



April 17, 2025

ENDORSEMENT OF THE APPLICATION FOR INCLUSION OF A.25 SUNSCREEN, BROAD-SPECTRUM – PREVENTION OF SKIN CANCER IN PERSONS WITH ALBINISM, ON THE ESSENTIAL MEDICINE LIST

Persons with albinism have an extremely high risk of developing skin cancer, suffering physical and psychological sequelae, and early death due to a preventable disease. Robust evidence shows that sunscreen prevents skin cancer. Adequate clothing, finding shade and avoiding midday sun are not enough to palliate the increased exposure to ultraviolet (UV) radiation, especially upon certain farming practices or climate changes.

All persons with albinism must use sunscreen as an essential medication. Infants, children, pregnant and lactating women with albinism could use inorganic or physical UV filters (zinc oxide, titanium dioxide) that primarily reflect or scatter UV radiation and are not absorbed per skin. [Infants/ young children have a larger ratio of skin surface to body volume than adults, increasing a child's systemic exposure to chemical or organic sunscreens. Pregnant and lactating women with albinism need to avoid exposure to chemicals that might be transferred per their placenta or breastmilk.]

We have evaluated hundreds of persons with albinism in the Caribbean Island of Puerto Rico. We have the highest world incidence of Hermansky-Pudlak Syndrome (HPS), a syndromic albinism that includes additional health problems besides albinism. In some parts of this island 1/21 people carry the altered gene, and 1/1,800 people have HPS. We have seen the benefit of regular sunscreen use on top of using protective clothing, hats and other

measures. Among hundreds of persons with albinism, we have not documented any death due to skin cancer.

We totally agree that sunscreens are included on the essential medicine list as solicited by both applicants of this petition: the UN Independent Expert on the Enjoyment of Rights by Persons with Albinism and the Global Albinism Alliance.

The use of sunscreen should be cost-free, universally available to all persons with albinism regardless of their geographic location, or incidence of UV radiation. [Other systemic conditions like Xeroderma Pigmentosa (XP), Vitiligo Universalis and Systemic Lupus Erythematosus could also benefit from the provision of sunscreen as an essential medication for their life.]

In summary, we fully and unconditionally support the inclusion of A.25 Sunscreen, broad-spectrum – prevention of skin cancer in people with albinism to the essential medicine list.

Cordially,

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