

## Retinopathy of Prematurity: Information for Parents and Frequently Asked Questions

SUJA MARIAM, PRAVEEN KUMAR, #DEEKSHA KATOCH, \$DEEPAK CHAWLA, \*ASHOK K DEORARI AND #MANGAT R DOGRA

From Division of Neonatology, Department of Pediatrics, Post Graduate Institute of Medical Education and Research, Chandigarh;

#Department of Ophthalmology, Advanced Eye Centre, Post Graduate Institute of Medical Education and Research, Chandigarh;

\$Department of Pediatrics, Government Medical College & Hospital, Chandigarh; and \*Division of Neonatology, Department of Pediatrics, All India Institute of Medical Sciences, New Delhi, India.

Correspondence: Prof Praveen Kumar, Department of Pediatrics, PGIMER, Chandigarh 160 023, India. drpkumarpgi@gmail.com.

This article contains important information in the form of frequently asked questions regarding Retinopathy of Prematurity (ROP). ROP is a condition of the eye in premature infants, which can lead to blindness. The purpose of this information is to make the parents of preterm neonates aware about ROP and educate them about how they can participate in preventing visual loss due to ROP. Healthcare workers and healthcare institutions can use these FAQs for education of parents in their respective settings. The information contained in this article can be supplemented, translated in local languages and adapted as required.

**Keywords:** Blindness, Parent education, Prevention, Preterm.

### What is Retinopathy of Prematurity?

Retinopathy of Prematurity also known as ROP is a condition of the “retina” of the eye which affects preterm and low birth weight babies, who are usually sick. The “retina” is a layer of special nerve cells inside our eyes, on which images of the objects we see are focused. In short, it acts like the screen of a cinema theatre. The retina has many blood vessels which start developing when the baby is inside the mother’s womb. The last three months of pregnancy are important in the development of eyes of the baby. The development of the blood vessels of retina is completed just before the normal time of delivery at 40 weeks. Hence, in a baby born premature, the blood vessels have not yet formed in a part of the retina (**Fig. 1**). If immature retina is exposed to excessive amounts of oxygen after birth, it may stimulate development of abnormal new vessels (**Fig. 2**). These abnormal blood vessels can pull and separate the retina from the underlying layers (retinal detachment), and lead to blindness (**Fig. 3**). Usually, ROP progresses through several stages and hence, if diagnosed and treated in time, the loss of vision can be prevented in almost all cases.

### Do all preterm babies develop ROP? Which babies are at risk?

No, all preterm babies do not develop ROP. Preterm babies who are sick, need oxygen or ventilator support for their breathing problems, who have infection, and who do not grow and put on weight normally are at a much higher risk.

The risk increases with decreasing duration of pregnancy. Following group of babies should be screened for ROP: (i) preterm babies born at or less than 34 weeks of pregnancy, (ii) if exact duration of pregnancy is not known, then those who weigh less than 2000 grams at birth, and (iii) babies born at 35 or 36 weeks of pregnancy, but were sick and required prolonged oxygen.

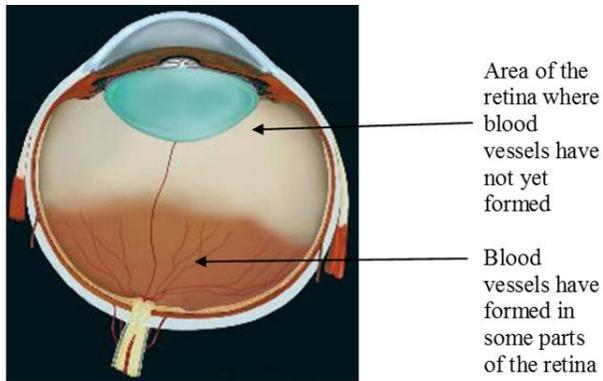
### How will I know whether my child has ROP?

It is not possible for you or the staff looking after your baby to know whether your baby has ROP as the eyes look entirely normal – this is because the problem is inside the eye. Therefore, it is important to detect it in time through a special test (ROP screening). This is done by an eye doctor. The first screening examination must take place by day 28 of life.

The examination can be done in the neonatal intensive care unit (NICU) / special care newborn unit (SCNU) if the baby is still admitted, and can also be done even if baby is inside the incubator. If your baby has been discharged before this age, the examination should be done during follow-up, on out-patient basis. At the time of discharge, you will be given an appointment for the same.

### How is a ROP screening test done?

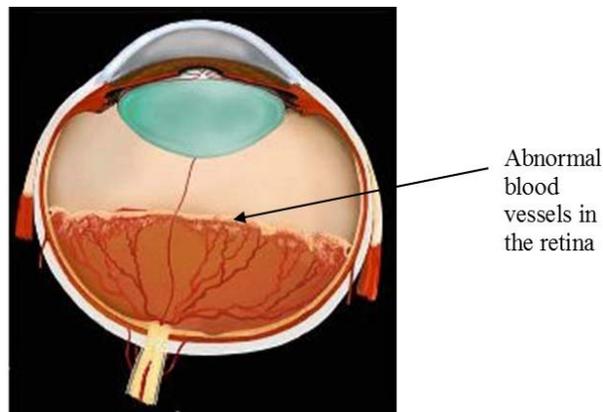
ROP screening is done by a trained eye specialist using an ‘Indirect Ophthalmoscope’. This is a lens and light system which allows the doctor to see inside the eye to find out whether the retina is normal or not. About an



In a premature baby the retinal blood vessels are not fully formed

**FIG. 1** Immature retina with incomplete development of blood vessels.

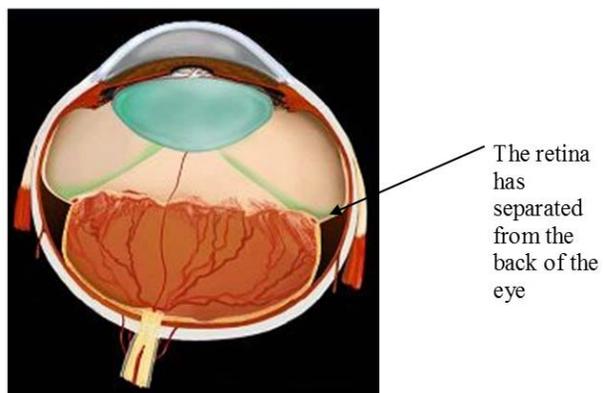
Image courtesy: Cybersight - [www.cybersight.org](http://www.cybersight.org).



In ROP the blood vessels in the retina grow abnormally

**FIG. 2** Abnormally grown blood vessels in Retinopathy of Prematurity.

Image courtesy: Cybersight - [www.cybersight.org](http://www.cybersight.org).



In severe ROP the retina can separate from the back of the eye (retinal detachment)

**FIG. 3** Retina pulled up by abnormally grown blood vessels (retinal detachment).

Image courtesy: Cybersight - [www.cybersight.org](http://www.cybersight.org).

hour before the examination, eye drops are put in the eyes of the baby to dilate the pupils so that the retina can be seen.

**Will this test cause pain to my baby?**

There is no needle or injection used in this test. No blood is taken. The baby may have mild discomfort and may cry during the procedure because of handling. To make the baby comfortable, the test is done about an hour after baby has been fed. The baby is swaddled and supported by the assistant. The baby may be allowed to suck on a soother and given local eye pain-relieving drops.

The total procedure lasts only 5-10 minutes. After the procedure, baby is closely observed for about 15 minutes. Majority of babies tolerate the procedure very well. A small number, especially those who are still very low in weight and are on respiratory support can vomit or forget to breathe for short period (apnea). This is self-limiting and babies recover within 12 to 24 hours.

**Can any eye doctor examine for ROP?**

ROP screening requires special training in using 'Indirect Ophthalmoscope' and expertise in handling small babies. Most retina specialists are able to do this, if they have been trained.

**Is a single examination sufficient or are repeat examinations required?**

A single examination may not be sufficient and most of the times the child needs repeat examinations. The findings on the first examination guide the eye doctor to decide about subsequent examinations. Usually the ophthalmologist will re-examine the eyes every 1 to 3 weeks until the retinal blood vessels have developed completely and normally. The number of examinations required depends upon how premature the baby is and findings in the previous examination. A child who develops ROP requires more follow-up visits than one who does not develop ROP. The eye doctor will give you the appointment for next examination.

**What will be done when my child is diagnosed with ROP?**

If an infant is diagnosed with ROP, the eye specialist will assess how severe it is. The majority of babies have mild ROP which gets better without any treatment. A very small number of babies develop more severe ROP which needs to be treated with LASER to prevent blindness. If the eye specialist makes an assessment that the ROP is severe enough to be a threat to vision, LASER should be done within 48-72 hours of diagnosis depending upon the severity of disease. LASER is not effective later if the diagnosis is delayed and the child presents at a late stage.

In advanced stages, where LASER may not be effective, your eye doctor will explain to you about other treatment options, including surgery to save vision.

#### **What is LASER treatment? How is it done?**

LASER is a high-energy light beam which has been used to treat eye conditions and other disorders for last 30 years and is very precise and safe. Laser treatment is done on a day-care basis by trained eye specialists in select centres. The baby is closely monitored during the procedure. Similar to the ROP screening examination, the doctor sees the retina through the special lens and focuses the LASER energy through the same lens onto the retina. The procedure takes 1-2 hours depending on the severity of ROP. The baby can be discharged to home the same day or latest by next day.

LASER treatment prevents abnormal blood vessels of retina from growing further thereby preventing complications like separation of the retina. With LASER treatment, the abnormal blood vessels disappear, greatly reducing the risk of loss of vision.

#### **What happens next? Once treated will my child's vision be normal? Can there be any other problem?**

LASER treatment is quite safe and the standard of care for several eye disorders including ROP. It has been used to treat ROP all over the world for last two decades. Majority of babies will have good vision after LASER treatment. On the other hand, advanced ROP, if untreated can cause complete visual loss. Apart from ROP, a baby born preterm is at a higher risk of other eye conditions such as squint (in-turning or out-turning eyes) and refractive errors (needing spectacles) which may affect vision. Those treated with LASER for ROP are also at risk for these conditions, which can be treated. Hence, premature infants, especially those who had ROP, should get eye check-up done every 6 months. Long term follow-up may be required to make sure that vision develops as normally as possible.

#### **What do doctors and nurses do to decrease the chance of your baby developing ROP?**

The doctors and nurses regulate the amount of oxygen

baby gets by monitoring oxygen saturation of blood by an instrument called pulse oximeter and take special precautions to prevent infection. They promote and encourage feeding of mother's milk to the baby, monitor baby's growth closely and advise Kangaroo care (skin to skin contact between adult and baby).

#### **What can I do to prevent my child from developing ROP?**

Prematurity is an inherent risk for ROP and therefore this condition is not entirely preventable. However, as a parent you can do the following to decrease the risk of ROP:

- Preventing infection: Maintaining your own hygiene and washing hands thoroughly before touching the baby decreases the chances of baby getting infection and therefore may reduce the risk of ROP.
- Giving mother's own milk for feeding of baby is a very effective way not only to reduce the chances of infection but also to provide nutrition for growth. This decreases the chances of ROP.
- Providing Kangaroo care (skin to skin contact between mother, father or any other adult and baby) also promotes growth of the baby and regular breathing. These are associated with reduced chances of developing ROP.
- It is your responsibility to follow the ROP screening appointments given by your doctor or nurse. Timeliness of screening and treatment if required is crucial to save the vision of babies. ROP can progress rapidly and does not have any external symptoms or signs till late. The baby may appear absolutely fine to you and yet have ROP. Therefore, do not miss on any of the appointments given for eye check-up for the baby. Delay may cause incurable blindness in both eyes for which no treatment is available at present. Eye transplantation is also not possible for ROP blindness.
- If you had a preterm baby and your doctor did not advise a ROP check-up by 3 to 4 weeks of age, do ask whether your baby needs one.

*Acknowledgments:* Dr. Clare E Gilbert for critical review of the content.