

The ROYAL COLLEGE of
OPHTHALMOLOGISTS

Information Leaflet for Parents/Guardians

Treatment for Retinopathy of Prematurity (ROP)

Date?

What is retinopathy of prematurity (ROP)?

ROP is a condition which 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 and sends messages to the brain, which allows us to see.

In severe ROP, blood vessels do not develop how they are meant to in the retina. These abnormal blood vessels grow because of a substance called VEGF (vascular endothelial growth factor; pronounced va-skyoo-luh en-dow-thee-lee-uhl growth fak-tuh) and they can later turn into damaging scar tissue.

Why do my baby's eyes need treatment?

Screening has found that your baby has severe **Retinopathy of Prematurity (ROP)**. Your baby needs treatment because ROP can cause permanent damage to their retina. If your baby is not treated, their vision may be seriously affected.

Where will my baby be treated?

ROP treatment needs to take place in a unit which has specialist staff and equipment. This may not be available in the unit where your baby is being cared for. Your baby may need to be transferred to another unit for the treatment. If your baby needs to be transported from one unit to another this is usually done by a specialist transport team.

What does the treatment involve?

Severe ROP is usually treated with laser therapy. This treatment works very well and reverses severe ROP about 90% of the time. Laser produces small mild burns to areas of retina without good blood supply and this stops abnormal blood vessels from growing further.

For some types of severe ROP, laser therapy will not work as well. In these cases, a drug (anti-VEGF solution) will be injected inside the eyes. This stops the action of VEGF [which means which means abnormal vessels almost always disappear, at least for a while. This treatment has also been shown to work well.

Sometimes, either treatment could be used. Anti-VEGF injections are slightly simpler treatments to perform, but need many months of regular eye examinations afterwards. They are also much more likely to need further treatment at some point.

Whichever treatment is used, both eyes are usually treated at the same time. Your baby's ophthalmologist (a specialist eye-doctor) will discuss treatment options with you and will be able to answer any questions you have. You will need to give written consent for your baby to receive treatment.

Your baby will usually be given a sedative or a general anaesthetic before the procedure and this might mean they will need a tube put into their airway to help with breathing.

When will treatment be given?

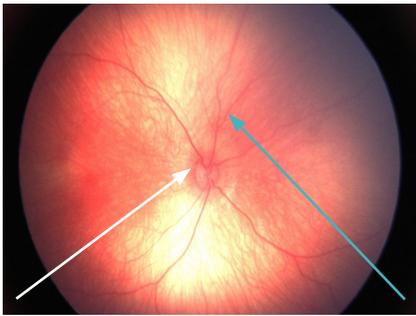
Severe ROP needs to be treated quickly. This will usually be within 48 hours of the severe ROP being diagnosed although it may be a little longer if your baby has to be transferred to another hospital.

Who will carry out the treatment?

The treatment will be carried out by an experienced ophthalmologist (eye specialist). This may not be the same person who has been screening your baby because ROP treatment is a specialist procedure. You should be given a chance to talk to the ophthalmologist before treatment to ask any questions, and give informed explicit consent.

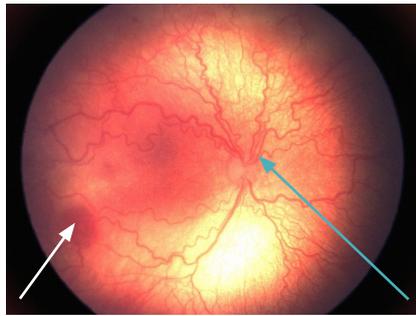
What will happen after the treatment?

Depending on the type of treatment that your baby receives, your baby is likely to be given some antibiotic and steroid eye drops to prevent infection and reduce swelling. The eyes are not painful but they may be puffy after the treatment. The neonatal team will closely monitor your baby's behaviour and clinical condition after the procedure and initiate a number of strategies including pain relief medication if your baby shows signs of any discomfort. Parents can also be involved in this through the use of skin to skin, comfort holding etc if they wish to.



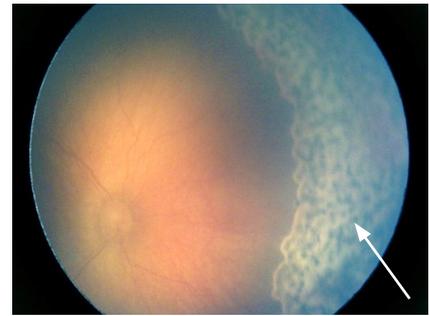
A normal retina.

The white arrow points to the optic nerve head and the green arrow points to the blood vessels.



Severe ROP that needs treatment.

The white arrow points to bleeding in the retina and the green arrow points to abnormal blood vessels.



A retina after laser treatment.

The laser burns are at the edge of the retina as shown by the arrow.

Your baby's eyes will need to be checked between 2 days and a week after their treatment took place. The ophthalmologist will do an exam to check if the treatment has stopped the abnormal blood vessels growing.

Most babies will only need one treatment, but some will need the treatment again at a later date. After laser treatment, a small number of babies (about 1 in 10) will need a second treatment around 2-3 weeks later. After anti-VEGF injection, up to a third of babies need a second treatment, usually within 4 months of the first treatment taking place.

Regular eye checks are needed after treatment. Only a small number of checks are needed after laser therapy. After anti-VEGF injection, your baby will need 1-2-weekly visits over a period of months. These check-ups are very important and it is essential your baby goes to these appointments. The long term eye check ups usually take place at the nearest local unit rather than in the hospital where treatment was given.

Are there any side-effects from the treatment?

Your baby will be carefully monitored during the treatment procedure. After the procedure your baby's eye may look red and swollen. There is a low risk (less than 1 in 100) of eye infection, detachment of the retina (where the retina comes away from the inside of the eyeball) or cataract (clouding of the lens).

Babies need normal amounts of VEGF so their organs can develop. After eye injections, anti-VEGF can get into the blood stream and move to other parts of the body and stop VEGF working in those areas too. While we do not think that anti-VEGF injections affect the development of other organs, at the moment we do not know this for certain.

Will my baby's vision be affected?

Studies have shown that if severe ROP is treated early then up to 80% of babies will have good or very good eyesight. Your baby's ophthalmologist will be able to tell you whether they expect your baby's vision to be affected.

Babies with ROP are more likely to be short-sighted or develop a squint. So, it is quite likely your baby will need glasses later. Your baby will have regular eye checks as they grow up so that any vision problems can be picked up.

Even if your baby does not have ROP, they might develop visual impairment as they get older. This is because after preterm birth, the baby's organs, including the brain, are not fully developed and are at risk of being injured. If the injury happens in that part of the brain which is needed for vision, then their eyesight can be affected. This is called cerebral visual impairment.

Where can I get more information?

The staff on the unit or the ophthalmologist treating your baby will be able to give you more information.

BLISS: is a national charity for babies born premature or sick. BLISS champions their right to receive the best care by supporting families, campaigning for change and supporting professionals, and enabling life-changing research.

www.bliss.org.uk
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About this leaflet

This leaflet has been produced with a guideline for the treatment of ROP developed by the Royal College of Ophthalmologists. Parents and professionals have helped to write the leaflet. The main guideline contains recommendations for health professionals about how to treat ROP, and this has been informed by research evidence.

The full guideline and further copies of this this leaflet can be found at www.rcophth.ac.uk

Scan here to access a digital version of the leaflet.

