



## GLOBAL CALL TO ACTION

# to End the Skin Cancer Epidemic in Persons with Albinism

JULY 9th, 2024

**The four co-hosting organizations of the Multi-Stakeholder Summit on Occupational and non-Occupational Skin Cancer held in Berlin, Germany on October 12th, 2023 – in cooperation with patient advocacy groups, humanitarian NGOs, scientific societies, occupational safety and health professionals, and UV-protective agent manufacturers – call for the implementation of a systematic approach to addressing the Skin Cancer Epidemic in Persons with Albinism (PWAs) in view of the following:**

- In many regions of the world – mostly in the tropics – a large proportion of persons with albinism (PWAs) develop skin cancer before the age of 30, with some even developing in childhood. Due to highly insufficient access to timely and effective diagnosis and treatment, skin cancer is the leading cause of excess premature mortality among PWAs in the affected regions.
- Despite very limited data and scanty publications, it is well known that PWAs develop non-melanoma skin cancer (NMSC; basal cell carcinomas [BCC] and squamous cell carcinomas [SCC]), which are preventable as well as curable when addressed early.
- NMSC in PWAs are generally induced by (solar) ultraviolet (UV) radiation and linked to the absence of protective melanin pigment that is the main feature of albinism. They are the consequence of even low exposure to the sun while people strive to access education and work, and can, therefore, be classified as occupational.
- Prevention schemes for skin cancer are effective. Measures can include the wearing of protective clothing such as wide-brimmed hats, long sleeved clothing. Application of UVA and UVB filtering sunscreen

on non-cloth covered sites (e.g. the facial area) is also advised. PWAs in tropical countries frequently lack access to these simple measures and have in particular little to no access to sunscreen, either because it is not available or it is not affordable. Lack of education and understanding (health literacy) regarding the impact of sun exposure on PWA skin compound these disadvantages.

**We urge the World Health Organization (WHO), Ministries of Health of national governments, policy makers, scientific societies, doctors and other health professionals, patient advocacy groups and organizations of persons with albinism to take 10 actions to stop premature death of persons with albinism from skin cancer:**

- 1 The WHO should add high SPF broad-spectrum sunscreen for PWAs to the model lists of essential medicines (EML and EML for children) and Member States should do the same in their own national lists.
- 2 The World Health Assembly (WHA) should recognize the long-lasting crisis of skin cancer in PWAs and address it through an ad hoc program similar to the one dedicated to the “Control of Neglected Tropical Diseases” (NTDs).
- 3 Governments, and pharma / cosmetic companies should actively engage with all stakeholders in finding and implementing solutions to make UVA and UVB filtering sunscreen accessible at no or affordable price to PWAs regardless of where they live.
- 4 Governments and Scientific Societies should find solutions to fill the gap left by the lack of dermatologists in the tropics, so that PWAs have access to regular skin cancer screening and management regardless of where they live.
- 5 Ministries of Health should implement adequate surveillance systems for health practitioners and establish patient registries in order to improve monitoring of skin cancer in PWAs.
- 6 Researchers and clinicians should actively work on developing new treatments to make skin cancer management in PWAs easier, particularly in low-resource settings.

- 7 Philanthropists, foundations, multilateral financial institutions, and bilateral development agencies should provide substantial support to NGOs and national albinism associations to implement skin cancer programs to address the short-term urgency, including access to high-SPF UVA and UVB filtering sunscreen.
- 8 Health practitioners, supported by their scientific societies, should collaborate with associations of persons with albinism to improve the health education of PWAs on skin cancer prevention.
- 9 Governments, in collaboration with albinism organizations and scientific societies, should develop awareness-raising programs targeting employers and educators of persons with albinism in addition to policies to provide PWAs with reasonable accommodation that will contribute to reducing their exposure to the sun and make adequate skin cancer prevention possible in the school and work settings.
- 10 Governments should develop policies and/or support actions to end the stigma and discrimination PWAs suffer in some countries, which ultimately create barriers to accessing proper health care.

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## SUPPORTING ORGANIZATIONS

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**Coletivo Nacional  
Das Pessoas com Albinismo – Brasil**  
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**Réseau des Organisations  
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**Association Jhony Chancel  
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**Genespoir**  
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**Brazilian Society of Dermatology**  
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**Colegio Iberolatinoamericano de  
Dermatología**  
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**French Society of Dermatology**  
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**Irish Association of Dermatologists**  
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**Hungarian Dermatological Society**  
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**Pigmentary Disorders  
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**Professional Association  
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