



# Retinopathy of Prematurity (ROP)

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Information for patients from the Orthoptic Department

## What is Retinopathy of Prematurity (ROP)?

Retinopathy of Prematurity (ROP) occurs when retinal blood vessels do not develop normally in babies that are born prematurely (born before their expected date of delivery). It can also occur in babies born at term but who have a low birth weight or who have general infections or surgeries.

**It can cause serious loss of vision if it is not diagnosed and treated early.**

## What are the causes of ROP?

The retina is the layer at the back of the eye containing light sensitive cells. It is responsible for the first image seen by the eye, which it transfers to the brain via the optic nerve allowing your baby to see. If a baby is born prematurely, their retinal vessels do not develop completely and abnormal blood vessels may grow. This can cause the retina to detach.

## What are the stages of ROP?

There are five stages of ROP, starting at stage one and progressing to stage five. Treatment is usually considered at stage three, as mild ROP at stages one to two is common and usually settles without treatment.

## What are the zones of ROP?

The retina is divided into three zones (zone I, II, and III), from the centre of the back of the eye to the outer area. The combination of the stage and zone of ROP will decide how often your baby is screened.

## Who will be screened for ROP?

All babies born more than eight weeks early or of a birth weight less than 3lbs or 1501g will be screened for ROP.

The screening is usually carried out on the Special Care Baby Unit (SCBU) or Neonatal Intensive Care Unit (NICU). Later screenings may be carried out in a paediatric outpatient clinic if your baby is discharged before their screening is complete.

Some babies only need one check, but most need at least two or three. Screening is carried out at weekly or fortnightly intervals.

### When and how often will my baby be screened for ROP?

The Royal College of Ophthalmology guidelines indicate babies who are:

- **less than 27 weeks at birth** have their first ROP check at 30 to 31 weeks (as if still in utero) as an inpatient on SCBU / NICU
- **27 to 32 weeks at birth** have their first ROP check four to five weeks after birth as an inpatient on SCBU / NICU
- **more than 32 weeks at birth but weighing less than 1501g** have their first ROP check four to five weeks after birth as an inpatient on SCBU / NICU.

All further checks are fortnightly until no ROP is found, or if your baby is at stage 3, in which case they will be checked weekly until no ROP is seen.

### What happens during screening?

The nurses in SCBU / NICU will put a series of drops into both of your baby's eyes to dilate their pupils, so the ophthalmologist (eye doctor) can view the back of their eye to assess the retinal vessels. The drops sting slightly but babies usually tolerate this very well. The ophthalmologist uses an indirect ophthalmoscope (eye telescope) to view the back of your baby's eye.

Occasionally the eyelids may need to be held open with a speculum (clip) and an indenter may be used to help rotate the eye for a better view of the peripheral retina. Local anaesthetic drops are used if these are necessary.

The light from the ophthalmoscope is very bright and may be uncomfortable, so your baby may cry but it is important to get a full view of the back of their eye. The light, speculum, and indenter do not hurt the eyes but occasionally a slight mark may remain on the lids from the speculum for a while afterwards. The ophthalmologist will try to keep this to a minimum.

In some centres a camera is used to take images of the back of the eye.

### How is ROP treated?

If the ROP needs treatment your baby will be sent to a specialist hospital for laser treatment. Laser treatment involves a general anaesthetic (your baby will be asleep) or sedative (your baby will be awake but will not feel any pain). The laser makes small burns on the retina to stop new blood vessel growth. Occasionally laser treatment will need to be repeated.

There is a newer treatment involving injecting medication into the eyes. However, this treatment is currently being investigated and is not yet within the national guidelines.

### Why has my baby been given eye drops after their procedure?

After treatment your baby will be given antibiotic and steroid eye drops to prevent infection and to reduce swelling.

### Are there any side effects of the laser treatment for ROP?

As it is a surgical procedure your baby will be carefully monitored throughout their procedure and may need to go back on oxygen for a while.

- The eye may look red, sore, and swollen after the laser treatment but the eye drops will help with this.
- Although the laser aims to help your baby's vision, it could result in restrictions to your baby's eyesight. This will be discussed with your ophthalmologist before your baby's procedure.

### What effects will ROP have on my baby's vision?

- If untreated, higher stages of ROP can cause serious sight problems and may even cause blindness.
- Unfortunately treatment is not always successful. Early treatment gives a 50 to 80% chance of preventing blindness.
- For mild cases, once resolved, the ROP has no effect on vision.
- There is a high risk that children needing treatment will develop a squint and / or need glasses.

### Will my baby need a follow-up appointment?

Babies who have been treated for ROP will be followed up in the eye clinic (either at the treating hospital or in an East Kent hospital) during infancy and early childhood.

If your baby is discharged from SCBU / NICU before screening is complete, you will be given an eye appointment for the paediatric ophthalmology clinic at your nearest main hospital site before you leave. **It is important that you keep to this appointment where at all possible.** You may feel that there is no problem with your baby's vision but you will not be aware of the changes taking place at the back of their eye until it may be too late to treat. Early treatment has been proven to improve visual outcome.

Please use the contact number at the end of this information leaflet if you are unable to attend the appointment date given and we will rearrange within the guidelines.

### What will happen at the follow-up outpatient appointment?

You will need to book in at the central outpatient reception desk or self check in at the hospital. Then you will be directed to the relevant outpatient eye clinic.

The orthoptist will be aware that you are waiting. They will call you into the clinic to apply the eye drops as per the procedure on SCBU / NICU. The drops take approximately 30 to 40 minutes to work and further drops may be necessary if sufficient dilation is not achieved with the first instillation.

The ophthalmologist will then repeat the examination of your baby's eyes and decide if your baby needs to be seen again (continued screening), can be discharged, or needs treatment.

### **What if I have any questions or concerns about the treatment?**

If you have concerns, please talk to your doctor, nurse, or orthoptist.

The Orthoptic Department at East Kent Hospitals can be contacted on 01227 868615. If you need to cancel or change your child's appointment, please call this number to let us know. If there is no answer, please leave your child's name and date of birth on the answering machine. Thank you.

### **Useful website**

- The Royal College of Ophthalmologists (<https://www.rcophth.ac.uk/wp-content/uploads/2021/10/Information-Leaflet-for-Parents-and-Guardians-on-Treatment-for-Retinopathy-of-Prematurity.pdf>)

**This leaflet has been produced with and for patients.**

**Please let us know:**

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

**You can let us know this by:**

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

**Any complaints, comments, concerns or compliments**, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email ([ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)).

**Patients should not bring large sums of money or valuables into hospital.** Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

**Further patient information leaflets** are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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