



Hermansky-Pudlak Syndrome Network, Inc.

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WHO Expert Committee on the Selection and Use of Essential Medicines
World Health Organization
Avenue Appia 20
1211 Geneva 27
Switzerland

Re: 25th Expert Committee on Selection and Use of Essential Medicines

Dear Members of the WHO Expert Committee,

On behalf of the Hermansky-Pudlak Syndrome Network, I am writing to express our strong support for the inclusion of sunblock on the World Health Organization's Model List of Essential Medicines (EML), particularly in recognition of its vital role in protecting the health and lives of individuals with albinism worldwide.

Hermansky-Pudlak Syndrome (HPS) is a rare genetic disorder that includes albinism as a primary feature. Individuals with HPS, like others with albinism, lack melanin, leaving their skin extremely vulnerable to ultraviolet (UV) radiation. This significantly increases their risk for sunburn, premature skin aging, and most critically, aggressive and often fatal skin cancers.

This risk is especially acute in regions near the equator, including many parts of Africa, where individuals with albinism are dying from preventable skin cancers at alarming rates due to prolonged sun exposure and lack of access to effective sun protection. For individuals with HPS, the stakes are also urgent: a diagnosis of skin cancer renders them ineligible for a life-saving lung transplant, a procedure often required due to the pulmonary fibrosis associated with the condition. In these cases, preventing skin cancer through proper sun protection is not only critical to long-term health, but can mean the difference between eligibility and exclusion from a potentially life-saving intervention.

Sunblock, therefore, is not a cosmetic product for these populations—it is a life-preserving, preventive tool that must be recognized as an essential medicine. In many low- and middle-income countries, however, access to adequate sun protection remains out of reach due to cost, supply limitations, or lack of public health prioritization.

We strongly urge the WHO to include sunblock on the Model List of Essential Medicines. Doing so would affirm the right to basic preventive healthcare for all individuals with albinism and help

address a preventable public health crisis that disproportionately affects vulnerable communities across the globe.

Thank you for your time and for your continued commitment to equity and access in global health.

Sincerely,

Donna Appell RN

Donna Appell RN
Executive Director and Founder
Hermansky-Pudlak Syndrome Network, Inc.