

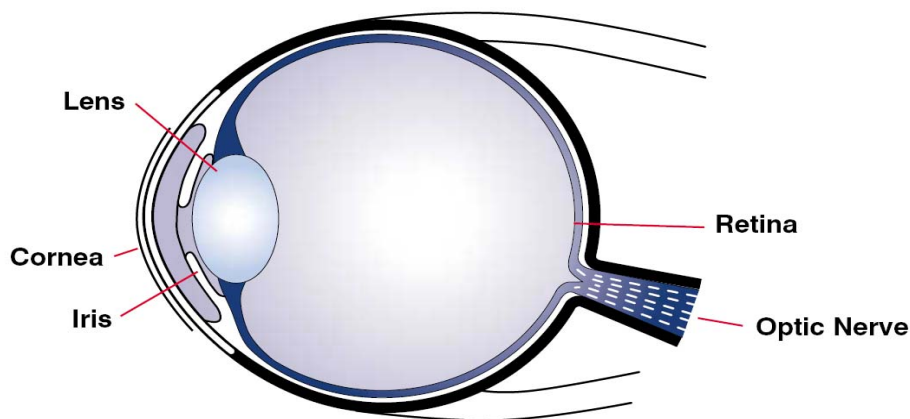
## LEBER'S AMAUROSIS (INFANTILE ROD-CONE DYSTROPHY)

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 is Leber's Amaurosis?**

Leber's Amaurosis is a congenital (present at birth) condition where the rods and cones in the retina do not grow properly. It often runs in families but can occur by chance.

### **How does this affect the way my child sees?**

#### **Vision.**

- Children with this condition usually have very poor or no vision.
- They may have Nystagmus (wobbly eyes) or roving eye movements due to the problems with their vision.
- Infants may poke their eyes to stimulate "flashing" effects in the eye.

### What can be done to help?

- Children can be helped to relate to, and learn about their environment.
- **Mobility training** is useful to help children learn to move safely and confidently.
- **Braille** (a form of reading using the fingers) may be recommended.
- **Genetic counselling.** Ask your eye specialist for help or details.
- **Emotional support.** Extra support for the whole family is often helpful. Many children are able to cope well with extra support.

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

- Create a safe environment for the child. Make as few changes as possible so that the child becomes familiar with it.
- Learn “sighted guide” techniques to help the child move safely.
- Make use of specialist equipment to improve the child’s independence.
- Be aware that the child may have learning difficulties in addition to the visual problems.

## 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

**People with Leber's Amaurosis Network (PLAN)**  
46 Blandford Avenue  
Oxford  
OX2 8DZ  
Tel: 01865 559084  
E-mail: [deval@plan.demon.co.uk](mailto:deval@plan.demon.co.uk)

**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.