Retinopathy of prematurity

What is retinopathy of prematurity?

Retinopathy of prematurity (ROP) is a disease of the eyes that only affects preterm infants. It is most common in very preterm infants who are born between 24 and 31 weeks of gestation.

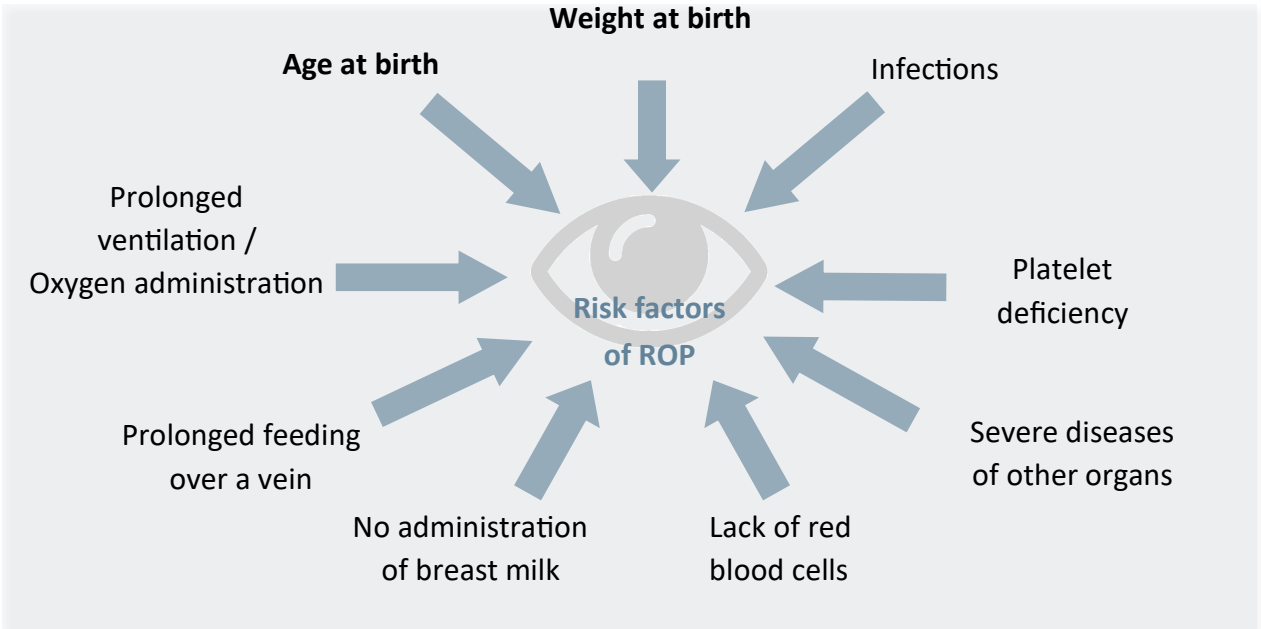
The retina in the eyes of a baby is only fully developed around the calculated due date. The retina is a layer that lines the inside of the eye like wallpaper and can receive light signals. It is in particular the blood vessels of the retina which need a long time to develop properly and fully.

When a baby is born preterm, the retina is not yet fully supplied with blood vessels. In case of ROP, this can lead to problems. The areas of the retina without vessels then produce a growth factor that is meant to stimulate the blood vessels to grow into these insufficiently supplied areas. But if too much of this factor is produced, the vessels' growth gets out of control and they grow partly out of the retina and into the vitreous body (the viscous substance between the retina and the anterior part of the eye). When this happens, the retina can detach from the underlying tissue, which can ultimately lead to permanent loss of vision and even blindness.

What are the risk factors for retinopathy of prematurity?

The most important risk factor for the development of ROP is the **age and the weight of the baby at birth**. Especially children with a gestational age at birth below 31 weeks of gestation or a birth weight of less than 1,500 g are in danger of developing ROP. The earlier the pregnancy ends and the smaller the baby is at birth, the larger is the area of the retina that is still without vessels.

But also after the delivery, there are certain **factors that increase the risk** for retinopathy of prematurity.



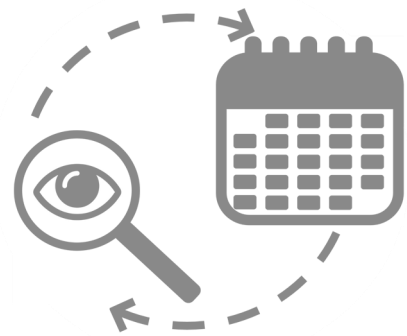
How is retinopathy of prematurity diagnosed?

Many stages of ROP return to normal without treatment.
However, if stages are reached that **require treatment,** this must take place without delay, usually within a few days. If treatment does not take place or is too late, the disease can progress.

Important to know:

Not every form of retinopathy of prematurity has to be treated, but every form of retinopathy of prematurity must be identified and classified correctly.

Screening is important!



Therefore it is especially important to **regularly examine** all babies with retinopathy of prematurity to identify those who require treatment. These regular examinations are called "screening". Unfortunately, since ROP changes over time, a single examination is not enough: ophthalmological examinations must take place repeatedly, usually at intervals of one to two weeks.

The first ophthalmological examination usually takes place when the baby is a few weeks old. From this time onward, the eyes are then examined regularly by a specialised ophthalmologist.

Before the start of the examination, eye drops are administered that enable the pupils to dilate so that the doctor can examine the retina with a special lens or camera. Since the doctor must clearly see the periphery of the retina inside the eye, the eye is turned with a small metal device during the examination. The head of the baby is held during the examination. Since the examination can be unpleasant for your baby, pain-relieving eye drops are given before the examination.

Depending on what the retina looks like, the eye is examined again after a few days or after one to three weeks. The examinations are continued until the critical phase of ROP has been overcome.

IMPORTANT:

Regular ophthalmological examinations of preterm infants are necessary and must not be missed without consultation of the attending ophthalmologist.

As parents, you can support your child by being present during the examination, if you like. Hold your child's hand, touch him/her and speak with him/her.

How is retinopathy of prematurity treated?

Certain stages of ROP must be treated to prevent retinal detachment. Up to a few years ago, almost all children who needed treatment were treated with laser. In the course of this treatment, the part of the retina that does not have any vessels is cauterised with a laser. This tissue can then no longer produce the growth factor that leads to the stimulation of (misdirected) vascular growth, and disease activity decreases. Laser therapy is still an effective and good treatment option today .

Active substances (so-called VEGF inhibitors) that are injected into the vitreous body and bind and inactivate the growth factor present there, offer a newer treatment alternative. The bound growth factor can then no longer lead to the stimulation of (misdirected) vascular growth, and disease activity decreases.

The vast majority of ROP stages can be treated with these two treatment options (laser or injection). Only very advanced (and fortunately rare) stages have to be treated surgically. Your attending paediatricians and ophthalmologists will assess with you which form of treatment is best suited for your child.

Advantages and disadvantages of laser and injection treatment

Both laser treatment and the injection of VEGF inhibitors have certain advantages and disadvantages:

	Laser treatment	Injection of VEGF inhibitors
⊕	• No risk of infection in the eye • Often only one treatment needed • Follow-ups can usually be ended earlier than after injection treatment	• The duration of the procedure is relatively short; therefore often possible with short general anaesthesia or local anaesthesia • Strong short-sightedness is less frequent than after laser treatment • Retinal tissue is not cauterised • Onset of the effect is rapid and usually already starts within the first day after treatment
⊖	• The procedure is long, therefore full anaesthesia is usually needed • Loss of retinal tissue due to cauterisation with the laser • It takes a few days until the onset of the treatment effect • Higher probability of strong short-sightedness than after injection treatment	• The injection into the eye can lead to an infection in the inside of the eye • Re-treatment is needed more often than after laser treatment • Follow-ups take place over longer periods than after laser treatment • Relatively new method, therefore less long-term data available

All advantages and disadvantages as well as the family situation and the state of health of the child in general should be assessed when choosing an option.

What happens after the treatment?

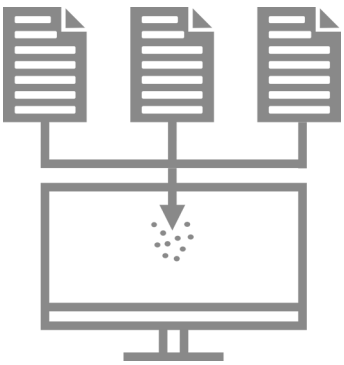
For both treatment options, the retina must continue to be examined by an ophthalmologist at regular intervals after the treatment, to check how the blood vessels develop. In some cases, re-treatment may be necessary.

After treatment with a VEGF inhibitor, the probability of having to repeat the treatment is somewhat higher than after laser treatment. In addition, re-treatment after injection may be required later than after laser treatment. To make sure that the need for re-treatment is not overlooked, regular ophthalmological follow-ups over a period of several months (also after discharge from hospital) must be performed after treatment with a VEGF inhibitor. Only after the blood vessels have covered the complete retina, or when no negative changes have been observed over a period of several months after injection, can the follow-ups be ended.

It is very important that you do not miss any ophthalmological follow-ups without consulting the attending physician. It would be best to immediately enter the appointment of the next examination in your calendar in red.

If you cannot keep an appointment, it is very important that you contact your ophthalmologist without delay and schedule an alternate appointment in the near (!) future.

Data collection on retinopathy of prematurity



Fortunately, retinopathy of prematurity requiring treatment is very rare. For example in Germany, most hospitals only treat 3 to 5 children per year. This makes it difficult for individual hospitals to perform a scientific analysis of their data and draw conclusions for the improvement of ROP treatment. For this purpose, many hospitals have joined forces and are compiling all data from patients with treated retinopathy of prematurity in a joint registry.

We would be pleased if you would agree to have data on the treatment of your child entered in the registry. No additional examinations are needed for this purpose, and the data are collected in pseudonymised form, which means without mentioning the name of your child. The data are evaluated for scientific purposes only and to improve the treatment of retinopathy of prematurity.

You will find more information at www.eu-rop.org, or you can contact your attending ophthalmologist.

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