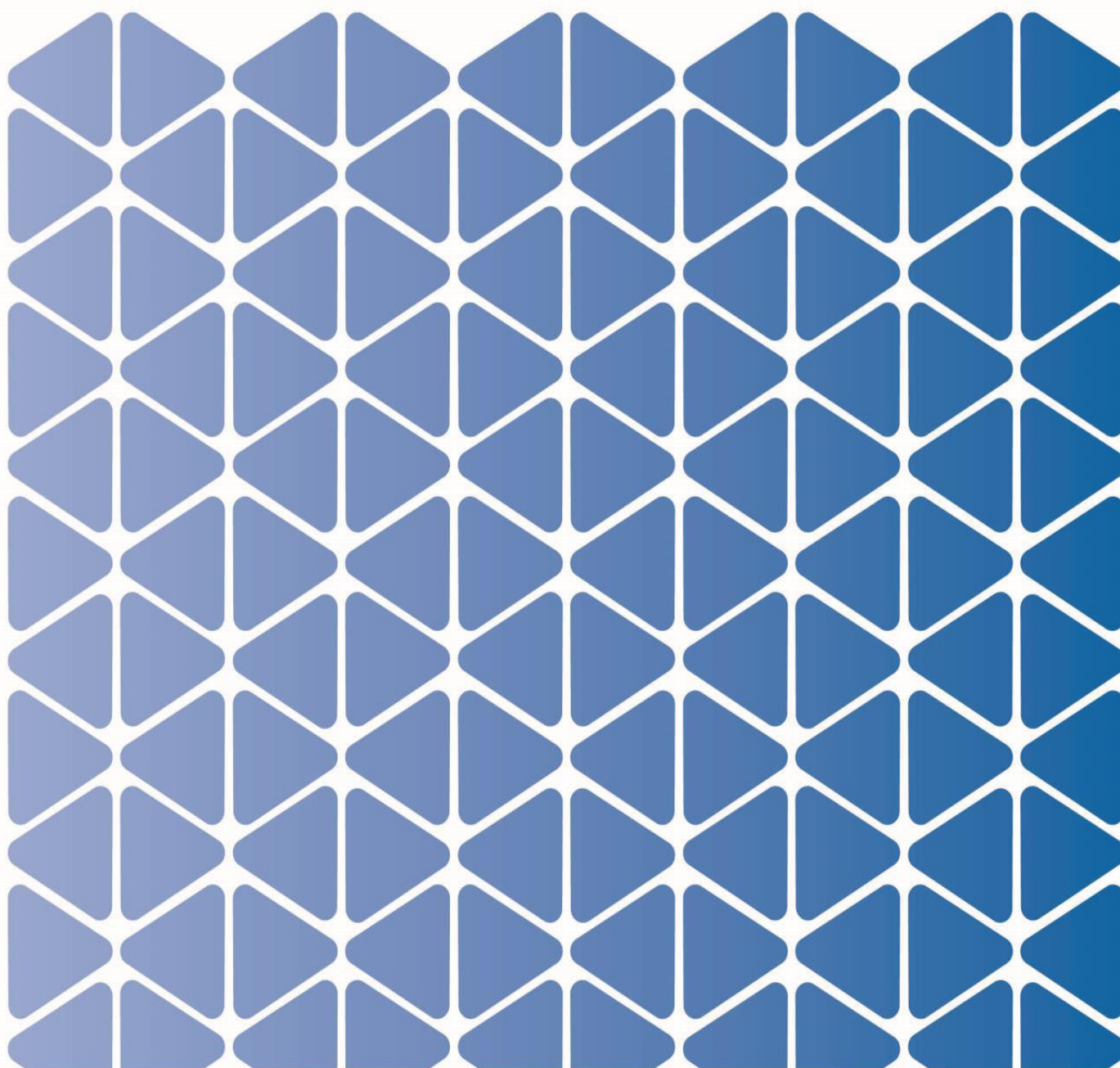


PARENT INFORMATION**SCREENING FOR RETINOPATHY OF
PREMATURITY (ROP)**

For parents of all babies born less than 31 weeks' gestational age (up to and including 30 weeks and 6 days) OR less than 1501g birth weight

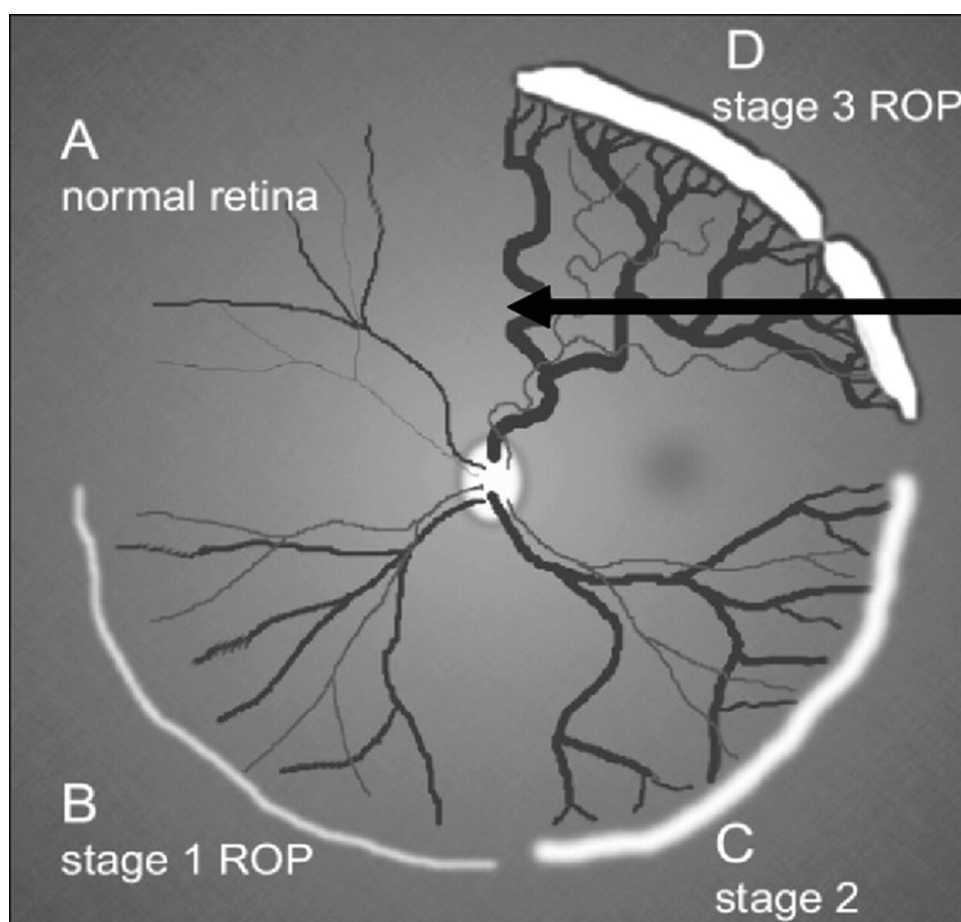
What is Retinopathy of prematurity?

The retina is the delicate tissue lining the back of the eye which detects light and allows us to see. Retinopathy of Prematurity (ROP) is an eye condition which affects the blood vessels of the retina.

What is screening for ROP?

ROP screening is the eye examination carried out by an ophthalmologist (or eye specialist) to look for any signs of ROP.

All babies weighing less than 1500 grams at birth or born more than 9 weeks early will need at least one eye screening.



Diagrammatic view of the retina as seen through the pupil.

The white oval in the centre is the optic nerve and the area towards the right is known as the macula. The macula is the part of the eye that allows us to see fine detail. The grey lines are the arteries and the black lines are the veins.

This diagram illustrates how ROP develops, usually progressing over time from Normal to Stage 1 through Stage 2 to Stage 3. Mild ROP of Stages 1 and 2 are very common and settle on their own. Only a small proportion of babies develop Stage 3 (indicated by arrow) which is more serious.

View diagram starting at letter A.

The blood vessels pointing towards A are normal.

At B there is a white line, at the growing tips of the blood vessels- Stage 2 ROP. The white line is the ROP.

At C the line has become thicker- Stage 2 ROP

At D, the line is much thicker because of the formation of very fine and abnormal new blood vessels. You can also see that the arteries have become very tortuous (wiggly), and the veins are much fatter- this is known as plus disease and are signs that the eye needs treatment.

All ROP stages are shown in small sections, as though in one eye, which they would never be.

How common is ROP?

ROP is common in premature babies affecting about 65% of babies less than 1250 gram birth weight. The condition is usually very mild and settles on its own without treatment. In very few babies (usually the smallest and most premature) the ROP does not get better and treatment is needed. If not treated, very severe ROP can seriously affect a baby's sight and even cause blindness.

Why does ROP occur?

No one knows exactly why. When a baby is born early the blood vessels of the retina are not yet fully developed. After birth something triggers the blood vessels to start to grow abnormally and this forms scar tissue which, if severe, can damage the retina. The main cause of ROP is prematurity itself, so the more premature the birth occurs the greater the risk of ROP occurring. The amount of oxygen treatment required and the baby's general condition may also influence whether ROP develops or becomes severe. However, some premature babies who have no serious illnesses still develop ROP, while others who have been very ill do not. Therefore, it is necessary to screen all babies born less than 31 weeks gestation or less than 1500 grams birth weight.

When will screening be done?

The first screening examination will be done when your baby is between 4 and 6 weeks old. Some babies will only need one examination although most babies need at least two.

What happens during screening?

About an hour before the examination, eye drops are put into the eye to make the pupil open widely so the retina can be seen. The ophthalmologist examines the retina using an ophthalmoscope (or sometimes a camera) placed gently on the surface of your baby's eye. They may also use a speculum (to hold the eyelid open) and an indenter (to rotate the eye) to enable a better view of the retina.

Is the examination painful?

Eye examinations can be uncomfortable even for adults and babies sometimes cry or show signs of distress when their eyes are examined.

The ophthalmologist will make the examination as quick as possible although they do need enough time to see the retina properly. If a speculum, indenter or a camera are used then anaesthetic eye drops should be given to minimise the discomfort to your baby.

Research has also suggested that wrapping your baby firmly, giving breast milk or sucrose drops can help keep these babies calm during the eye examination. The nurses on the unit will have a lot of experience in preparing babies for eye examination and will be able to explain what their practise is. You are encouraged to be present or nearby to comfort your baby during and immediately after the examination. The parents' voice and touch is familiar and will give comfort to your baby during the procedure.

What happens if my baby is ill when the eye examination is due?

There is no evidence that ROP screening is harmful for babies but the doctors may decide to postpone the examination for a short while until your baby is stronger. However, screening must not be postponed so long that the opportunity for treatment is missed.

What happens if ROP is found?

This depends on how serious it is:

- If ROP is mild, there will need to be a follow-up examination 1 to 2 weeks later. If the follow-up examination shows it has not become worse, the ROP will settle on its own.

- More severe ROP will require an earlier re-examination.
- In a very few cases the ROP may be severe enough to require treatment. If your baby requires treatment at any stage the ophthalmologist will talk to you to explain exactly what will happen.
- There is a separate leaflet with more information called 'Treatment for ROP'.

Will screening finish when my baby goes home?

Your baby will be discharged as soon as they are well enough to go home. This might be before the last eye screening. If this is the case, staff should arrange an out-patient appointment before you take your baby home.

It is very important that you bring your baby back for their eyes to be checked if you are asked to.

When you are ready to take your baby home ask the staff if you need to bring them back and when. They may also write to remind you about the appointment.

Where can I get more information?

If you have any questions or need more information, please ask your nurse or medical staff and they will be happy to help.

About this leaflet

This leaflet has been produced to accompany a guideline for the screening and treatment of ROP, developed by the Royal College of Paediatrics and Child Health, the British Association of Perinatal Medicine and the Royal College of Ophthalmologists.

Parents and professionals have helped to write the leaflet. The main guideline contains recommendations for health professionals informed by research evidence.

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If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.