- **Capacity Development** Provide capacity-development support to empower persons with albinism and their communities to actively participate in decision-making processes related to climate change adaptation and resilience.

**6. Please provide any additional information you believe would be useful to support climate action and justice that promotes the full enjoyment of human rights in the context of loss and damage.**

- Recognize and address the intersectionality of vulnerabilities. Individuals may face multiple layers of disadvantage, and climate policies should be sensitive to these intersections. This includes considering how gender, age, disability, and other factors such as albinism compound the impacts of climate change.
- Promote legal empowerment of marginalized communities. This involves ensuring that communities, including persons with albinism, are aware of their legal rights, have the capacity to claim those rights, and are supported in accessing legal mechanisms when necessary.
- Involve young people in climate decision-making processes. Youth with albinism are not only highly affected by climate change but also important advocates for sustainable and equitable solutions. Their active participation ensures intergenerational equity in climate action.
- Implement participatory monitoring and evaluation mechanisms for climate projects. Involve local communities, including persons with albinism, in the assessment of the effectiveness and impact of adaptation and mitigation measures.
- Build the capacity of local governance structures to effectively plan, implement, and monitor climate initiatives. Local authorities play a crucial role in translating global and national policies into actionable measures that address the specific needs of communities.
- Conduct inclusive research and data collection that captures the diverse experiences of communities. Ensure that data is disaggregated by gender, age, disability, and other relevant factors to inform evidence-based decision-making.