

**Myth:** Albinism is contagious.

**Fact:** This is not true. Albinism is a genetic condition and is caused by a mutation in the gene that affects melanin, a pigment that gives hair, eyes and skin its colour.

**Myth:** Persons with albinism are ghosts and cannot die.

**Fact:** This is not true. Persons with albinism are human beings just like everyone else. The lack of skin colour put them at risk for sunburn and may affect their eyesight.

**Myth:** It is the mother's fault that a child has albinism.

**Fact:** This is not true. Albinism is not a mistake, and it is not caused by anyone's wrongdoing. Both mother and father must carry the gene for a child to have albinism. This happens to one in 3,900 of the South African population. There is no way to prevent or cure albinism.

There are organisations that help families who have a family member with albinism.

They have support groups available.

Albinism Society of South Africa: +27 11 838 6529

Vanilla Mamas: +27 83 200 2133

Reamogeleng Community Organization:

+ 27 78 818 7334



Created by the Mothering and Albinism research project, supporting and promoting the human rights of persons with albinism and their families.

[www.motheringandalbinism.com](http://www.motheringandalbinism.com)

<https://africaalbinismnetwork.org/>



Africa  
Albinism  
Network



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# Mothering and Albinism in South Africa

## What is albinism?

Albinism is a genetic condition where both mother and father must be carriers of the gene for a child to have the condition. It is caused by the lack of or limited amount of melanin, a pigment in the hair, skin, and eyes. Thus, many persons with albinism have a lighter skin complexion.



Many persons with albinism are sensitive to the sun and can get sunburned easily, increasing their risk to skin cancer. They may also have vision problems. There is no cure for albinism but there are strategies to help with managing it.



## First year of life

- It is recommended for you as parents to have genetic counselling soon after birth so that you are given education about the cause of the condition and needs of a child with albinism.
- It is also recommended for your baby with albinism to be seen by a skin and eye doctor before they are one year old.
- You can ask for a referral for these services from your family doctor or nurse.



## Caring for your child with albinism

- Before going outside, ensure your child with albinism uses sunscreen with a Sun Protection Factor (SPF) of at least 50 to protect their skin. Sunscreen must be applied everyday. It is recommended that sunscreen is applied 15 minutes before going outside and reapplied every two hours. Children must wear long-sleeve clothing and large-brimmed hats. It may also be beneficial for children to use umbrellas and tinted glasses (sunglasses).
- Limit your child's exposure to the sun, especially between 10:00 am and 3:00 pm. It is harmful to their skin.
- Children need to have skin checkups regularly with your nurse, family doctor or a dermatologist for cancer screening.
- When children with albinism start going to school, they need to see an eye doctor and have their eyes tested. They may need to wear prescription eyeglasses regularly.