Retinopathy of Prematurity (ROP) Resent information leaflet

Parent information leaflet

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Your doctor has recommended that your baby is screened for Retinopathy of Prematurity. This leaflet will explain about the test, how it is performed and why it is required.

What is ROP?

Retinopathy of prematurity is an eye condition which affects the blood vessels of the retina. The retina is the delicate tissue lining the back of the inside of the eye and functions similar to the film at the back of a camera, allowing for detection of light which enables us to see. The vessels are necessary to provide a blood supply to the eye.

ROP is common in premature babies and about 65% of babies born less than 1251 grams (2lb 12oz) will have some degree of ROP which is mild and settles on its own without treatment.

ROP can occur in various degrees from mild to severe. Mild forms usually settle on their own without treatment. Severe forms can rarely cause blindness if left untreated. Treatment usually prevents this.

Why does ROP occur?

The exact cause is unknown.

Normally blood vessels grow along the retina from the centre towards the outer retina. This process continues until around 40 weeks gestation.

After preterm birth something triggers the vessels in the retina to start to grow abnormally. Babies born before 32 weeks of gestation are at greater risk of developing ROP. The move from a relatively poor oxygen environment (womb) to a rich oxygen environment (e.g. incubator with added oxygen) impacts on the growth of these vessels, therefore the balance of need for oxygen with the risks of ROP are carefully weighed up. Some premature babies who have no serious illness or require oxygen still develop ROP, while those who have been very ill, do not.

How and why is the test performed?

All babies born less than 32 weeks of gestation and/or weighing less than 1501 grams (3 lb 5 oz) should have ROP screening once they are between 28-35 days old or before discharge if your baby is well enough to be discharged before. Follow up screening may be required. Your ophthalmologist will inform you at the time of the test.

Around one hour before the examination the nurses will put eye drops into your baby's eyes; this is to dilate the pupils to allow a better view for the ophthalmologist to see the retina. They can be a little uncomfortable but do not significantly distress your baby.

A small clamp is then placed gently over the surface of your baby's eye. This holds the eye lid open. A light called an ophthalmoscope, is then used to view the retina and vessels with the aid of a small probe to help rotate the eye.

The examination itself can be uncomfortable. Sucrose (sugary water) is given to your baby prior to the procedure to distract from the discomfort. Often sucking on a dummy and other methods can be used such as swaddling them.

What do I need to do?

You are more than welcome to stay with your baby whilst this is being done, but if you prefer to wait outside then that is not a problem. A member of the nursing team will be with your baby throughout the whole procedure to provide care and support.

What happens if ROP is detected?

This will depend on the severity detected.

If it is mild then a repeat test will be performed in 1-2 weeks' time. If this test shows it has not become worse then it will usually settle on its own.

More severe cases will require an earlier follow up, usually in one weeks' time.

In a small proportion of severe cases the ROP will require treatment. Your ophthalmologist will explain this to you and will discuss what will happen. The nursing staff can also provide you with written information should you require it.

Aftercare and follow up

Normal care may resume after the test has been carried out. After the procedure your baby's eyes may be red and puffy, but this should improve within a few hours. They may also be a little unsettled that day. The nursing team will continue to monitor your baby but if you have any concerns, please speak to the nurse or doctor looking after your baby.

Not all follow up tests need to be performed whilst your baby is an inpatient on the unit and can be undertaken as an outpatient.

Your baby will be discharged home when they are well and the doctors will discuss this with you. This may mean your baby has not received a follow up check. Please rest assured that your baby will receive this follow up test as an outpatient and we will write to you with a date.

It is important that you bring your baby to this appointment.

If you have any further questions please speak to you baby's nurse or doctor.

Online resources:

https://www.rcpch.ac.uk/resources/screening-treatment-retinopathy-prematurity-guidance https://www.bliss.org.uk/parents/in-hospital/about-neonatal-care/tests

Feedback

We want your visit to be as comfortable as possible. Please talk to the person in charge if you have any concerns. If the ward/ department staff are unable to resolve your concern, please ask for our Patient Advice and Liaison (PALS) information. Please be assured that raising a concern will not impact on your care. Before you leave the hospital you will be asked to complete a Friends and Family Test feedback card. Providing your feedback is vital in helping to transform NHS services and to support patient choice.



The hospital can arrange for an interpreter or person to sign to assist you in communicating effectively with staff during your stay. Please let us know.

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