



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 blocking 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 blocking 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 blocking 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.

GAA
Antoine Gliksohn
Executive Director

ILDS
Dr. Henry W. Lim
President

GlobalSkin
Marc Yale
Board President

EADV
Dr. Martin Röcken
President

SUPPORTING ORGANIZATIONS



**Coletivo Nacional
Das Pessoas com Albinismo – Brasil**
Joselito PEREIRA DA LUZ
Founder and Coordinator



Africa Albinism Network
Ikponwosa Ero
Executive Director



**National Organization for Albinism
and Hypopigmentation**
Karen Bly
Executive Director



Standing Voice
Harry Freeland
Executive Director



Beyond Suncare
Mafalda Soto Valdés
CEO



**Réseau des Organisations
des Personnes Atteintes
d'Albinisme d'Afrique Centrale**
Jhony Chancel Ngamouana
President



**Association Jhony Chancel
pour les Albinos**
Jhony Chancel Ngamouana
President



Genespoir
French Albinism Association
Elisabeth Rivaux
President



Fundación Africa Directo
Guadalupe Martín-Laborda García
de la Rasilla
Secretaria del Patronato



Albina
Czech Albinism Association
Soňa Daňková
President



Euromelanoma
Véronique del Marmol
European Chair



Action for XP
Richard Barlow
Chair Person



**African Society of Dermatology
and Venereology**
Moez Ben Salem
President-Elect



Brazilian Society of Dermatology
Heitor de Sá Gonçalves
President



**Colegio Iberolatinoamericano de
Dermatología**
Jose Luis López Estebaranz
President



French Society of Dermatology
Gaëlle Quéreux
President



Irish Association of Dermatologists
Mary Laing
Director



**Norwegian Association of
Dermatology and Venereology**
Ingeborg M. Bachmann
Leader NFDV



Austrian Society of Dermatology
Peter Worlf
Chairman



Turkish Society of Dermatology
Ertan Yilmaz
President



Hungarian Dermatological Society
Norbert Wikonkál
President



**Nigerian Association
of Dermatology**
Tahir Mohammed
President
Dasetima Altriade
in coming President



**Pigmentary Disorders
Society of India**
Rashmi Sarkar
President



**Professional Association
of German Dermatologists e. V.**
Ralph von Kiedrowski
President



**Oslo University Hospital,
Norway Dep of Dermatology
and Venereology**
Jan Cezary Sitek
Head of Department



**Oslo University Hospital,
Norway Dep of Occupational and
Environmental Medicine**
Britt Randem
Head of Department



**Regional Dermatology
Training Center**
Daudi Mavura
Principal



**The Norwegian Radiation and
Nuclear Safety Authority**
Per Strand
Director General



**BASF Personal Care
and Nutrition GmbH**
Christian Cremer
Director Global Development &
Technical Service UV Protection



La Roche Posay
Julien WINTENBERGER
Global Image & Communication
Director