Screening for retinopathy of prematurity

Information for parents and carers

The ROYAL COLLEGE of OPHTHALMOLOGISTS

British Association of Perinatal Medicine

Bliss for babies born premature or sick

RCPCH Royal College of Paediatrics and Child Health

Leading the way in Children's Health

You have been given this leaflet because your baby was born at less than 31 weeks of pregnancy (very premature birth) or had a birthweight under 1501 grams and is at risk of developing retinopathy of prematurity (ROP). ROP is a condition which affects your baby's eyes and can cause severe problems with vision.

Most babies will not develop ROP or will have a mild condition which will usually go away by itself. The only way to see if your baby has ROP and to see if it will need treating is to look at the back of their eyes with special equipment. This is called screening for ROP.

This leaflet will:

- give you more information about ROP
- clarify what happens during screening, and how you can support your baby
- explain what happens after screening.

As well as reading this information, the medical team looking after your baby will talk to you about screening for ROP. You will be able to discuss any questions or concerns you have with them.

What is ROP?

ROP is a condition that affects blood vessels (which carry blood around the body) in a part of the eye called the retina. The retina is at the back of the eye – it detects light which allows us to see. After a very premature birth, these blood vessels can start growing abnormally, resulting in ROP.

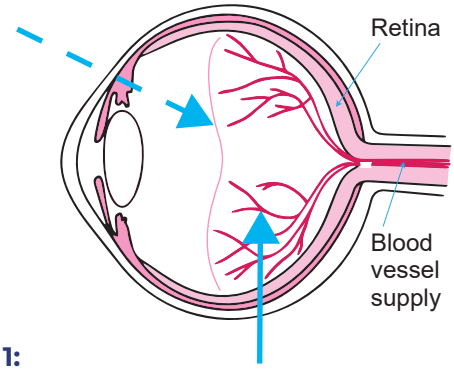
The main cause of ROP is a very premature birth. Other health problems associated with a very premature birth may also affect whether your baby will develop ROP, or if it will become severe.

In most babies, ROP is mild and will get better by itself, but for a small number (around one in twenty) of very premature babies, it may become severe. This can lead to partial or total loss of sight (blindness).

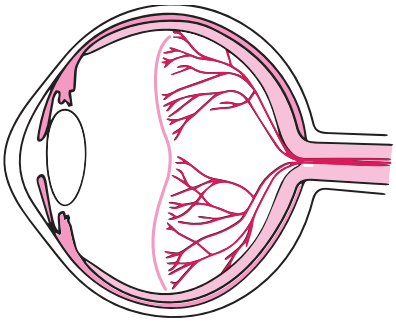
As it is not possible to tell if your baby has ROP from looking at the outside of the eye, we need to regularly look at the retinas of all babies who are at risk of ROP to find out if it is developing. Finding and treating ROP before it becomes severe can reduce the risk of sight loss. ROP is classified by numbered stages which are shown in the diagram below.

What does ROP look like?

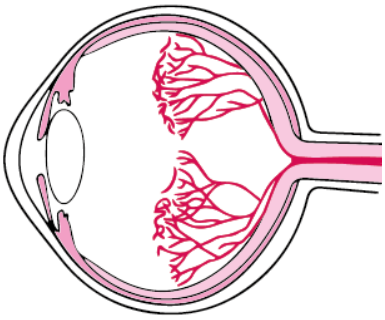
The diagrams show the stages of ROP. Mild ROP of stages 1 and 2 is very common and usually settles on its own. Only a small proportion of babies develop stage 3, which is more serious and may need treatment. By screening for ROP and providing treatment if needed, the most serious stages (4 and 5) can usually be prevented.



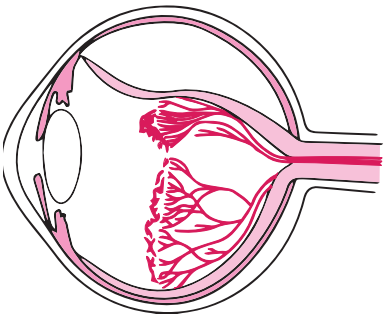
Stage 1:
Blood vessels (solid arrow) in the retina normally develop from the back of the eye to the front. In stage 1, a thin line (dashed arrow) is seen between the part of the retina that has blood vessels and the part that does not.



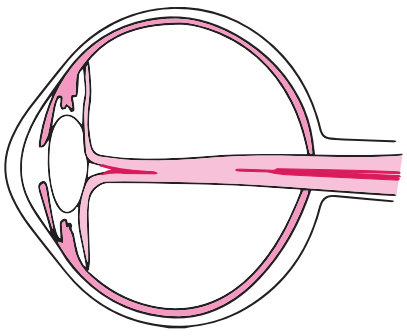
Stage 2:
The thin line becomes more prominent.



Stage 3:
Disorganised new blood vessels are present.



Stage 4:
The disorganised blood vessels begin to pull the retina away from the wall of the eye (known as partial retinal detachment).

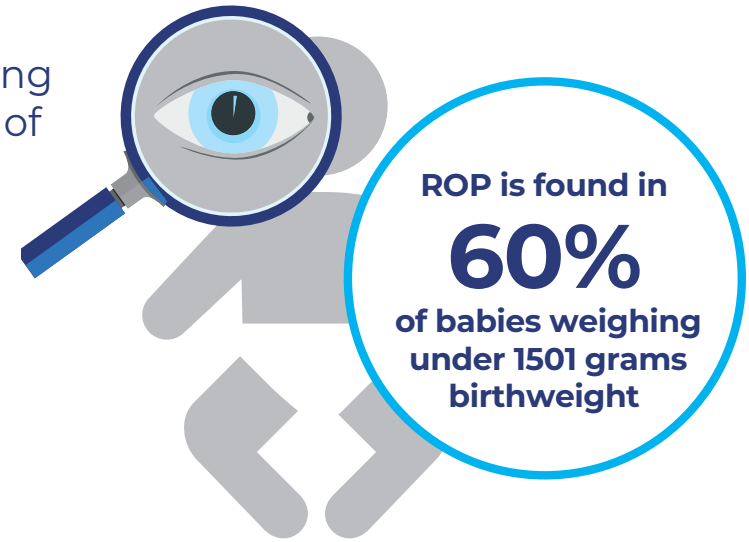


Stage 5:
The retina has fully detached.

We acknowledge Prof Rebeccah Slater and Ms Sarah Chamberlain, Paediatric Neuroimaging Group, Department of Paediatrics and National Perinatal Epidemiology Unit (NPEU), University of Oxford for providing these diagrams.

How common is ROP?

ROP is found in 60% of babies weighing less than 1501 grams at birth; in most of these babies, the ROP is only mild.



What is screening for ROP?

ROP screening is an eye examination that looks for signs of ROP. The examination is done at the cotside. A headlight and lens or a special camera are used so the retina can be seen. About an hour before the examination, eye drops will be put in each eye – this is to make the pupils open widely so the retinas can be seen. Instruments called a speculum (to hold the eyelid open) and an indentor (to roll the eye) may also be used to help see the retina more clearly.

We know these eye examinations are uncomfortable for your baby and your baby is likely to cry and show signs of distress. Your baby's comfort is important to us and there are things we can do to make your baby as comfortable as possible before and during screening. These may include:

- putting anaesthetic drops in their eyes to numb any pain
- swaddling your baby in a blanket to help them feel secure and calm
- giving them small amounts of milk or sugar drops.

After the procedure your baby might be more unsettled, and their eyes may be a bit red and puffy. This should improve within a few hours after the examination. Even if no ROP is found, most babies will need to be examined more than once.

What can I do as a parent/carer?

The nurses on the unit are experienced in getting babies ready for the eye examination and supporting them during it. They will be able to explain how they do this and will involve you as much as possible.

If you choose to be present, you may be able to comfort your baby before or after the examination. Being present will also give you another opportunity to ask any questions that you may have.

What happens if my baby is too unwell for an eye examination?

If your baby is very unwell, senior doctors may decide to delay the examination. It will be rescheduled as soon as possible to make sure that no changes to your baby's eyes are missed. Screening must not be delayed so long that ROP is missed.

What happens if ROP is found?

If ROP is found, the eyes will be re-examined one to two weeks later. In a small number of cases, the ROP may be severe enough to need treatment. If your baby needs treatment, the ophthalmologist (a specialist eye doctor) will explain what will happen.

The Royal College of Ophthalmologists have produced a separate leaflet with more information on the treatment for ROP. Copies can be downloaded from: www.rcophth.ac.uk/trpuk

Will screening finish before my baby goes home?

Your baby will be discharged as soon as they are well enough to go home. This might be before the first or last eye examination. If this is the case, staff should arrange an outpatient appointment for ROP screening before you take your baby home. More than one ROP screening appointment might be needed as an outpatient.

It is very important that you bring your baby back for their outpatient eye appointment if they have one.

How can ROP affect my baby's vision?

If the ROP is mild, your baby's eyes and vision are unlikely to be affected. If the ROP is more severe, problems such as short-sightedness and a squint could develop as your baby grows older, and your child might need to wear glasses.

If your baby is not being seen as an outpatient in the hospital, their eyes and vision will be examined at routine health checks for children that are performed by GPs and health visitors during early childhood. Your child's eyes and vision will also be checked when they start school.

If you have concerns about your baby's eyesight or the presence of a squint, please talk to your doctor – either your GP or when your baby is seen for follow-up as an outpatient in the hospital.

Any other questions?

If you have any further questions about your baby, please ask the nurses or doctors in charge of your baby's care.

Where can I get more information?

Please contact the following member of staff:

Name.....
Tel.....
Email.....

About this leaflet

To see or print this leaflet, scan this QR code or go to: www.rcpch.ac.uk/ROP-leaflet.

This leaflet has been produced to accompany a guideline for the screening of ROP developed by the Royal College of Paediatrics and Child Health. Parents and professionals have helped to write this leaflet.

The main guideline contains recommendations for health professionals informed by research evidence and can be found at www.rcpch.ac.uk/ROP.

Other sources of support

Bliss: for babies born premature or sick.
Bliss's vision is for every baby born premature or sick to have the best chance of survival and quality of life. They offer a wide range of services to support parents and families who have experienced neonatal care.
Email: hello@bliss.org.uk
www.bliss.org.uk

RNIB (Royal National Institute of Blind People) Helpline
Tel: 0303 123 9999
Email: helpline@rnib.org.uk
www.rnib.org.uk/children

The Royal College of Paediatrics and Child Health
www.rcpch.ac.uk/ROP

The Royal College of Ophthalmologists
www.rcophth.ac.uk

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