

Understanding Albinism



Albinism is a rare condition that is inherited. It is not contagious. People with albinism have less of a pigment (or colour) called melanin in their skin, eyes and hair.

Albinism occurs all over the world. People with albinism are often very pale, they cannot see well, and their skin and eyes are vulnerable to radiation from the sun. In all other ways people with albinism are just like everyone else. Both boys and girls can have albinism.

Albinism is more common in sub-Saharan Africa than in other parts of the world.



Important Things to Know About Albinism

- Albinism is a genetically inherited condition. Sometimes there is only one person in a family with albinism, sometimes there are more.
- Albinism is a condition that people are born with and it lasts throughout life.
- You cannot catch albinism from someone.
- Albinism has nothing to do with the devil or a spirit or with special powers (for good or for evil). The only difference in people with albinism is in the amount of pigment that they produce.
- People with albinism have the right to do all the things that everyone else does: go to school, have a job, get married, have children, etc.

For information, advice and support regarding albinism please contact the Sierra Leone Association of Persons with Albinism. (SLAPWA) on **076429890**

Albinism and Eyesight



People with albinism almost always cannot see well. They are not blind and the condition will not worsen. Eyesight will be different for everyone.

Bright lights can be uncomfortable for people with albinism and they can often appear to be squinting or closing their eyes. We can all help people with albinism by listening to what support they need. They may need to sit at the front of a class, to have school materials in large print, to have more time to write from the board, to sit where the sun does not shine in their eyes.

With or without glasses, most people with albinism have to hold text very close to their eyes to read it clearly and comfortably. Some people may use devices like a book stand, a monocular telescope, or a magnifying glass. Some people will use reading glasses and some people will wear sunglasses, outdoors and indoors.

Albinism and Sun Protection

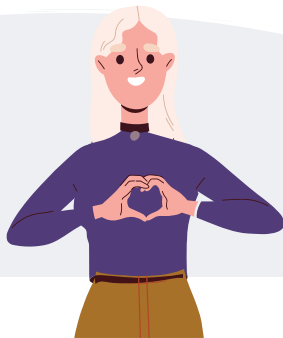


Skin cancer is one of the major challenges facing people with albinism. People with albinism are extremely sensitive to the damaging ultraviolet rays of the sun. They may develop blisters, hard skin and sores which can develop into skin cancer. People with albinism must protect themselves from the sun every single day (even on cloudy days).



People with albinism should avoid sun exposure as much as possible:

- Wear a hat with a brim wide enough to cover the whole face, including ears and nose, and the neck
- Wear sunglasses to protect their eyes from glare
- Cover up as much skin as possible by wearing long-sleeved shirts and long trousers or skirts
- Use sunscreen to protect parts of the body that are still exposed even when wearing protective clothing, such as the hands, ears, nose, forehead, cheeks, chin and neck
- Seek shade and avoid sun whenever possible, especially in the middle of the day



How to be a Good Friend to Someone with Albinism



Because it is difficult for people with albinism to hold eye contact and read facial expressions, social interaction can be challenging. This can easily be mistaken for shyness, rudeness or inattention. Get to know people with albinism in your school and the community by talking to them and inviting them to join in your activities.



Some people with albinism struggle to judge distances and speeds. As a result, they may have difficulties with fast-moving sports. Find ways to adapt games or choose another activity so that everyone can join in.



Do not use words such as Jus, Fenfu/Mulat in Temene, Jaiwi in Mende, Pullijor in Fullah and 'Disappointed African' – and do not refer to people with albinism as 'albino'. Use the personal name of the person with albinism at all times.



Support people with albinism to be comfortable to use the supportive devices that they need – the telescopes, umbrellas, large hats, etc. Do not mock people, or laugh when others mock them. Help people to feel accepted, safe and supported. The use of hats, umbrellas and sunscreen will help people with albinism to live a longer life; we can all help people to be comfortable wearing and using items that they need to protect their health.



Tell a teacher or another responsible adult if you see someone being bullied.

Albinism

WORDSEARCH



HAT
SKIN
UMBRELLA
ALBINISM
MELANIN
GLASSES
CANCER
SHADE
SUNSCREEN
PIGMENT



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