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Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Enjoyment of human rights by persons with albinism

Note by the Secretary-General**

The Secretary-General has the honour to transmit to the General Assembly the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond, in accordance with Human Rights Council resolutions [28/6](#) and [55/18](#).

* [A/80/150](#).

** The present document was submitted after the deadline for reasons beyond the control of the submitting office.



Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond

The right to health and persons with albinism in the context of skin cancer

Summary

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism provides analyses on the right to health for persons with albinism, focusing particularly on how this right relates to skin cancer. She sets out the health concerns and determinants for persons with albinism and highlights the obligations of States to prevent and treat skin cancer, including preventing deaths. She further makes recommendations for ensuring the full realization of the right to health for persons with albinism.

The Independent Expert also outlines in the present report activities undertaken in the implementation of her mandate over the period from July 2024 to July 2025, including collaborative work and research initiatives, community- and State-level engagements, and training programmes.

I. Introduction

1. The present document is submitted to the General Assembly pursuant to Human Rights Council resolutions [28/6](#) and [55/18](#).
2. In preparing the report, the Independent Expert on the enjoyment of human rights by persons with albinism sent a call for input in the form of a questionnaire to Member States and held consultations with civil society and non-governmental entities through virtual meetings and surveys. In addition, the Independent Expert interviewed 19 experts, comprising albinism rights advocates in Africa, Europe and Latin America, as well as organizations directly providing health services for persons with albinism, including through implementation and support of local production of sunscreen lotion.
3. In response to the questionnaire, the Independent Expert received submissions from seven Member States, namely, Paraguay, Saudi Arabia, South Africa, Cuba, Colombia, Australia and Brazil, while 36 civil society actors from Africa, Latin America, the Middle East, Europe and North America responded with data and information.
4. In the report, the Independent Expert builds on the work of the previous mandate holder, Ikponwosa Ero, on the right to health for persons with albinism,¹ focusing particularly on how this right relates to skin cancer. She sets out the health concerns and determinants for persons with albinism and highlights the obligations of States to prevent and treat skin cancer, including preventing deaths. She further makes recommendations for ensuring the full realization of the right to health for persons with albinism.
5. Albinism is a rare, non-contagious genetic condition that affects people worldwide regardless of ethnicity or gender. It results in a lack of melanin pigment in the hair, skin and eyes, which makes persons with albinism vulnerable to the harmful health effects of ultraviolet radiation from sunlight.² Global estimates of the occurrence of albinism are contested. However, the most recent study estimates that an appropriate prevalence rate would be between 1 in 12,000 and 1 in 15,000 in Western societies, and between 1 in 4,000 and 1 in 7,000 in Africa. The study estimates the highest prevalence rates were found in population isolates, ranging from 1 in 22 to 1 in 1,300.³ Often, there is a lack of disaggregated data on the status of persons with albinism,⁴ which remains a major hindrance to the effective formulation of a rights-based approach to their situation.

Activities of the Independent Expert in 2025

6. During the reporting period, the Independent Expert undertook various activities in the implementation of her mandate, some of which are highlighted below.
7. The Independent Expert conducted a country visit to the United States, including Puerto Rico, from 7 to 18 October 2024, where she met various stakeholders, including federal and state officials and a broad representation of civil society organizations. The visit presented the Independent Expert with the opportunity

¹ [A/HRC/37/57](#).

² See Mark T. Carew and others, “Unprotected: the consequences of climate change for the health of persons with albinism”, in *BMJ Global Health*, vol. 9 (8 September 2023).

³ Jennifer G. R. Kromberg, Kaitlyn A. Flynn and Robyn A. Kerr, “Determining a worldwide prevalence of oculocutaneous albinism: a systematic review”, in *Investigative Ophthalmology & Visual Science*, vol. 64, No. 10 (July 2023).

⁴ See General Assembly resolution [78/171](#).

to assess the human rights situation of persons with albinism and those with Heřmanský-Pudlák syndrome. She participated in conferences and workshops, both in person and virtually, on topics that included disability-based violence, persons with albinism as human rights defenders, climate change and harmful practices related to witchcraft accusations and ritual attacks.

8. The Independent Expert continued to engage with albinism groups around the world, including by participating in activities organized by those groups and carrying out capacity-building programmes for persons with albinism. From 9 to 11 September 2024, the Independent Expert participated as an *amicus curiae* in a hearing of a case brought against the Government of the United Republic of Tanzania at the African Court on Human and Peoples' Rights. In addition, the Independent Expert conducted workshops and engagements with diplomatic entities, including senior government officials, to follow up on issues affecting persons with albinism and future plans of the mandate.

9. On 5 May 2025, the Independent Expert made an oral statement at an open hearing at the twenty-fifth World Health Organization (WHO) Expert Committee on Selection and Use of Essential Medicines. The Independent Expert, in collaboration with other partners, including the Special Rapporteur on the promotion and protection of human rights in the context of climate change, submitted an application for the addition of sunscreen to the national essential medicines list. Furthermore, the Independent Expert continued consultations with the African Committee of Experts on the Rights and Welfare of the Child, including by providing technical assistance in the finalization of a guidance note on reporting on the rights and welfare of children with albinism in Africa.

II. Health concerns for persons with albinism

10. There are different types of albinism worldwide, each of which is accompanied by unique health challenges. Oculocutaneous albinism is thought to be the most common globally. It is characterized by a lack of melanin in the eyes, hair and skin. Ocular albinism, by contrast, is a form of albinism characterized by a lack of melanin in only the eyes. Both types of albinism result in visual health concerns. Persons with oculocutaneous albinism also have skin-related health concerns, including vulnerability to skin cancer.

11. Other rarer forms of albinism have accompanying unique health challenges. Heřmanský-Pudlák syndrome is a rare form of albinism with an estimated prevalence of 1 in 1,000,000 individuals worldwide. In addition to a lack of melanin and visual impairments, persons with Heřmanský-Pudlák syndrome have platelet dysfunctions, leading to prolonged or excessive bleeding due to difficulties in forming blood clots.⁵ Depending on the type of Heřmanský-Pudlák syndrome, they may also experience gastrointestinal complications and lung disorders, with some having to receive a double lung transplant. Among communities of Puerto Rican heritage, the prevalence is 1 in 18,000.⁶

12. Chédiak-Higashi syndrome is another rare form of albinism characterized by easy bruising, abnormal functions of the white blood cells and recurrent pyogenic infections.⁷ In adulthood, this albinism can affect the nervous system, leading to

⁵ See Justin R. Federico and Karthik Krishnamurthy, "Albinism" in *StatPearls* (2025).

⁶ See <https://rarediseases.org/rare-diseases/hermanskypudlak-syndrome/>.

⁷ See Anitha Ajitkumar, Siva Naga S. Yarrarapu, Kamleshun Ramphul, "Chédiak-Higashi syndrome", in *StatPearls* (2025).

weakness, difficulty with walking and seizures.⁸ According to estimates, there are fewer than 500 reported incidences worldwide.⁹

A. Vision disabilities

13. The condition of albinism includes reduced visual acuity, nystagmus, photophobia, refractive error, foveal hypoplasia, optic nerve misrouting and, in some cases, strabismus. The conditions cannot be corrected but could be managed with visual aids, such as glasses and bioptics, which can enhance vision.¹⁰ Glare from sunlight exacerbates existing concerns with visual perception and causes extreme discomfort.¹¹ Thus, sunglasses with appropriate ultraviolet radiation protection may also assist in relation to photophobia, while glasses, prisms, vision therapy and, in some cases, eye muscle surgery can help improve visual alignment in relation to strabismus. The various visual concerns mean that persons with albinism require regular visits to eye specialists, specifically ophthalmologists.

B. Susceptibility to skin damage, including skin cancer

14. Persons with albinism are highly susceptible to skin damage from the sun and are particularly vulnerable in areas with high ultraviolet index. The various forms of skin damage include sunburn, photoaging, solar lentigines and actinic keratoses (pre-cancerous lesions), as well as skin cancer. Persons with albinism globally are at much higher risk of developing skin cancer from ultraviolet radiation exposure than the general population due to their lack of melanin. In Africa, persons with albinism are up to 1,000 times more likely to develop skin cancer, compared with the general population,¹² and an estimated 98 per cent do not live beyond 40 years of age if sun protective precautions are not adopted, with skin cancer being responsible for at least four fifths of those deaths.¹³

15. Among persons with oculocutaneous albinism, squamous cell carcinoma is the most commonly diagnosed skin cancer, accounting for 75 to 88 per cent of cases, followed by basal cell carcinoma (9 to 23 per cent) and rare cases of melanoma (1.3 to 3 per cent).¹⁴ Globally, basal cell carcinoma and squamous cell carcinoma have higher mortality rates.¹⁵ According to data by the Global Cancer Observatory, there are over 69,000 deaths globally from these,¹⁶ with the highest number of deaths occurring in Asia (32,027), Europe (13,111) and Africa (9,269).

16. While these data are not disaggregated to enable identification of the number of persons with albinism affected, albinism organizations report high rates of pre-cancerous

⁸ See <https://www.ncbi.nlm.nih.gov/medgen/3347?report>.

⁹ “Chédiak-Higashi syndrome” (2025).

¹⁰ See A/HRC/58/57/Add.1, para. 10.

¹¹ See A/78/167, para. 24.

¹² See Musab A. Dfallahand others, “Exploring the intersection of albinism and Trichilemmal carcinoma: A case of bilateral trichilemmal carcinoma in the axilla”, in *International Journal of Surgery Case Reports*, vol. 128 (2025).

¹³ See “Unprotected” (2023).

¹⁴ See Molikuo Harriet Makuru and others, “Clinico-pathologic profile of skin cancers in oculocutaneous albinism at Universitas Academic Hospital”, in *Health SA Gesondheid*, vol. 30 (2025).

¹⁵ See Amdad Hossain Roky and others, “Overview of skin cancer types and prevalence rates across continents” in *Cancer Pathogenesis and Therapy*, vol. 3, No. 2 (2025), pp. 89–100.

¹⁶ See Global Cancer Observatory, “Non-melanoma Skin Cancer”, factsheet, 8 February 2024. Available at <https://gco.iarc.who.int/media/globocan/factsheets/cancers/17-non-melanoma-skin-cancer-fact-sheet.pdf>.

skin lesions and skin cancer diagnosis among their members. For example, in April 2025, the Albinism Fellowship of Australia surveyed 100 of its members, and 83 per cent reported to have received a cancer diagnosis. Of those diagnosed, 38 per cent were aged 21 to 30 years, while 45 per cent were aged 31 to 50.¹⁷ Standing Voice, a civil society organization, reports that, in Malawi and the United Republic of Tanzania, a combined total of between 400 and 500 persons with albinism are referred for skin cancer surgery each year. It further notes that, in 2024, there was a total of 420 referrals (335 in the United Republic of Tanzania and 85 in Malawi) with 54 per cent of all tumours identified on the scalp, neck, eyes, ears and face. Beyond Suncare, a civil society organization, reported that, from 2022 to 2025, there were 46 cases of skin cancer within the albinism community in Rwanda, including 13 cases involving children.¹⁸ Corporación Albinos Chile reported that, of its 400 members, approximately 30 had been diagnosed with pre-cancerous skin lesions, and 15 with skin cancer. Stakeholders from Brazil reported that, out of 390 members surveyed, 98 reported a skin cancer diagnosis.¹⁹ In addition, out of 700 members, over 60 per cent reported having pre-cancerous skin lesions.

17. Skin cancer often occurs on sun-exposed areas, including the head, neck or face,²⁰ resulting in disfigurement and extreme pain, leading to negative psychosocial effects.²¹ Sunscreen and good sun protection are critical for skin cancer prevention.²²

C. Increased mental health concerns due to stigma

18. In addition to skin cancer and other physical health challenges, persons with albinism suffer from low self-esteem and, in some cases, suicidal ideation. There is a lack of psychosocial support for those who struggle with mental health issues arising from the widespread discrimination, exclusion and bullying they endure in many societies globally.²³

19. Discrimination on the basis of skin colour is a dominant experience for all persons with albinism, regardless of age or any other status, which has a negative impact on their mental health.²⁴ As one young person from the United Kingdom of Great Britain and Northern Ireland shared, “I was bullied mercilessly. They would pull my hair out because they said it wasn’t real and they’d make me open my eyes and shove my head at the sun, and the kids were burning cigarettes in the back of my neck because they said I had devil eyes.”²⁵ Bullying is also common for adults with albinism. In Madagascar, one female lawyer with albinism was hired at a salary lower

¹⁷ Albinism Fellowship of Australia.

¹⁸ Response from Beyond Suncare.

¹⁹ Colectivo Nacional das Pessoas com Albinismo.

²⁰ See P. T. Lekalakala, “Oculocutaneous Albinism and Squamous Cell Carcinoma of the Skin of the Head and Neck in Sub-Saharan Africa”, in *Journal of Skin Cancer* (2015).

²¹ See Zilefac Brian Ngokwe and others, “Non-melanoma skin cancer in the context of albinism with an associated facial nerve palsy”, *International Journal of Surgery Case Reports*, vol. 125 (2024).

²² See “Unprotected” (2023).

²³ See Ikponwosa Ero and others, “People With Albinism Worldwide: A Human Rights Perspective” (2021).

²⁴ See Sarah L. Bosha and others, “The Forgotten Ones: The Impact of Climate Change on the Health and Well-being of Persons with Albinism” (O’Neill Institute for National and Global Health Law, 2025).

²⁵ Muluka-Anne Miti-Drummond and others, “Persons With Albinism And Their Right To Health, Education And Employment In The UK: Preliminary Research Findings” (2024), p. 26. Available from <https://www.ohchr.org/sites/default/files/documents/issues/albinism/Persons-with-albinism-right-health-in-the-UK.pdf>.

than that of her peers in the same position and was continually told that her presence was a liability for the company. She later left the company due to the bullying.²⁶

20. Victims of attacks, particularly mutilation, experience trauma and significant impacts to their mental health following the highly traumatic experiences. In a group discussion, leaders of albinism groups identified that the discrimination, bullying and microaggressions, and sometimes physical aggression, lead to a form of racial trauma. However, few – if any – receive psychological support following the attacks. It is evident that there is a need to provide mental health support to persons with albinism.²⁷

III. Legal and policy framework

A. International and regional human rights laws and standards

21. The Convention on the Rights of Persons with Disabilities, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, and the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, provide varying forms of protections to persons with albinism, including their right to health.

22. Article 12 of the International Covenant on Economic, Social and Cultural Rights protects the right to the highest attainable standard of physical and mental health for every person. Article 25 of the Convention on the Rights of Persons with Disabilities emphasizes the principle of non-discrimination in the enjoyment of the right to health, emphasizing access to quality, free or affordable healthcare, of the same standard as provided for other persons, including those living in rural areas, and equal access to health insurance programmes. It also mandates the provision of health services needed by persons with disabilities tailored to their needs, including early identification and intervention.

23. Various regional human rights instruments also guarantee the right to health and obligate States Parties to provide the necessary healthcare benefits, including preventative services. For example, article 16 of the African Charter on Human and Peoples' Rights, article 35 of the Charter of Fundamental Rights of the European Union, article 39 of the Arab Charter of Human Rights, and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, provide for a progressive right to healthcare.

24. The right to health is subject to progressive realization, requiring States to monitor regularly efforts to realize the right to health, in order to ensure they are making adequate progress based on the available resources.²⁸ States have an obligation to mobilize resources for health access, including through international cooperation.²⁹

25. In addition, the right to health for persons with disabilities is distinctly protected in the Protocol to the African Charter on Human and Peoples' Rights on the Rights of

²⁶ See [A/HRC/52/36/Add.1](#), para. 64.

²⁷ See [A/HRC/58/57/Add.2](#), para. 49.

²⁸ Lisa Montel and others, "How should implementation of the human right to health be assessed? a scoping review of the public health literature from 2000 to 2021", in *International Journal for Equity in Health*, vol. 21 (September 2022).

²⁹ See Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) on the right to the highest attainable standard of health, para. 38.

Persons with Disabilities in Africa, which requires that they be given access to health services on an equal basis as those without disabilities, and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, which mandates States to provide for the physical, economic and social needs of women with disabilities.

B. Relevant international and regional policies

26. In its general comment No. 14 (2000) on the right to the highest attainable standard of health, Committee on Economic, Social and Cultural Rights outlines the “availability, accessibility, acceptability and quality” framework for the protection and promotion of human rights. Availability is the existence in sufficient quantity of functioning public health and healthcare facilities, goods and services. Accessibility means that health facilities, goods and services are accessible to everyone without discrimination. Acceptability means that health facilities, goods and services must be respectful of medical ethics and culturally appropriate and sensitive to statuses such as disability. Quality means that health facilities, goods and services must be scientifically and medically appropriate and of good quality, including skilled medical professionals.

27. In its general comment No. 9 (2006) on the rights of children with disabilities, the Committee on the Rights of the Child indicates that health policies should provide early detection of disabilities and early intervention as necessary, such as providing physical aids. The Committee recommends that States Parties provide post-natal healthcare services and develop campaigns to inform parents and caregivers on the basic healthcare needs of the child. Moreover, healthcare professionals providing services to children with disabilities should be highly skilled and trained to deliver child-centred services.

28. States have a responsibility to advance health equity for persons with disabilities, pursuant to achieving universal health coverage.³⁰ This includes ensuring that all people, including those with albinism, have access to the full range of quality health services they need, when and where they need them, without financial hardship. Universal health coverage addresses the continuum of care encompassing health promotion, prevention, treatment, rehabilitation and palliative care across the course of life.³¹ It is central to achieving Sustainable Development Goal 3, to “ensure healthy lives and promote well-being for all at all ages”.

29. The African Union Regional Action Plan on Albinism in Africa (2017–2021) and the subsequent Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031) serve as key policy tools.³² The Plan of Action calls upon Member States to build the capacity of health workers, including traditional midwives, to enhance not only the promotion and protection of human rights of persons with albinism, but also the provision of psychosocial and medical support to victims and survivors of attacks. It further provides that States must ensure access to health services and goods, including visual aids, sunscreen lotion, skin cancer prevention and treatment, and low vision and dermatological care for all persons with albinism, particularly in rural areas.

³⁰ WHO, *Global Report on Health Equity for Persons with Disabilities* (Geneva, 2022).

³¹ WHO, “Universal Health Coverage”, factsheet 26 March 2025. Available at [https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-\(uhc\)](https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)).

³² See A/HRC/49/56, paras. 32 and 71.

30. In 2024, the Southern African Development Community adopted the Declaration on the Protection of Persons with Albinism,³³ in which it called on member States to add sunscreen lotion to their national essential medicine lists.³⁴ Furthermore, special mechanisms, such as a special envoy for persons with albinism in the African Union, have been proposed to support human rights protection.³⁵

31. In 2018, the African Court on Human and Peoples' Rights issued a pivotal judgment in which it noted that lack of access to sun protection, including sunscreen lotion, constitutes "the thin line between good health and serious infirmity" for persons with albinism. Further noting that States are obligated to seek international assistance to ensure access to sun protection for persons with albinism, and to raise awareness and provide medical information about albinism.³⁶

32. In the case of *Vera Rojas and Others v. Chile*, the Inter-American Court of Human Rights held that States have a duty to regulate, monitor and oversee the activity of all public and private actors that finance the healthcare system.³⁷ In addition, the Court held that children and their caregivers should have access to information related to their disabilities, including causes, treatment and prognosis.

IV. Determinants of health for persons with albinism

A. Socioeconomic determinants

33. The right to health of persons with albinism is influenced by social determinants of health,³⁸ that is, the conditions in which they are born, grow, work, live and age. For persons with albinism, stigma and discrimination permeate their lived experiences and contribute to social exclusion in education and access to employment. In Japan, persons with albinism have been rejected after job interviews because of the colour of their hair, while, in Colombia, some employers have been unwilling to employ persons with albinism because of perceived liability for sunburn and skin damage at work. Owing to these barriers, many persons with albinism are self-employed, which often involves working outdoors with dangerous levels of sun exposure.³⁹ This results in high rates of poverty among persons with albinism,⁴⁰ low wages and high job insecurity. As a result, they are unable to afford access to good health services or transportation and other associated costs of care. This social exclusion is experienced from birth and throughout their lifetimes and is directly linked to poor physical and mental health outcomes and, in some cases, affects their health-seeking behaviour and their ability to gain access to quality, inclusive healthcare services.⁴¹

³³ See <https://dirco.gov.za/communique-of-the-44th-ordinary-summit-of-sadc-heads-of-state-and-government-17-august-2024/>.

³⁴ Southern African Development Community, "Declaration on the Protection of Persons with Albinism" (2024). Available at <https://www.ohchr.org/en/documents/statements/declaration-protection-persons-albinism>.

³⁵ See A/HRC/58/57, para. 39.

³⁶ African Court on Human and Peoples' Rights, *Centre for Human Rights and Others v United Republic of Tanzania*, Application No. 019/2018, paras. 345, 349 and 354.

³⁷ See https://www.corteidh.or.cr/docs/casos/articulos/seriec_439_ing.pdf.

³⁸ See https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1.

³⁹ See A/78/167, para. 41.

⁴⁰ See A/76/769.

⁴¹ See "The Forgotten Ones" (2025).

B. Climate change and health

34. Climate change is also a social determinant of health.⁴² The incidence of skin cancer has been increasing globally due to climate change. By 2050, there will be an additional 90 million skin cancer cases in North-Western Europe alone.⁴³ Ultraviolet radiation exposure is the primary cause of skin cancer and is considered a complete carcinogen due to its ability to act as a mutagen and initiate tumour formation without the presence of another factor. Globally, for every 1 per cent decrease in ozone layer thickness, the incidence of melanoma is projected to increase by 1 to 2 per cent, squamous cell carcinoma by 3 to 4.6 per cent and basal cell carcinoma by up to 2.7 per cent.⁴⁴

35. Thus, in the age of climate change, skin cancer is a major health concern for persons with albinism globally.⁴⁵ Access to sun protection is therefore essential for skin health. This includes broad-spectrum sunscreen with a high sun protection factor, protective clothing (e.g. hats and long-sleeved shirts made of dense, ultraviolet-resistant material) and environmental modifications (e.g. shaded coverings and ultraviolet protective window film).⁴⁶

C. Lack of access to sunscreen lotion

36. Access to good-quality sunscreen lotion with a sun protection factor of 50 and above, as an essential medicine, is central to protecting the right to health of persons with albinism. Studies show that sunscreen dramatically lowers the incidence of skin lesions and cancers in high-risk groups. At the time of writing, sunscreen was not designated as an essential medicine globally, which hinders its availability for persons with albinism, particularly in resource-limited settings where the product is prohibitively expensive.⁴⁷ In November 2024, the Independent Expert, in partnership with the Special Rapporteur on the promotion and protection of human rights in the context of climate change and civil society groups, including the Global Albinism Alliance and the Africa Albinism Network, applied to WHO for the addition of sunscreen products to its Model List of Essential Medicines.⁴⁸

37. To advance the realization of Sustainable Development Goal 3 for persons with albinism, and in the light of the health impacts of climate change, it is essential that global and national health actors designate sunscreen lotion as an essential medicine⁴⁹ and facilitate its accessibility to all individuals. The designation of sunscreen lotion

⁴² See Maya I. Ragavan, Lucy E. Marcil and Arvin Garg, “Climate change as a social determinant of health”, in *Pediatrics*, vol. 145, No. 5 (2020).

⁴³ See A/78/167, para. 21.

⁴⁴ See Eva Rawlings Parker, “The influence of climate change on skin cancer incidence – a review of the evidence”, in *International Journal of Women’s Dermatology*, vol. 7, No. 1 (2021), pp. 17–27.

⁴⁵ See A/78/167, paras. 20–28.

⁴⁶ See A/72/169.

⁴⁷ See <https://www.who.int/groups/expert-committee-on-selection-and-use-of-essential-medicines/25th-expert-committee-on-selection-and-use-of-essential-medicines/a.25-sunscreen-broad-spectrum-prevention-of-skin-cancer-in-people-with-albinism>.

⁴⁸ See https://cdn.who.int/media/docs/default-source/2025-eml-expert-committee/addition-of-new-medicines/a.25_sunscreen.pdf?sfvrsn=697a69cd_2.

⁴⁹ Sarah L. Bosha and Adi Radhakrishnan, “Climate change, albinism and health: an urgent call to the global health community to fulfill SDG3” (O’Neill Institute for National and Global Health Law, 2023).

as an essential medicine ensures its procurement is prioritized in local health centres⁵⁰ and that healthcare workers are trained on the benefits and its importance for the health of persons with albinism. To date, most countries do not have sunscreen on their national essential drugs lists. For example, in Paraguay, sunscreen is currently not an essential medicine, and is not available in government health facilities, pharmacies or dispensaries.⁵¹

D. Economic barriers to access sunscreen lotion and health services

38. In the absence of State-supported access to sunscreen lotion, persons with albinism incur out-of-pocket costs to ensure a steady and adequate supply. However, the low level of employment and high levels of poverty for persons with albinism make the costs of sunscreen lotion a major barrier to access, particularly for those in rural areas. For example, in Lesotho, Uganda and Zimbabwe, one bottle of sunscreen lotion of approximately 100 millilitres costs between US\$15–US\$16, or as much as US\$30 for sunscreen lotion with a sun protection factor of 50 and above, which is an exorbitant cost for ordinary individuals earning minimum wages. In many African countries, where wages are low, individuals can spend a large portion of their income on sunscreen lotion, or be forced to choose between food and accommodation, or sun protection. For example, in Lesotho, the minimum wage for a domestic worker is 827 maloti per month (US\$45),⁵² which means one third of the total salary would go to a small bottle of sunscreen priced at US\$15 that is unlikely to last for more than one month. It is recommended that adults apply 35 millilitres of sunscreen 20 minutes before going outdoors and reapply every two hours, because the protection can wear off due to sweating.⁵³

39. To overcome economic barriers in gaining access to sunscreen lotion, civil society organizations source donations from international partners for free distribution to communities.⁵⁴ However, because sunscreen is considered a cosmetic in many countries, import duty tax on donated supplies creates an additional financial barrier to consistent access. Even in countries with tax exemptions for sunscreen,⁵⁵ other costs related to mandatory product safety testing and customs storage fees can create prohibitive costs for organizations. In Uganda, civil society organizations reported paying approximately 530,000 shillings⁵⁶ (US\$144) for product testing and average storage costs of US\$100 per day⁵⁷ for each consignment received.

40. Failure to recognize skin impairment as a disability for persons with albinism hinders their access to disability health benefits in some countries. In Australia, the National Disability Insurance Scheme, which provides support to caregivers and families of Australians aged 7 to 65 with a permanent and significant disability, does not reimburse the costs of sunscreen lotion because a lack of melanin in the skin is not recognized as a disability.⁵⁸

⁵⁰ Jane Hutchings, Keith Neroutsos and Kathleen Donnelly, “Making the list: the role of essential medicines lists in reproductive health”, in *International Perspectives on Sexual and Reproductive Health*, vol. 36, No. 4, (2010).

⁵¹ Submission by the Government of Paraguay.

⁵² See <https://lesotholii.org/akn/ls/act/2024/27/eng@2024-04-05>.

⁵³ See <https://www.cancer.org.au/cancer-information/causes-and-prevention/sun-safety/about-sunscreen>.

⁵⁴ See A/HRC/58/57/Add.2, para. 25.

⁵⁵ See <https://www.advantageafrica.org/skin-cancer>.

⁵⁶ See <https://unbs.go.ug/e-services/testing-fees/>.

⁵⁷ Interview with The Source of the Nile Union of Persons with Albinism.

⁵⁸ Albinism Fellowship of Australia.

41. Similarly, in France, skin impairment due to albinism is not recognized as a disability, so disability benefits do not cover access to sunscreen. Only visual impairments due to albinism are recognized as a disability,⁵⁹ and thus eligible for economic support. In Israel, albinism rights activists have been lobbying for the recognition of albinism as a disability in order to support access to wider disability benefits through the National Insurance Institute, Israel's social security agency. As of 2021, only those with poor vision were eligible for financial assistance.⁶⁰

42. In other contexts, preventative specialist services routinely needed by persons with albinism for their skin health are not covered by health insurance programmes. In the United States, stakeholders reported that some specialist services are not automatically covered by Medicaid or Medicare, and even with private health insurance, individuals still pay between US\$50 to US\$150 in out-of-pocket costs per visit.⁶¹ In Kenya, the National Health Insurance Fund only covers costs such as radiotherapy and chemotherapy,⁶² but does not cover biopsies or other tests, or the costs of travel, food and accommodation.⁶³ In Australia, while the Medicare Benefits Schedule covers diagnosis and treatment of skin cancers, there are no specific items covered under the Schedule for skin cancer screening, although a skin check may be undertaken as part of a standard consultation. In Panama, individuals with albinism in Guna Yala often request financial support from civil society organizations or donors to cover the cost of treatment for skin lesions or cancer.⁶⁴

43. Persons with albinism also face financial barriers relating to the costs, such as travel and accommodation, associated with gaining access to specialist health services. In Australia, stakeholders in remote areas also faced high transport and accommodation costs due to the distance to major cities where specialist services are concentrated.⁶⁵ In rural Puerto Rico, individuals reported that they often had to hire private taxis to gain access to specialist services in urban areas, due to a lack of access to transport.⁶⁶ In some African countries, persons with albinism in rural areas may need to walk in the sun to gain access to healthcare, thus increasing their susceptibility to skin cancer.

E. Barriers to local production of sunscreen lotion

44. Where possible, local production of sunscreen should be supported and encouraged by Governments to improve accessibility and affordability for communities.⁶⁷ Major barriers to sustaining local production include tedious and bureaucratic regulatory processes and the high cost of importing the filters necessary to produce sunscreen with adequate sun protective factors for persons with albinism.⁶⁸ Stakeholders in Côte d'Ivoire, Mali and Togo reported that applying for tax exemption

⁵⁹ Interview with Global Albinism Alliance.

⁶⁰ See <https://www.jpost.com/middle-east/persons-with-albinism-in-the-mena-region-fight-for-their-rights-670853>.

⁶¹ See A/HRC/58/57/Add.1, para. 32.

⁶² See Ashley Nmoh, "Cancer Management in Kenya – Awareness and the Struggles Patients Face to Access Treatment, Care and Support", in *Independent Study Project (ISP) Collection*, 2019, p. 17.

⁶³ Ibid; and Joel Lehman and others, "Economic and Social Consequences of Cancer in Kenya: Case Studies of Selected Households in Kenya", World Bank Group (2020) p. 9. See also <https://www.knchr.org/Portals/0/Albinism%20Mapping.pdf>.

⁶⁴ See A/HRC/55/45/Add.1.

⁶⁵ Interview with Liz Beales, Albinism Fellowship of Australia.

⁶⁶ See A/HRC/58/57/Add.1, para. 47.

⁶⁷ See https://cdn.who.int/media/docs/default-source/2025-eml-expert-committee/addition-of-new-medicines/a.25_sunscreen.pdf?sfvrsn=697a69cd_2.

⁶⁸ See <https://www.basf.com/global/en/media/news-releases/2022/03/p-22-176>.

for consignments of the main filters poses a significant barrier for production, due to the costs and bureaucracy of the approval process, which can take up to six months. While the formulations to produce sunscreen may vary, the Independent Expert has compiled a list of over 20 filters that can be used to produce sunscreen lotion with a sun protection factor of 50 and above, including titanium dioxide, which primarily provides protection against UVB radiation, and zinc oxide, which provides broad-spectrum protection against UVA (I and II) and UVB radiation, and drometrizole trioxolane, which absorbs UVA and UVB radiation.⁶⁹

45. In addition, the lack of sustained government investment in production plants results in a decline in or end to operations once an international non-profit ceases operation in the country. Currently, local production in regions such as Africa is heavily funded through technical and financial assistance from organizations such as the Fondation Pierre Fabre and Beyond Suncare, which facilitate access to the filters and train local staff.

F. Low prioritization of preventative services and specialists to address skin cancer

46. Because persons with albinism are a minority, the incidence of skin cancer in the general population is relatively low compared with other cancers. Currently, WHO has three global cancer initiatives, focused on cervical cancer,⁷⁰ breast cancer⁷¹ and childhood cancer.⁷² There are a myriad of resources and global initiatives geared towards these cancers, presenting a clear opportunity for countries to gain access to international development assistance. For example, the WHO Global Breast Cancer Initiative and the Cervical and Breast Cancer Coalition, supported by the World Economic Forum, have supported national and global efforts for cervical and breast cancer early detection, diagnosis and management.

47. The low prioritization of skin cancer has an impact on international resource mobilization and thus national budget allocations and priorities, with resources instead targeted towards cancers with higher mortality and morbidity rates in the general population, such as breast, cervix and prostate cancers. This lack of resources includes the lack of knowledgeable and skilled personnel to support the health needs of persons with albinism. Skin cancer has high morbidity and mortality rates among persons with albinism and should be prioritized in national cancer programmes. States are duty-bound to ensure adequate resource allocation to protect the right to health of persons with albinism.

G. Discrimination and lack of knowledge about albinism in healthcare services

48. Stigma and discrimination have a negative impact on the accessibility and acceptability of health services for persons with albinism. In Lesotho⁷³ and Zimbabwe, mothers of infants with albinism reported discriminatory behaviour from maternal healthcare staff, who often avoided assisting the mother and child. Similarly,

⁶⁹ See <https://www.who.int/groups/expert-committee-on-selection-and-use-of-essential-medicines/25th-expert-committee-on-selection-and-use-of-essential-medicines/a.25-sunscreen-broad-spectrum-prevention-of-skin-cancer-in-people-with-albinism>.

⁷⁰ See <https://www.who.int/initiatives/cervical-cancer-elimination-initiative>.

⁷¹ See <https://www.who.int/initiatives/global-breast-cancer-initiative>.

⁷² See <https://www.who.int/initiatives/the-global-initiative-for-childhood-cancer>.

⁷³ See A/HRC/58/57/Add.2.

in Türkiye and the United Kingdom,⁷⁴ parents reported that there was no system to guide and provide accurate information about albinism and appropriate services for infants with albinism.⁷⁵ Even where persons with albinism seek treatment for common ailments unrelated to their disability, they do not receive adequate care, sometimes leading to deadly consequences. In Uganda, stakeholders reported that, in 2022, a young boy with albinism died from malaria after nurses refused to touch or treat him. In the Democratic Republic of the Congo,⁷⁶ individuals reported being turned away from healthcare centres when they sought malaria treatment.

49. The lack of knowledge and limited medical understanding about albinism among healthcare professionals⁷⁷ hinders the enjoyment of the right to health. In Australia, stakeholders reported that general practitioners did not know that persons with albinism were highly susceptible to skin cancer.⁷⁸ In Rwanda, healthcare workers questioned whether albinism could be prevented through vaccination, underscoring a major gap in medical knowledge on the genetic nature of the condition and a stigmatized attitude towards it.⁷⁹

50. The lack of knowledge applies to other health needs of persons with albinism. In the United Kingdom, one person with albinism who requires frequent eye tests due to nystagmus reported being seen by different opticians each time, with each questioning why his eyes could not be kept still.⁸⁰ In Puerto Rico, persons with Heřmanský-Pudlák syndrome reported not having access to haematologists with specialized knowledge of the condition. Often, blood transfusions are prescribed which can later lead to lung transplant rejection.⁸¹

51. Persons with albinism have reported receiving substandard care, or no care at all, for skin lesions and wounds associated with skin cancer. In Zimbabwe, stakeholders reported that hospital staff were often reluctant to admit individuals with albinism with advanced skin cancer. When admitted, patients were not provided with pain medication or assessed by a physician.⁸² In Kenya, individuals reported that skin cancer was not viewed as a very serious condition because it only occurred in persons with albinism.⁸³ When individuals presented with skin lesions or pre-cancerous wounds, they were bandaged, rather than referred for biopsies, because their lesions were misinterpreted as a normal part of having albinism.⁸⁴ Some Zimbabweans with albinism reported being prescribed Betadine (povidone-iodine), an antiseptic solution, for their lesions or cancerous wounds – a treatment that caused wounds to expand and deepen.⁸⁵

52. Gaining access to timely diagnostic care in the form of biopsies was identified as a major barrier to care. For instance, in Kenya, stakeholders reported that persons with albinism were often given biopsy appointments, several weeks after presenting

⁷⁴ See “Persons With Albinism And Their Right To Health, Education And Employment In The UK” (2024), p. 21.

⁷⁵ See Berkay Omer Unal and Ahmet Tayfur Arslan, “Violations of Rights Faced by Individuals with Albinism” (2021). Available at <https://www.albinizm.org.tr/uploads/ef/afcef9a8fc.pdf>, p. 24.

⁷⁶ See <https://www.corbettardc.org/en/home>.

⁷⁷ See “People With Albinism Worldwide” (2021).

⁷⁸ Albinism Fellowship of Australia.

⁷⁹ Interview with Beyond Suncare.

⁸⁰ See “Persons With Albinism And Their Right To Health, Education And Employment In The UK” (2024).

⁸¹ See A/HRC/58/57/Add.1, para. 36.

⁸² See “The Forgotten Ones” (2025), p. 19.

⁸³ Interview with Alex Munyere.

⁸⁴ See “People With Albinism Worldwide” (2021).

⁸⁵ See “The Forgotten Ones” (2025).

for care, and were sent home with only painkillers. Furthermore, patients had to travel back and forth to the hospital first to have samples taken, then to receive their results, which were necessary for hospital admission, and to have access to treatment such as chemotherapy, radiotherapy or surgery.⁸⁶ Brazilian communities reported similar challenges. Activists reported that a 23-year-old woman with albinism with skin lesions was given a biopsy appointment six months from the date she sought treatment. Family and friends had to fundraise money for her to have access to timely care in private healthcare services.⁸⁷

H. Lack of qualified public health specialists

53. The lack of access to dermatologists, particularly in high ultraviolet radiation settings, is a barrier to skin cancer prevention. Countries require a dermatologist density of 4 dermatologists per 100,000 people to support the lowering of skin cancer mortality rates and improve diagnosis. In Africa, excluding North Africa, there may be only one dermatologist available for every million people. For example, Lesotho has no dermatologists in the public health services,⁸⁸ while Madagascar only has three specialists in dermatology servicing the entire country.⁸⁹ Similarly, in Fiji, there is only one dermatologist in the country.⁹⁰ Such scarcity is common in many countries in that region.

54. In many African countries, including Zimbabwe and Uganda, cryotherapy – an early-intervention curative therapy that uses liquid nitrogen to remove pre-cancerous lesions – is often only available in private healthcare settings, or offered by civil society-run skin cancer prevention programmes.⁹¹ Civil society organizations reported that the cost of liquid nitrogen, a lack of access to cryotherapy equipment and transportation challenges hindered the provision of services, particularly for remote communities. In the Democratic Republic of the Congo, the organization Corbetta RDC reported that the high cost of liquid nitrogen, priced at US\$320 for 20 litres, and a lack of sufficient medical equipment hindered the provision of care. The organization had one cryotherapy kit to service patients at three sites in the country. Medical supplies and equipment had to be shipped to remote areas by way of the Congo River – a process that took up to one month. Making liquid nitrogen generators available in rural locations can improve timely access to cryotherapy.

V. State obligations in skin cancer prevention

A. Health budgeting to support skin cancer prevention, treatment and care

55. On average, at least 5 per cent of a low- and middle-income country's gross domestic product (GDP) should be allocated to health spending to achieve universal health coverage.⁹² Furthermore, States should ensure that revenue is raised, allocated

⁸⁶ Interview with Alex Munyere.

⁸⁷ Interview with Nereida Palko.

⁸⁸ See [A/HRC/58/57/Add.2](#), para. 45.

⁸⁹ See [A/HRC/52/36/Add.1](#), para. 60.

⁹⁰ See <https://www.fbcnews.com.fj/news/early-detection-is-vital-dr-whitfeld>.

⁹¹ See Fondation Pierre Fabre, "Prevention and early management of skin cancer for people with albinism". Available at <https://www.fondationpierrefabre.org/en/our-programmes/tropical-dermatology/prevention-management-skin-cancers-albinism/>.

⁹² See [A/HRC/55/54](#), para. 40 (b).

and spent in a manner that addresses inequalities in society.⁹³ In national budgeting, States should consider the needs of persons with albinism and ensure these are included in health financing resource mobilization and allocation. Although achieving health equity for persons with disabilities requires additional investment to ensure non-discriminatory realization of rights, the improved access to health results in higher economic and societal dividends for the State.⁹⁴ To mobilize resources to address the gap in health financing, States should tackle tax evasion or avoidance, ensure a progressive tax system, including by widening the tax base for multinational corporations and the rich, and reprioritize expenditures to fund public services.⁹⁵

56. Unfortunately, the crippling debt burden that the most indebted countries face is unsustainable and constitutes one of the principal obstacles to providing basic services for the realization of economic, social and cultural rights.⁹⁶ For example, only two countries in Africa meet the 15 per cent GDP health spending target outlined in the Abuja Declaration.⁹⁷ The Independent Expert believes that, in cancelling all debts, along with conditionalities, global institutions such as the International Monetary Fund, the World Bank and all multilateral and bilateral lenders would enable Governments to use their fiscal and monetary instruments to provide basic services and ensure social protection for all people.⁹⁸ States have committed to joint and separate international cooperation to support the realization of the right to health. One approach is for creditor countries to cancel debt for low- and middle-income countries, to support increased health spending. The Debt2Health programme is an example of an approach to “debt swap” agreements, where creditor countries cancel debt in exchange for the money being invested in health systems.

B. Education and awareness-raising

57. The Committee on Economic, Social and Cultural Rights indicates that, even in times of severe resource constraints, the vulnerable members of society must be protected through the adoption of relatively low-cost targeted programmes, for example, through health information dissemination and through legislative measures.⁹⁹ However, multiple stakeholders reported that Governments have failed to provide consistent health information, awareness or education on skin cancer for persons with albinism, or on sun protection measures. It is not enough for countries to rely on International Albinism Awareness Day to raise awareness on albinism, discrimination and health.

58. In countries in Africa, Europe and Latin America, stakeholders reported that civil society organizations were on the front lines of regularly providing health and other information on albinism to communities. In Argentina, organizations such as La Fundación Nacional de Albinismo Simplemente Amigos¹⁰⁰ provide relevant health information on albinism to support the health and well-being of children with albinism in school systems.

⁹³ See A/75/170, para. 82.

⁹⁴ WHO, *Global Report on Health Equity for Persons with Disabilities* (Geneva, 2022).

⁹⁵ See A/HRC/55/54, para. 39.

⁹⁶ See Human Rights Council resolution 20/10, preamble.

⁹⁷ See Riya Sawhney and others, “Diverted dollars: the health impact of Africa’s debt crisis”, PLOS Global Public Health. Available at <https://speakingofmedicine.plos.org/2024/11/20/diverted-dollars-the-health-impact-of-africas-debt-crisis/>.

⁹⁸ See A/HRC/55/54, para. 55.

⁹⁹ See Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000), para. 18.

¹⁰⁰ See <https://albinismo.org.ar/>.

VI. Good State practices

A. Laws and policies for healthcare access and services

59. Countries such as Guinea,¹⁰¹ Panama,¹⁰² Puerto Rico¹⁰³ and most recently Brazil¹⁰⁴ have adopted specific legislation on the rights of persons with albinism. These laws provide for access to healthcare services for visual impairment and for skincare, although in the case of Brazil access to skin care is provided under a separate resolution rather than the law.¹⁰⁵ In Puerto Rico, Law 109, although yet to be implemented, nonetheless provides for access to specialized care for Heřmanský-Pudlák syndrome. Argentina has also proposed a specific law on albinism that includes access to healthcare services for eyes and skin.

60. The Governments of Angola,¹⁰⁶ Malawi,¹⁰⁷ Mozambique,¹⁰⁸ Uganda¹⁰⁹ and the United Republic of Tanzania¹¹⁰ have adopted national action plans on albinism that include access to dermatological care and wide-brimmed sun hats for persons with albinism. In addition, there is mandated training of healthcare workers to understand albinism and improve health access. In Uganda, the national action plan also includes a budget allocation of US\$4.9 million for implementation.¹¹¹

61. In Nigeria, the 2012 national policy on albinism¹¹² provides for free skin cancer treatment and prevention services for persons with albinism and mandates access to health information for visual and skin health. In Colombia, Statutory Law 1751 of 2015 affords protection to vulnerable groups, including persons with disabilities, in the healthcare system. At least 70 per cent of persons with disabilities are affiliated with the subsidized social security healthcare scheme.

62. In some countries, persons with albinism are designated as persons with disabilities based on skin and visual impairment, which facilitates their access to the full range of health-related benefits. For example, disability laws in Ghana¹¹³ and Uganda¹¹⁴ specifically recognize persons with albinism as persons with disabilities. In other countries, such as Brazil,¹¹⁵ Malawi and Nigeria, disability laws use models that consider not only the clinical condition but also environmental, social and personal factors that limit the full and effective participation of the individual in society, thus enabling persons with albinism to benefit from them.

¹⁰¹ Law No. 0016/AN of 2021.

¹⁰² Law No. 210 of 2021.

¹⁰³ Law No. 109 of 2022.

¹⁰⁴ Law No. 15.140/2025 of 28 May 2025.

¹⁰⁵ Brazil, Ministry of Health National Health Council, “Resolution No. 725 of 9 November 2023”, (2023).

¹⁰⁶ Angola, “National Action Plan for the Protection and Promotion of the Human Rights of Persons with Albinism” (2023–2027).

¹⁰⁷ Malawi, Ministry of Gender, Children, Disability and Social Welfare “National Action Plan on Persons with Albinism in Malawi”, (2018–2022).

¹⁰⁸ Mozambique, Ministry of Justice, Constitutional and Religious Affairs, “Multisectoral Action Plan to Address the Issue of the Protection of Persons with Albinism”, (2015).

¹⁰⁹ Uganda, Ministry of Gender, Labour and Social Development, “National Action Plan for Persons with Albinism”, (2020–2025).

¹¹⁰ United Republic of Tanzania, Prime Minister’s Office Labour, Youth, Employment and Disability, “National Action Plan on the Rights and Welfare of Persons with Albinism”, (2024).

¹¹¹ Uganda, Ministry of Gender, Labour and Social Development, “National Action Plan for Persons with Albinism”, (2020–2025).

¹¹² Nigeria, Federal Ministry of Education, “National Policy on Albinism in Nigeria”, (2019).

¹¹³ Ghana. Persons with Disability Amendment Bill 2020, sects. 62 (3) and 82 and first schedule (7).

¹¹⁴ Uganda. Persons with Disabilities Act No. 3 of 2020, schedule 3, sect. 1.

¹¹⁵ Brazil. Inclusion of Persons with Disabilities Law (Law No. 13, 146/2015). 2015.

B. Health financing for prevention and care

63. In Brazil and Kenya, the healthcare needs of persons with albinism are included in the national budgets. In Kenya, the Albinism Support Program¹¹⁶ was allocated K Sh 100 million in 2024¹¹⁷ to support the free distribution of sunscreen lotion, lip balms and after-sun care lotions. The programme also procured 20 cryogenic kits for distribution in county healthcare centres.¹¹⁸ Through a 2020 ordinance, the Government of Brazil allocated financial resources to improve equity for persons with albinism to gain access to healthcare in the primary healthcare centres of municipalities.¹¹⁹ In Cuba, there is free healthcare for all, including persons with albinism, with access to specialized services such as dermatological and ophthalmological care.¹²⁰

64. In Australia, the Government allocated \$A15 million over two years for a nationwide skin cancer prevention campaign aimed at increasing sun protective behaviours and challenging problematic attitudes around suntanning.¹²¹ The campaign will target high-risk groups, including those living in rural areas.

65. Governments can also provide financial grants to help persons with albinism overcome financial barriers in gaining access to health services. South Africa provides grants to persons with albinism that can be used to gain access to products for their skin.¹²² In the United Kingdom, the Social Security (Personal Independence Payment) Regulations 2013 provide social welfare payments, and the Disability Living Allowance disburses allowances to persons with disabilities. However, albinism groups in both contexts have highlighted challenges in gaining access to such grants.

C. State-sponsored access to sunscreen lotion

66. Designating sunscreen lotion as an essential medicine or assistive device supports greater access to the medical product. The abovementioned Law No. 109 in Puerto Rico, as well as Law No. 2021/0016/AN in Guinea, and the national disability policy and national strategy for assistive technology and products priority in Zimbabwe, designate sunscreen lotion as an assistive device. Similarly, in Uganda, under the 2023 revised national policy on persons with disabilities, assistive devices are designated broadly as all goods and services that support persons with disabilities to participate effectively in all aspects of life.¹²³ In South Africa, the Primary Health Care Standard Treatment Guidelines provide guidance on the use of sunscreen for persons with albinism and designate sunscreen as an essential medicine, enabling access at all levels of care, throughout the nine provinces in the country. Other countries have added sunscreen to their national essential drug lists, including Australia, in 2018; Kenya, in 2023; South Africa, in 2020; and the United Republic

¹¹⁶ See <https://ncpwd.go.ke/albinism-support-program/>.

¹¹⁷ See www.kenyanews.go.ke/council-rolls-out-nation-wide-cancer-screening-for-persons-with-albinism/.

¹¹⁸ See <https://www.mygov.go.ke/national-council-persons-disability-distributes-cancer-prevention-and-diagnostic-equipment-counties>.

¹¹⁹ See <https://www.in.gov.br/en/web/dou/-/portaria-gm/ms-n-3.354-de-16-de-dezembro-de-2020-294933667>.

¹²⁰ Submission by the Government of Cuba.

¹²¹ Submission by the Government of Australia, Department of Health and Aged Care, 2025.

¹²² Submission from the Government of South Africa.

¹²³ See <https://mglsd.go.ug/wp-content/uploads/2023/07/FINAL-REVISED-NATIONAL-POLICY-ON-PWDs-2023.pdf>.

of Tanzania, in 2021.¹²⁴ In Fiji, the Ministry of Health recently announced a programme to provide free sunscreen to persons with albinism in the country.¹²⁵ Paraguay is working on measures to include sunscreen and sunblock on the basic list of essential medicines.¹²⁶

D. Public-private partnerships for health access

67. In Malawi, the Ministry of Health partnered with international and local non-governmental organizations to create the national skin cancer prevention programme, targeting access to prevention, treatment and care, and mental health services for persons with albinism.¹²⁷ The programme runs skin clinics in 118 health centres every four months, where persons with albinism receive comprehensive sun protection education, sunscreen lotion and access to health services, including cryotherapy, excision surgery and referral to skin cancer treatment. In 2024, some 85 people diagnosed with skin cancer were referred to several central hospitals, and 39 underwent surgery at various district hospitals

68. In the United Republic of Tanzania, a similar partnership between international and local non-governmental organizations and the Government resulted in improved access to decentralized specialized care for skin cancer prevention and treatment. Under the skin cancer prevention programme, surgical officers and dermatovenereology officers at the district level have been trained to perform minor excision surgeries and cryotherapy. This has reduced waiting times for patients with pre-cancerous wounds and tumours and relieved the pressure on resources at large public health institutions. In 2024, minor skin cancer procedures were accessible in 14 of the country's 26 regions and growing.

E. Education and training on albinism for health and care workers

69. In Brazil, the Universidade Federal do Rio de Janeiro created an educational programme¹²⁸ to train health professionals on albinism. The programme offers graduate and post-graduate courses and has educated over 200 students and professionals, including those who work in Rio de Janeiro health services.

70. In the United Republic of Tanzania, the Regional Dermatology Training Centre has trained more than 290 graduates from 17 African countries in its advanced diploma in dermato-venerology.¹²⁹ One of the notable graduates, Dr. Gaylord Inena from the Democratic Republic of the Congo, founded Corbetta RDC, which provides free skin cancer prevention and treatment services to persons with albinism. The organization has trained 32 doctors in the country to treat skin lesions using

¹²⁴ South Africa, National Department of Health, "Primary Healthcare Standard Treatment Guidelines and Essential Medicines List for South Africa", seventh edition (2020); Kenya, Ministry of Health, "Kenya Essential Medicines List" (2023); and United Republic of Tanzania, Ministry of Health, Community Development, Gender, Elderly and Children, "Standard Treatment Guidelines and National Essential Medicines List for Tanzania Mainland", sixth edition, (2021).

¹²⁵ Elena Vucukula, "A life-saving initiative: Minister announces free sunscreen for people with albinism", *The Fiji Times*, 15 June 2025.

¹²⁶ Submission by the Government of Paraguay.

¹²⁷ See <https://news.standingvoice.org/skin-cancer-prevention-programme>.

¹²⁸ See <https://portal.ufrj.br/Inscricao/extensao/acaoExtensao/acao?id=BF488C91-ECC9-43E4-9868-33EA9B3585CE&cid=383845&conversationPropagation=nested>.

¹²⁹ See <https://rdctanzania.org/about-us/>.

cryotherapy and conduct excision surgeries for persons with albinism in the Democratic Republic of the Congo.

71. In Fiji, the Government has supported the training of five additional dermatologists to provide care in the prevention and treatment of skin cancer for persons with albinism.¹³⁰

F. Access to information, education and awareness

72. In Saudi Arabia, the Sehhaty application¹³¹ supports wide access to information and raise awareness on the genetic nature of albinism, and sun protection measures for persons with albinism. In Malawi, the Government has made available a toll-free telephone “albinism helpline”, which is used to send text messages targeting high-risk patients who have had skin cancer before or are in a high-risk category for skin cancer. Through the helpline, alerts and reminders on upcoming skin clinics and other health information are widely distributed.

G. Community-based models for early detection and improvement in health services

73. In the United Republic of Tanzania, civil society organizations train midwives to effectively support mothers of children with albinism with adequate information and education on skin care for infants with albinism. There, an action group for mothers with albinism provides a helpline to respond to requests for support.¹³² In many countries, civil society organizations provide health information and education on maintaining skin health for persons with albinism.

74. In Uganda, Albinism Umbrella has developed a monitoring tool, the “health community scorecard”, to improve the experience of persons with albinism in healthcare centres and address discrimination that negatively affects health-seeking behaviour. Through these engagements, persons with albinism advocate directly to their local health and care workers about the services they need to have access to in their hospitals and come up with a work plan to monitor the changes and progress.

VII. Conclusion and recommendations

A. Conclusion

75. Persons with albinism face significant barriers globally in the enjoyment of the right to health. These include stigma and discrimination, which affects access to quality care from skilled public health professionals; low resource allocation at the national and global levels to address skin cancer prevention, treatment and control; and legal and policy barriers that hinder the access of persons with albinism to disability grants. Addressing these challenges requires concerted efforts at the national and international levels, and will require more awareness-raising, education, advocacy, community engagements, and legislative and policy reforms.

¹³⁰ Simione Tuvuki, “Early detection is vital”, *FBC News* (13 June 2024).

¹³¹ See <https://www.moh.gov.sa/en/HealthAwareness/EducationalContent/Diseases/Dermatology/Pages/012.aspx>.

¹³² Standing Voice Tanzania.

B. Recommendations

76. The Independent Expert recommends that Member States:

(a) Add sunscreen to their lists of essential medicines and ensure that quality sunscreen and other sun protection products are made available and are physically and financially accessible to persons with albinism;

(b) Allocate funds in their national budgets for access to sun protection measures and products;

(c) Invest human and financial resources in local sunscreen production operations, by exploring private-public partnerships and implementing legal and policy frameworks, including tax exemptions, to support the importation of critical ingredients/filters;

(d) Develop and support outreach programmes in partnership with private actors and adopt measures to make first-necessity items – such as sunscreen, sun protective clothing, sunglasses and low-vision devices – accessible and affordable;

(e) Include access to health information about albinism and skin cancer prevention in public health centres;

(f) Build the capacity of health workers in understanding albinism and conduct periodic anti-discrimination training to promote inclusive care for persons with albinism;

(g) Initiate reparations for attacks against persons with albinism, including rehabilitation and psychosocial support;

(h) Ensure that genetic testing is available for children born with albinism and other variations, such as Heřmanský-Pudlák syndrome and Chediak-Higashi syndrome;

(i) Introduce incentives to encourage the employment of persons with albinism in the formal sector. This will support their economic well-being and ability to afford necessary health services and products;

(j) Increase the share of total government expenditure allocated to public health, to improve the availability of specialist services, such as dermatology and ophthalmology;

(k) Ensure the systematic collection of disaggregated data on persons with albinism, including regarding discrimination against persons with albinism in healthcare systems, the employment sector and education.

77. The Independent Expert recommends that WHO:

(a) Add sunscreen lotion to its Model List of Essential Medicines as global policy guidance and best practice for skin cancer prevention;

(b) Engage diverse stakeholders, including persons with albinism, in the development of national indicators and the tracking of national data on skin cancer and the health challenges faced by persons with albinism.

78. The Independent Expert recommends that the African Union appoint a special envoy on albinism to support the monitoring, protection and promotion of human rights at the regional level.

79. The Independent Expert recommends that global financial entities:

(a) Support debt cancellation for low- and middle-income countries;

(b) **Forge partnerships with States to support international cooperation in advancing the right to health and to increase health spending, such as through “debt swap” agreements, in exchange for prevention and treatment interventions for persons with albinism.**
