

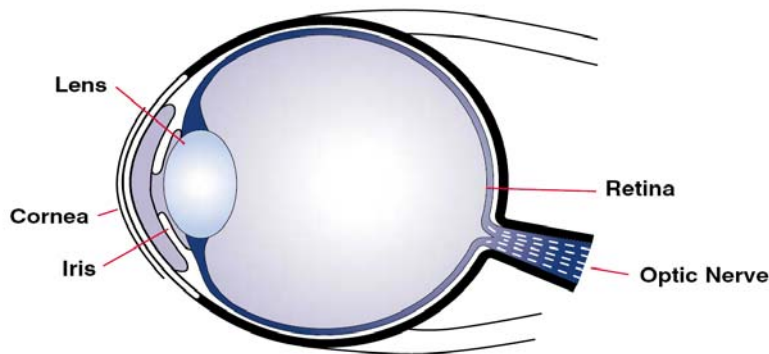
RETINAL (rod and cone) DYSTROPIES

What we see is in fact made in the brain. The brain makes sight from signals given to it by the eyes.

What is the normal structure of the eye?

The eye is made of three parts.

- A light focusing part at the front (cornea and lens).
- A light sensitive film at the back of the eye (retina).
- A large collection of communication wires to the brain (optic nerve).



Retina.

The retina has two types of light sensitive cells called Rods and Cones.

Rods are good at 'seeing'

- Things that move
- In the dark
- In black and white
- Less detail
- Mostly 'outer' / peripheral vision

Cones are good at 'seeing'

- Things that are still
- In daylight
- In colour
- In fine detail
- Mostly 'central' vision

What are Retinal Dystrophies?

- Dystrophy just means a condition a child is born with.
- Most cases are genetic, that is there is a problem with the chemical make up of the body.
- The photoreceptors either do not work from the day a child is born or else slowly stop working over a period of time.

Retinal Dystrophy occurs in a wide range of eye conditions and is divided into 2 main groups:-

- Rod – Cone Dystrophy where the rods are mainly affected such as Lebers Amaurosis, Retinitis Pigmentosa, Ushers Syndrome and Batten's Disease.
- Cone – Rod Dystrophies (Macular Dystrophy) where the cones are mainly affected such as Stargardts disease, Best's Disease and Lawrence-Moon-Bardet- Beidl Syndrome.

How does this affect the way my child sees?

Vision

- If rods are mainly affected then "Tunnel vision" may occur. These children may find their vision is worse at night and in dull conditions.
- If cones are mainly affected then there will be a reduction of central vision. In some cases the children look slightly to the side because their central vision is so poor. These children will be unable to give eye contact, because of this, and this can be mistaken for shyness or rudeness. These children may have poor colour vision.

Photophobia / Glare

- Children may be uncomfortable in bright light. This may cause their eyes to water.

Nystagmus

- Children may develop nystagmus (wobbly eyes) or roving eye movements.

What can be done to help?

There is no operation / treatment to cure Retinal Dystrophy. There are however, things that can be done to help children see better.

- **Glasses.** In Cone Dystrophy glasses may be needed and tinted lenses may help reduce glare.
- **Hats.** To reduce glare a peaked hat or visor may be useful.

- Be aware of possible need for help to and from school especially in the winter months.
- **Low Vision Aids.** Equipment such as magnifiers may be useful.
- **Genetic counselling.** Ask your eye specialist for help or details.
- **Emotional support.** The child and the family may benefit from this.
- **Mobility.** Advice or training may be necessary.

How can parents, family, friends and teachers make a difference?

- Be aware of the problems with **glare**. Where possible the child should be seated close to the teacher, away from windows if there are no blinds and close to the board and TV.
- **Outdoor protection.** Encourage the child to wear a peaked hat or specially tinted glasses if prescribed.
- Wherever possible use **matt surfaces** for desktops, whiteboards, paper, wall, floors etc. Shiny surfaces, snow and water can reflect light, causing glare.
- **Near work.** A close reading position may be preferred and should not be discouraged.
- Be aware that some children may have **difficulties with colours** and/or have a **reduction of night vision**
- For some children, **adaptation and modification of materials** may be necessary e.g. large print, desk copies of board work and adapted ICT display.
- **School Equipment.** Many children with Retinal Dystrophy, at Key Stage 2 and above, benefit from using some type of magnifier. This enlarges print making reading less tiring. It may sometimes be helpful to provide a desk stand or a copyholder, which will bring work to eye level and prevent discomfort and poor posture.
- **Learn about the condition** and how it may affect your child's vision.
- **Career advice** needs to take the long-term effects of **Retinal Dystrophy** into consideration.

Useful contacts.



Birmingham Focus on Blindness

Tel: 0121 478 5200

RNIB

Tel: 0845 766 9999

LOOK (for families with visually impaired children)

Tel: 0121 428 5038

There may be separate support groups for individual eye conditions.

This leaflet is also available in large print.

This information is intended to describe most aspects of the condition but each child is different and there will always be exceptions.

Acknowledgements

This leaflet was compiled by a multidisciplinary team from the eye departments at Birmingham Children's Hospital and Birmingham Heartlands Hospital, Birmingham Focus on Blindness and Birmingham Specialist Support Services.