Retinopathy of Prematurity
Information Booklet

You may have many worries and anxieties, as your baby has been born so prematurely. This is a very difficult time for you. Additionally you have now been told that your baby has Retinopathy of Prematurity, a potentially damaging condition.

We hope that this short information booklet will help you to understand the condition and the doctor's explanation.

We have included a short account of one of our families who is further along the road. We hope that you will find this encouraging.

All the staff of the Ophthalmic Department will be striving to obtain the most positive outcome for your baby's vision.

In a normal eye, light passes through the front of the eye (cornea) to the back of the eye (retina) through the lens. The lens and cornea focus the light so that an image is formed at the back of the eye (retina). The retina is a very complex and sensitive structure that converts the light image into nerve impulses that are transferred via the optic nerve to the brain enabling us to see. All babies use their eyes from the day they are born stimulating the visual area of the brain. If these areas are not stimulated permanent visual loss can occur.

To understand why infants develop retinopathy of prematurity (ROP) it is important to have some understanding of the normal development of the eyes in babies. Babies' eyes develop throughout the 40 week gestational period. Blood vessels begin to supply the retina with both oxygen and nutrients from 16 weeks gestation. They begin to grow from the optic disk and gradually fan out towards the edge of the retina. Between 28-30 weeks these blood vessels begin to grow much more rapidly. The retina is not, however, fully supplied with blood vessels until the baby is full term. Once a baby is born and opens its eyes light passes through the lens and is focused onto the retina. The image is passed via nerve cells and fibres, through the optic nerve to the visual area in the brain. When babies are born more than 8 weeks early (32 weeks) problems may arise with the development of the retina.

Many babies born so soon require extra oxygen to help their developing brain but the Oxygen as well as other changes in the baby's environment may interfere with the normal development of the retinal vessels. Eventually scarring may occur on the retina. This damage is known as retinopathy and can lead to vision loss. The degree of vision loss is determined by the amount of damage the developing eye suffers.

There are five stages of retinopathy of prematurity.

Stage 1: The outer aspect of the retina is affected by the diminished blood supply and is shown by a clear demarcation line separating the well vascularised retina from the area where the vessels have not developed. About 80% of babies born more than 10 weeks early will suffer some degree of Stage 1 retinopathy. This usually resolves spontaneously without any significant effect on vision.

Stage 2: Any damage remains in the outer aspect of the retina but the demarcation line becomes thickened and ridged.

Stage 3: New blood vessels developing on the ridge will be abnormal. These abnormal vessels can loose there elasticity and begin to contract and may bleed.

Stage 4: The contracting blood vessels and scar tissue begin to pull the retina away from the back of the eye.

Stage 5: The retina is totally detached from the back of the eye.

Retinopathy of prematurity only occurs in premature infants. The survival of premature infants is improving all the time, but retinopathy remains a difficult problem to prevent. As more premature infants survive the more common retinopathy of prematurity becomes.

What are the symptoms of retinopathy of prematurity?

There are no symptoms of retinopathy therefore all small babies born less than 32 weeks gestation are screened by a specialist eye doctor (Ophthalmologist). Usually the screening begins when your baby is either six weeks old or is 33 weeks gestation and usually takes place fortnightly until the blood vessels in your baby's retina are mature.

What happens during the screening checks?

Drops will be put into your baby's eyes to enlarge (dilate) the pupils, this is necessary for the doctor to see your baby's retina. Once you baby's pupils are enlarged anaesthetic drops may be put into the eye if necessary. Your baby does not feel any pain during the examination. The doctor will hold your baby's eyelids open, either by hand or with a small instrument, and look closely at the back of your baby's eyes with a special light. The doctor may need to gently press around your baby's eyes with a special probe, in order to get a better look. The examination only takes a few minutes. Your baby may not like the examination but should only feel slight pressure, but no pain.

Your baby's nurse will keep you fully informed about the state of your baby's retina and let you know if treatment is needed.

How is retinopathy treated?

Stage 1 & 2: If your baby has either of these two stages no treatment is necessary, but your baby's eyes will still be closely monitored.

Stage 3: If your baby has stage 3 retinopathy, laser treatment will be given. The laser is a special piece of equipment that emits a very bright and fine beam of laser light.
This laser light destroys the peripheral retina which stimulates the growth of abnormal blood vessels. Laser treatment involves your baby having a general anaesthetic and usually takes about one hour. Normally only one laser treatment session is necessary; but the doctors will continue to check your baby's eyes on a regularly. Laser treatment can cause your baby's eyes to become a little red and inflamed but this settle down in a few days.

The nurses will put special drops and/or ointment into your baby's eyes to help them to heal.

Stage 4 &5: Stage 4 and Stage 5 retinopathy are very rare and the treatment is complicated. Your baby's ophthalmologist will discuss this with you in great detail.

What is the long term outlook for babies with retinopathy?

Currently 80% of babies with Stage 3 retinopathy do well and have good vision, but will be regularly checked. Even with treatment a small number of babies with Stage 3 retinopathy will have significant visual loss. Any child with significant visual loss will be referred for further advice and support to the local Specialist teacher for Visual Impairment. Developmental advice and monitoring will also be provided by a Community or Developmental Paediatrician.

Most babies, whose eyes do well initially, will continue to see well. However, all pre-term babies have an increased risk of developing eye problems as they grow older. These problems are not directly related to the ROP and include:

- *Amblyopia (Lazy eye):*
- *Strabismus (Squint):*
- *Myopia (Short-sightedness):*
- *Glaucoma (raised pressure within the eye).*

All of these conditions, if they arise, will be discussed in much greater detail by your baby's eye doctor.

If your baby has had Stage 1 and Stage 2 retinopathy, regular visits to the Ophthalmic Outpatient's Department are not normally necessary. If any eye problems develop in the future your child will be referred back to the Ophthalmologist by your own GP.

However, if your baby has had either Stage 3, 4 or 5 retinopathy, your baby's eyes will need to be checked frequently. Initially you and your baby will attend the Ophthalmic Outpatient's Department every two to three months, then every six months and finally on a yearly basis until your child is about 5 years old. Once discharged from the Ophthalmic Department your own GP will make the referral back if any further problems arise with your child's eyes.

For the vast majority of infants, referrals back to the Ophthalmic Department are not necessary.

Paediatric Sub-committee
The Royal College of Ophthalmologists

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