

## the Fellowship

The Fellowship is a voluntary self-help, sociable and positive organisation that aims to provide information and support for people with an appropriate interest in the condition. Our vision is that all people with albinism have the opportunity to realise their full potential.

### our mission is to:

- Provide information about albinism.
- Raise positive awareness of the condition.
- Arrange opportunities for people to meet and for support.
- Encourage the sharing of experiences.

### services offered:

- Twice yearly magazine, Albinism Life
- Website resource
- Local support through Contact Persons
- Telephone support on 01282 771900
- Annual regional events
- Conference every two years

## contact details

If you want to find out more about albinism, the Fellowship, or would like to become a member of the organisation, please do get in touch with us. Our contact details are below. We look forward to hearing from you.

The Albinism Fellowship is a sociable organisation that aims to be supportive and positive in all that it does.

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Do you or someone you know need information or support?

## what is albinism?

Albinism is a rare genetic condition, associated with a total lack or reduction of the pigment melanin in the body, and a visual impairment.

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## the types of albinism

### **Oculo-cutaneous albinism (OCA)**

Usually affects the eyes, skin and hair.

### **Ocular albinism (OA)**

Usually affects the eyes only.

People with albinism typically have a normal lifespan.

People with albinism, particularly those with OCA, have to take care to protect their skin and eyes from the harmful effects of the sun.

In all types of albinism the eyes are usually affected by:

- A visual impairment - due to under development of some parts of the eye (e.g. the macula and retina).
- Photophobia - an extreme sensitivity to bright light, sunlight, and glare. The eyes are usually coloured blue/grey or sometimes brown, not pink or red.
- Nystagmus - rapid involuntary eye movements.
- Squint - people with albinism may have or develop a squint (strabismus).

Families affected by albinism should be aware of, but not alarmed about:

### **Hermansky-Pudlak Syndrome (HPS)**

A very, very rare type of albinism. This usually affects people in the same way as OCA, but is also associated with other medical issues including a blood platelet dysfunction. Specialist medical advice is required.



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