

Anti-VEGF injections for babies with retinopathy of prematurity (ROP)

This information leaflet for parents and carers explains the use of anti-VEGF injections, a treatment for retinopathy of prematurity (ROP). If you have any further questions or concerns, please speak to a doctor or nurse caring for your baby.

What is retinopathy of prematurity (ROP)?

ROP is a condition that can happen in premature babies. It may lead to the growth of abnormal blood vessels in the eyes and can lead to blindness.

The blood vessels in the eyes grow during pregnancy and are fully developed by 40 weeks. Babies who are born prematurely do not have fully grown blood vessels and this means abnormal vessels can develop. Babies who are born before 32 weeks of pregnancy, or weigh less than 1500 grams at birth, are automatically entered into a national screening programme to monitor the growth of these vessels. Your baby will have been seen by an ophthalmologist (eye doctor) regularly who will have examined their eyes.

Most babies who develop ROP will not need treatment because the condition corrects itself. However, a small proportion of babies (around 4%) will reach the stage of ROP where treatment is considered to be in their best interests to avoid future sight-threatening complications.

What is anti-VEGF?

VEGF is short for vascular endothelial growth factor. This is a molecule produced by the body to help blood vessels grow and develop. In ROP, it can tell the body to build new blood vessels that are fragile and may lead to bleeding, scarring and retinal detachment. A retinal detachment can lead to blindness and may need urgent surgery.

Anti-VEGF is a treatment that reduces the growth of abnormal blood vessels.

What happens during the treatment?

Anti-VEGF is given as an injection into the eye. As a parent or carer, this can be an upsetting thought but we would like to reassure you that the procedure is quick and straightforward, and your baby will remain comfortable. Before the procedure, you will have a discussion with the paediatric ophthalmology team who will run through all the information you will need to know. If you are worried, they will be able to answer any further questions or concerns you might have.

You will then be asked to sign a consent form to ensure you are happy with the treatment and plan. The injection is usually carried out on the ward at the bedside. During the injection you will be asked to leave the bedside and wait in the waiting area or take the time to get yourself some refreshments. You may be away from your baby for around half an hour but most of this time is spent getting the equipment ready.

Eye drops will be given to your baby in both eyes to widen (dilate) the pupil and to numb their eyes (local anaesthetic). Following this, a series of photographs are normally taken to record and document the stage of ROP. After setting up the equipment required, the anti-VEGF injection is then given. The injection is very quick and painless. The team will then immediately invite you back to be with your baby.

Why is this treatment being considered for my baby?

The ophthalmologist will consider the specific type of ROP that they have identified during your baby's examination. Evidence has shown that ROP affecting the very back of the eye (posterior disease) benefits from treatment with anti-VEGF medication.

What are the benefits?

The aim of the treatment is to stop further progression of ROP and reduce the risk of visual loss.

What are the risks?

As with any medical treatment there are risks. These are summarised below but the paediatric ophthalmology team will help you to understand and weigh these up before the procedure. You will have the opportunity to talk about any concerns before giving consent.

Infrequently your baby may have bleeding inside the eye, infection, retinal detachment, cataract formation (cloudy lens), glaucoma (raised eye pressure) and the ROP may continue to progress despite treatment, in which case further treatment may be needed. Anti-VEGF treatment for ROP is relatively new, meaning there is little long term data to provide evidence of whether there are any longer term side effects of treatment.

When will treatment be given?

The treatment will be carried out within 48 hours of identifying the need for treatment.

Who will carry out the treatment?

The injection will be given by an ophthalmologist who is suitably trained in performing this procedure. On most occasions there will be a small team of ophthalmologists present to provide assistance.

What will happen after the treatment?

Your baby may cry after the injection which is completely normal and expected. This doesn't mean that they are in any pain. There may also be a small amount of redness on the white of the eye where the injection took place, which can take around 1-2 weeks to resolve.

Your baby may be prescribed antibiotic eye drops for a couple of days following the injection. Please note your baby will usually have dilated pupils for the remainder of the day, which will gradually wear off. Your baby will likely remain on the same ward after the injection, unless you have a plan to return to another hospital.

Will my child have a follow-up appointment?

The ophthalmologist will return to review your baby on the ward within one week. After this review, your baby will continue under the care of the ophthalmology team for several months, at least until they are 54 weeks post-menstrual age (their age in weeks from the time of Mum's last menstrual cycle). Most babies do not require further treatment. As of May 2020, 12 infants have been treated at St Thomas' hospital with anti-VEGF and only one baby required another injection due to continued disease progression.

We know that babies who develop ROP are more likely in the longer term to require glasses and/or develop a squint than babies who do not develop ROP. This is the case whether treated or not treated and therefore your child may continue to see the ophthalmologist throughout their childhood for other associated conditions.

Are there any alternative options?

This is the course of treatment that has been determined is right for your baby. The alternative would be not to proceed with the injection, as you always have the choice of whether to proceed or not. This is informed consent and within your rights. You will have the opportunity to speak to the ophthalmologist in detail before the treatment, as well as the neonatal team and anaesthetic doctor if required. The risk of significant visual impairment without treatment is around 60-70% based on early studies.

Contact us

If you have any questions or concerns, the paediatric ophthalmology team at St Thomas' Hospital are around daily within working hours. If you need to contact us then please let your neonatal team know.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [w: www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748, Monday to Friday, 9am-5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111 **w:** www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

Leaflet number: 4974/VER1

Date published: May 2020

Review date: May 2023

© 2020 Guy's and St Thomas' NHS Foundation Trust
A list of sources is available on request