



Sun & Skin Protection Factsheet

The Albinism Fellowship

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Everyone's skin needs extra protection from the sun, but people with Albinism are particularly vulnerable to sunburn because of the reduction or absence of melanin in the body that they experience. Melanin is the pigment, which is the skin's natural protection against sun damage.

The areas most at risk are those where the skin is thinnest or often exposed, e.g. eyelids, nose, ears, lips, neck, backs of the hands and legs, and the head if a sun hat is *not* worn. Children with Albinism, especially babies, are very vulnerable and should be protected when they are out of doors or even sitting in a car as the sun's harmful rays can pass through glass.

People with Albinism can enjoy the outdoors by limiting their exposure to sunlight, wearing appropriate hats and clothing, and using sunscreens diligently. Holidays in sunny locations are realistic providing sensible precautions are taken to protect the skin from sun damage.

What is UVA? (A for Ageing)

UVA rays are the longest of all the ultraviolet rays that reach the earth. They penetrate deep into the skin and can cause premature ageing, wrinkles and dryness. UVA can trigger a number of skin allergies.

What is UVB? (B for Burning)

UVB rays are the middle length rays; some of these are prevented from reaching the earth by the ozone layer. The rays that do reach us are mainly absorbed in the upper layers of the skin. It is in the base of these upper layers, that the pigment producing cells (melanocytes) are found.

What is SPF?

SPF stands for Sun Protection Factor and you will find that these can vary from as low as 2 to as high as 50. The amount of SPF that people *without* Albinism need for protection of their skin is determined by their skin type. There are six types:

<i>Skin Type</i>	<i>Factor Needed for Sun Protection</i>
1. Always burns, never tans	Factor 25 = SPF 25 or higher
2. Burns easily, tans eventually	Factor 15 = SPF 15
3. Sometimes burns, tans slowly	Factor 15 = SPF 15
4. Occasionally burns, tans well	Factor 8 = SPF 8
5. Hardly ever burns, tans well	Factor 6 = SPF 6
6. Never burns	Factor 2 = SPF 2

People with Albinism, certainly those with Oculocutaneous Albinism (OCA), which usually affects the eyes, hair and skin, should **ALWAYS** be treated as having skin type 1. SPF provides protection against UVB rays; for protection against UVA rays, you will need to choose sun protective products that provide both UVB and UVA protection.

There is a four star system for UVA protection which is designed to illustrate how it relates to UVB protection. The four stars represent four categories, which relate to the skin type and UVB chart above in the following way:

<i>Skin Type</i>	<i>SPF needed</i>	<i>No. of Stars Needed for UVA Protection</i>
1 & ALL people with OCA	SPF 25 or more	* * * *
2 & 3	SPF 15	* * *
4	SPF 8	* *
5 & 6	SPF 2 to SPF 6	*

Therefore, people with Albinism, and particularly those with Oculocutaneous Albinism (OCA) should use sunscreen with a Sun Protection Factor (SPF) of at least 25 and ideally more and four stars for UVA protection.

Choice of Sunscreens

There is a bewildering selection of sunscreens on the market. Choice of product is largely a matter of personal preference and everyone will be able to determine the best product for themselves. Follow the guidelines above, and seek advice from your doctor or pharmacist as appropriate. If your doctor is unsure how to manage your skincare, in some situations he/she will decide to refer you to a Dermatologist (skin specialist) for specific advice.

Sunscreens and Prescriptions

Because sun protection is so important for people with Albinism, sunscreen should be obtainable on prescription from your doctor, though some doctors are not aware of this. If your doctor is unsure about whether they can prescribe for you, you might suggest that they look in MIMS (under 'Skin'). They will find that sunscreen is prescribable for people with photosensitive skin conditions, which must surely include people with Albinism.

Suncare for Babies

Babies, especially those with Albinism, who are under six months of age, should **not** be exposed to the sun. The use of sunscreen at this age is **not** recommended

because a child's skin is more delicate and permeable than an adults. The concern is that babies may absorb too much of the chemicals in a sunscreen through their skin, and these may cause unforeseen problems. As long as babies are protected from the sun in other ways, for example by using sunshades on pushchairs, the outdoors can still be enjoyed as advised below.

Key Points for Sun Protection

General

- ✓ Be sensible about sun protection. The level of precautions required partly depends on the time of year. Extra care should be taken when visiting very sunny locations, especially for people from the UK who are used to a milder climate.
- ✓ Keep out of the sun at high-risk times of day, for example between 11.00 a.m. and 2.00 p.m., but especially around Noon.
- ✓ Planning outdoor activities for morning or evening is the single most important measure for people with Albinism to avoid sun damage.
- ✓ Don't forget that snow, sand and water can reflect the sun's rays, which increases the likelihood of burning.
- ✓ Harmful UV rays can penetrate glass and water. Ultraviolet rays can go through wet lightweight cotton T-shirts worn for swimming.
- ✓ It is possible to burn even when you feel cool. UV rays can penetrate quite dense cloud. A cold wind can make you feel cool but will not protect you from the sun.
- ✓ Even in the shade, you can be exposed to the surrounding sunlight by reflection.
- ✓ Sunlight is more intense at higher altitudes.
- ✓ Can I use a sun-bed? This would be very unwise for people with Albinism, so there is really only one word of advice - **don't!**

Using Sunscreens

- ✓ Apply sunscreen about half an hour before going out in the sun. Some sunscreens take time to absorb into the skin and become active.

- ✓ Apply enough sunscreen. Most people only apply about half as much as is needed to achieve the required sun protection factor.
- ✓ Apply sunscreen evenly. Don't forget about those exposed areas including tops of ears, and the backs of arms and legs, for example.
- ✓ Lips are particularly vulnerable to sunburn so do use a high factor lip screen too.
- ✓ Sunscreens marked 'water resistant' may slightly prolong protection, but the best advice is to reapply sunscreens often.
- ✓ Rubbing with towels or friction from clothing can remove protection, so it may be necessary to reapply sunscreen in these situations.
- ✓ You might think you're not burning. Don't be caught out! Sunburn develops 2-4 hours after sun exposure, and may peak in intensity as long as 24 hours after sun exposure. Always use sunscreen.
- ✓ Using sunscreens with a SPF higher than 30 offers little benefit. Paying a higher price for a few more SPF points is probably a waste.
- ✓ Sunscreen products have a short 'shelf life'. Check the 'use by' date. Ideally, you should acquire a new sunscreen before going on holiday in a sunny location or each summer season.
- ✓ A good moisturising cream may also help, especially for easing any soreness from sunburn, and to counteract dryness of the skin.

Specific Points for Parents

- ✓ Don't pile too many clothes and covers onto your little one in an effort to protect him/her from the sun. In hot weather especially, too much covering may cause even more discomfort, from overheating.
- ✓ Prepare a shady play area or try a Wendy house or other type of playhouse outside.
- ✓ Set a good example yourself by ensuring you and your family always wear sun hats when outside. Encourage your friends to wear hats also - start a trend.

Clothing

- ✓ Closely woven fabrics provide better protection against the sun than loosely woven fabrics do.
- ✓ Avoid very bright colours (e.g. white) that may reflect light. Darker, perhaps pastel colours may be helpful.
- ✓ Hats are essential! Those with wide brims and/or a flap at the back to protect the neck are ideal. Peaked caps are also a good method of reducing glare when outside, even on the not so sunny days.
- ✓ Several manufacturers are promoting densely woven breathable synthetic fibre clothes for sun protection. These allow protection with long sleeves in warm weather.
- ✓ Specialist sun protective synthetic fibre clothing can be expensive, although with time it may become less expensive. It is not necessary to have a large selection of this clothing, but perhaps a T-shirt or suit for generally hot sunny days or swimming outside is a good idea.



Sunglasses

- ✓ If buying off-the-shelf sunglasses choose some that absorb at least 95% of UV radiation; the wrap-around type can be effective. Buy from a reputable optician where good advice is available.
- ✓ If requiring prescription sunglasses, or when experiencing particular problems due to glare, consult a qualified optician.
- ✓ Fixed or variable tint or specialist photochromic (react to light) lenses for spectacles, or fixed tint contact lenses can be considered. Seek advice from an optician.
- ✓ It is now possible to buy spectacle lenses which are photochromic and also have a fixed tint. Instead of being almost clear indoors, the lenses have a visible fixed tint in them which darkens further once exposed to bright light.
- ✓ We understand that glass spectacle lenses which are 'react to light' will go darker than their plastic equivalent. This is due to the construction of the material used in plastic lenses.



Useful Addresses

Products:

UV deflective swim/action wear.

Range of 'Sun Smart' products including sun protective suits, T-shirts, hats and beach shelters.

Sun hats & sun protective suits for children.

UV protective buggy covers.

Sunshades for prams.

Supplier:

Koala Konnection UK Ltd.
Grove Mills
Cranbrook Road
Hawkhurst
Kent, TN18 4AS

Tel. 01580 754477

Retro UK Ltd.
28 Station Approach
Hayes
Bromley
Kent, BR2 7EH

Tel. 0181 462 1438

Cotton Moon Ltd.
P O Box 280
London, SE3 8DZ

Tel. 0181 305 0012

Supercover (Bolton) Ltd.
Lake Side View
Bentinck Street
Farnworth
Bolton, BL4 7EP

Tel. 01204 861007

Petite Star Productions Ltd.
Unit 3
Hill Farm Industrial Estate
Leavesden
Watford, WD2 7SA

Tel. 01923 663355

Points to Remember

People with Albinism can prevent serious problems arising from sunburn, and significantly reduce the risks of skin cancer, by taking sun protection seriously, and seeking advice from a doctor if any cause for concern arises.

Please do remember, as was said earlier, people with Albinism can enjoy the outdoors by limiting their exposure to sunlight, wearing appropriate hats and clothing, and using sunscreens diligently. Holidays in sunny locations are realistic providing sensible precautions are taken to protect the skin from sun damage.

Enjoy the outdoors but remember to take care!

The Albinism Fellowship provides advice and support to people with Albinism, their families, and professionals with an interest in the condition. It also aims to raise positive awareness about Albinism mainly in the UK & Ireland. Its main services include:

- A bi-annual Newsletter
- Further information about Albinism and related issues
- Opportunities for contact with other individuals & families affected by Albinism
- A Telephone Helpline from 2-3.00 p.m. on Tuesdays and Fridays of most weeks
- Occasional regional meetings & social events
- A bi-annual National Conference
- A bi-annual Focus Day for Adults

For more information about Albinism and the work of the Fellowship, please contact:

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We wish to acknowledge the following publications as providing information for inclusion in this guidance on sun and skin protection:

Marion Lesage for the Vitiligo Society, 1997, Vitiligo: Understanding the loss of skin colour.

Sheila M. Brown for The Albinism Fellowship, 1999, From Early Days to Optimism.

NOAH USA National Organisation for Albinism & Hypopigmentation, Albinism Information Bulletins - Sun Protection.

Averil Legg, 1953, A Parents Guide to Albinism.