



Information about Albinism

National Organization for Albinism and Hypopigmentation

Sun Protection

People with albinism can enjoy the outdoors by limiting their exposure to sunlight, wearing appropriate hats and clothing, and using sunscreens diligently. However, the task of preventing damage to the skin over a lifetime is a difficult one. Preventing sunburn is important, but not sufficient to prevent sun-damaged skin.

It is an invisible part of the light spectrum of the sun, the ultraviolet light, that damages skin. The shorter wavelength ultraviolet light, UVB, has a much bigger role in causing sunburn than the longer wavelength UVA. Manufacturers made sunscreens to block UVB and not UVA, so normally pigmented people could tan without burning. Newer research suggests that UVA, since it penetrates more deeply, may cause skin cancer and premature “aging” of the skin. Now sunscreen manufacturers label sunscreens as “broad spectrum,” which means they block both UVB and UVA.

Sunscreens

People with albinism should use sunscreens labeled SPF of 20 to 30. “SPF” means “sun protection factor.” This number comes from a standard test in a laboratory. The test measures the time it takes people wearing a standard amount of sunscreen to sunburn under a standard ultraviolet lamp, compared to the time with no sunscreen. In theory, if a person could stay in the sun 10 minutes without burning with no sunscreen, he or she could wear an SPF 20

sunscreen and stay in the sun 20 times 10 minutes or 200 minutes before burning.

The current SPF system focuses on sunburning, and mainly measures UVB protection. Since UVA penetrates the skin deeply but has much less energy for burning, researchers have become concerned that sunscreens could create a false sense of security, and allow people to sustain damage to their skin. The FDA is considering adding a second rating system for UVA protection.

In actual use, a sunscreen may not provide as much sunburn protection as expected from its SPF rating, largely because people do not apply enough. Most people apply about half as much as the amount used for SPF tests. Full body protection for an adult requires nine portions of one-half teaspoon each, or a total of about an ounce. For sunscreens that come in four-ounce bottles, this amounts to one-fourth of the bottle per application.

People often develop a blotchy sunburn from spots missed with sunscreen lotions. Since sunburn develops two to four hours after the sun exposure, and sunburn may peak in intensity as long as 24 hours after sun exposure, it is important to apply the sunscreen systematically. Don’t forget the tops of ears, and the backs of arms and legs. Bicyclists need to protect the low back, where shirts often ride up.

It helps to apply the sunscreen one-half hour before going into the sun, since some of the screening chemicals bind to the skin. Remember that rubbing with towels or

friction from clothing such as between the legs can remove protection. Simple immersion in water does not remove protection of sunscreens marked “very water resistant” (80 minutes in water by FDA definition) or “water resistant” (40 minutes in water). The FDA has proposed dropping the term “waterproof.” Most people, especially children, do more in the water than just immerse themselves. They may rub off some of the sunscreen, and the old warning to “reapply after swimming” may be wise.

Which sunscreen should people with albinism use? It is difficult to recommend a specific sunscreen, because formulations change. Consumer Reports publishes a review of sunscreens every couple of years, and their evaluations show that labels of SPF and water resistance are usually accurate. In the Consumer Reports cost comparisons, some products cost as much as six times more than others. Some manufacturers are now marketing sunscreen in bigger bottles at much less cost.

Should people with albinism go for the highest SPF available? Using sunscreens with SPF higher than 30 offers little benefit, and more concentrated chemicals might be more likely to irritate or cause an allergic rash. The FDA has proposed limiting the number to 30. In my view, it would seem wise to use any number of products that have an SPF of 20 to 30. Paying a high price for a few more SPF points is probably a waste. Sunscreens with SPF in this range will include oxybenzone or a similar chemical that makes them “broad spectrum.” Oxybenzone blocks some UVA light, but not the longest UVA wavelengths. Another chemical, Parsol 1789 or avobenzone, provides “broader” spectrum coverage and might help people with fair skin prevent sun damage. Unlike oxybenzone, avobenzone is patented and expensive, and therefore it is not used in many products (Shade UVA Guard is one). Titanium

and zinc oxide screens provide very broad spectrum coverage and, if you have the patience to rub them in, may serve very well with little risk of allergic reactions.

Individual preferences will determine the best product, and factors such as consistency and smell may play a big part in the choice. Some products have an alcohol base that goes on easily but may sting and dry the skin. Others have a lotion base like baby lotion. Oil-based lotions are more likely to aggravate acne. Dry lotions contain plastic like polymers that make them very water resistant. Although they don’t feel oily, they can make your skin feel sealed.

Spray sunscreens are very sticky and hard to apply evenly. Self-tanning lotions contain chemicals that develop into a brownish color in sunlight. While this product might seem attractive to people with albinism, in actual use the skin may look mottled or dirty because the chemicals accumulate in skin lines and pores.

Problems with Sunscreens

Sunscreens can cause troublesome allergies. One sunscreen ingredient, PABA, causes allergic reactions frequently, and now all products are “PABA free.” It is possible to develop allergies to any of the usual UV-blocking chemicals or even to “inactive” ingredients of the lotion or fragrance. People who develop allergic reactions should seek advice from a dermatologist. A day before you intend to use a new sunscreen, apply it to a small area on one arm and wait to see if any itching or rash occurs. To prevent allergic reactions to sunscreen, it might help to wash sunscreens off at night.

Some sunscreens are marked for “sensitive skin.” Some of these contain the usual UV-blocking chemicals and may have no special properties to prevent allergy. Others contain

titanium dioxide, an inert (chemically inactive) substance often used as a white pigment in paint. To work as effectively as the active chemicals, titanium dioxide has to be thick enough to be visible; that is, it does not “rub in” easily and leaves a whitish color. Some sunscreens combine an opaque pigment like titanium dioxide with bright colors to apply across nose, cheeks, or ears like face paint, and these might serve to augment regular sunscreens for children.

Sunscreens also include the warning “consult physician before using on babies under six months age.” The concern is that babies will absorb more of the chemicals through their skin, and the chemicals may cause unforeseen problems. It is unlikely that research on the safety of sunscreens for babies will ever be done. Sunscreens containing inert blocks like titanium dioxide are probably safe, but babies should not have direct sun exposure in any case.

Avoiding Harmful Rays

Even for older children and adults with albinism, it is important not to rely on sunscreens, and to limit exposure to the sun. Most ultraviolet rays come between 10 a.m. and 2 p.m. Standard Time, or 11 a.m. and 3 p.m. Daylight Savings Time. Planning outdoor activities for morning or evening is the single most important measure for people with albinism to avoid sun damage.

The National Weather Forecasting Service gives predictions of UV risk on a scale of 1 (low) to 10 (high) for many communities. They base these predictions on the angle of the sun at noon at that place and date, the altitude, and the predicted cloud cover. These are how these factors come into play:

- Latitude: A person who can tolerate one hour of sun in Florida without burning can

tolerate two hours of sun in New Jersey under the same conditions.

- Season: The greatest intensity of ultraviolet light occurs at the summer solstice, about June 22. May 1 has as much intensity as August 15.

- Altitude: Each 1000-foot increase in altitude adds 4% to the intensity of the sunburning rays. The intensity of sunlight at 5000 feet is about 20% greater than at sea level.

- Weather: A bright day with a thin cloud cover has 60 to 80% of the ultraviolet rays that are present on a clear day. Clouds can cool and give a false impression that there is little risk of sunburn.

In addition to the UV forecast, consider your surroundings. Sand reflects 25% or more of ultraviolet rays so that it is possible to get sunburned while sitting in the shade on a beach. Fresh snow reflects 70 to 90% of ultraviolet rays. Water can also reflect UV rays. Reflected light may burn areas which are usually shaded, such as those under the nose or chin. As much as 96% of ultraviolet rays can penetrate clear water.

Clothing and Hats

Clothing is important. Up to 50% of the ultraviolet rays can go through wet cotton tee shirts worn for swimming. Colored clothing and denser-woven clothing allow less light penetration. Several manufacturers are promoting densely woven “breathable” synthetic fiber clothes for sun protection. These allow protection with long sleeves in warm weather. With time this type of clothing may become less expensive and more common.

Hats are essential. Hats with brims at least 3 inches wide all the way around are best for protecting the face, ears, and neck. Hats with narrower brims, such as tennis hats, at least protect the ears.

Sun Damage: What to Watch For:

Ultraviolet light over many years creates “actinic” changes in skin, and increases the risk of skin cancers. These problems are a cause for concern, but not alarm.

Actinic changes include fine wrinkling, yellowish discoloration, leathery thickening, and dilated capillaries branches, which appear as clusters of tiny red streaks on the skin surface.

The best treatment for these actinic changes is prevention. It is difficult to reverse these changes with chemical or surgical treatments.

One treatment for actinic changes is application of tretinoin (Retin A, Renova, other brands). Tretinoin cream or ointment can reverse some of these changes, at least temporarily. Tretinoin must be applied daily for months, and redness, irritation, and increased sun sensitivity are usual side effects. The use of tretinoin for people with albinism has not been studied, but original studies were performed on albino hairless mice, and it seems likely that tretinoin could work for people with albinism who can bear the side effects. Tretinoin is a prescription medicine, and should be used only under a physician’s supervision.

UV damage can also result in actinic keratoses (carrot-TOE-seez). These are small reddish or tan thickenings with an irregular rough or scaly surface. These develop mainly on the face and the backs of hands, and especially on bald scalps. Over years, some of these can develop into squamous cell skin cancers if left untreated. Physicians can remove small numbers of actinic keratoses by applying liquid nitrogen to freeze them. For more widespread actinic keratoses, dermatologists may prescribe an

irritant ointment such as 5-fluorouracil, which creates redness and peeling.

Most skin cancers are basal cell cancers. These look like dome-shaped pink bumps, with “a raised pearly edge and visible red capillary blood vessels. They may show scaling or scabbing in the center. In most instances, basal cell skin cancers can be removed with relatively simple surgery, and they do not tend to spread through the system.

Squamous cell cancers are less common among people with albinism in the United States, but can be more troublesome. They appear as firm red bumps that go on to form an ulcer surrounded by a firm border. They usually occur on the scalp, ears, back of the hands, or the lower lip. If treated early, squamous cell skin cancers also can be cured with surgery, but techniques must be used to be sure all of the cancer is removed. Squamous cell cancers starting on the skin spread through the system in about three percent of cases. If they spread, they are life-threatening, since therapy is limited.

People with albinism can prevent serious problems with skin cancers by taking protection against the sun, by examining their own skin for long-lasting “irritated” spots, and by getting “regular physician exams” of skin as adults.

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