### **Patient Information**



# Information for Parents of Children who have Congenital Cataracts

### What is a congenital cataract?

A congenital cataract is an opacity (cloudiness) in the lens of the eye that is present at, or develops shortly after birth. It can affect one or both eyes.

The lens is located behind the coloured iris and its job is to focus light on the retina (the photographic film at the back of the eye). The lens should be clear like glass but when a cataract is present it becomes cloudy and blurs or blocks the vision to the retina.

### How does a congenital cataract affect the vision?

How the cataract affects the vision depends on the size, density and position of the cataract. If the cataract is slight then vision may develop normally. However if the cataract is significant then it will severely affect the development of vision.

In newborn infants and babies the cataract stops images from reaching the visual system (brain) and means the vision cannot develop and the child will not learn to see well out of the affected eye(s).

This causes amblyopia (poor vision caused by under-development of the visual system). If left untreated this reduced vision can be permanent.

### What causes congenital cataract?

The usual cause is a genetic mistake in the code for the lens of the eye. This is sometimes inherited, but most occur spontaneously.

A small number of cases are related to other developmental abnormalities. Your child may be referred to a Paediatrician (specialist doctor for children) to rule out other problems.

# What treatments are available for congenital cataracts?

If your child has a cataract that is affecting vision, then treatment needs to take place as soon as possible to allow visual development to occur as early as possible.

Sometimes treatment is not recommended if the cataract is mild or, if it is very dense and has been present for a long time. The most effective treatment is surgical removal of the lens that contains the cataract.

Because the lens has strong focusing power it needs to be replaced by either a false lens (intraocular lens implant) or by using a contact lens or glasses. These false lenses do not change the focus of images from near to distance like a normal human lens. Glasses or contact lenses are still needed to allow the child to see clearly for near and distance.

The Consultant Ophthalmologist will talk to you about the surgical options and risks.

#### Who will I see?

The Consultant Paediatric Ophthalmologist will manage the surgical treatment of the cataract. Your child will also be seen by the Orthoptist who will measure and monitor your childs vision and the Optometrist who will test for glasses and or contact lenses. You will be allocated an Orthoptist.

### What happens after the surgery?

Unlike cataracts in adults, the operation to remove the cataract is only the beginning of the treatment. It is not a quick fix.



#### **Eye Drops**

Immediately after the surgery you will be given eye drops to put in your child's eyes at home. Initially the drops have to be put in every hour and frequently thereafter. The Ophthalmologist will explain in more detail about the drops and how to put them in.

#### Glasses/contact lenses

Because the surgery changes the way the eye focuses, your child will need glasses or contact lenses from around one week after the operation. It is important that your child wears the glasses/contact lenses when they are awake so that they have a clear focused image on the retina, the 'photographic film' of the eye.

The Hospital Optometrist will test for and prescribe the glasses or contact lenses. Glasses can be specially made for young babies. In the first few weeks the hospital Optometrist may lend you a pair of glasses.

When your child is older they will need bifocal glasses to allow them to be able to focus on near objects as well as distance.

It is likely that your child will need to continue to wear glasses all of the time until they are at least aged 8 years old. They are likely to require glasses and /or contact lenses all of their life.

#### **Patching (Occlusion)**

It is likely that your child will need to have some patch treatment after the surgery, especially if the cataract is only in one eye. Patching is needed to improve the vision after the cataract is removed. The Orthoptist will give you instructions about the patching and monitor your child's vision.

### How often will my child be seen?

Initially after the surgery you will need to bring your child to frequent (every1-2 weeks) appointments at the Eye Unit in Exeter. Once the eye(s) has healed after the surgery your child will be seen less frequently (about every 6 weeks).

Your child will need to be seen regularly for the rest of their lives, although later (after age 8-10 years) this may be with your local optometrist.

If you have been referred to the West of England Eye unit from another area it may be possible at some stage for your child to be transferred back to your local Hospital.

# Will my child's vision improve with treatment?

The vision should improve with treatment but it is difficult to predict how well your child will be able to see as an adult. The Ophthalmologist and Orthoptist will talk to you about your child's vision.

# What support is available for parents and children?

You will receive support and guidance from all those involved in your child's treatment at the hospital.

Additional help is available from the Advisory Teachers for the Visually Impaired and the Rehabilitation Officers for Visually Impaired Children. They will be able to advise you about education, social services and links with other organisations.

## More information is available on these websites

- www.nhsdirect.nhs.uk
- www.viscotland.org
- www.rcophth.ac.uk

# Who can you contact if you have any more questions?

Please telephone **01392 406004** to speak to the Consultant Paediatric Ophthalmologist's secretary who will forward your enquiry.

The Trust cannot accept any responsibility for the accuracy of the information given if the leaflet is not used by RD&E staff undertaking procedures at the RD&E hospitals.

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