



Retinopathy of prematurity (ROP)

Studer Family 
Children's Hospital
Ascension Sacred Heart



Planning care for you and your baby

Reading this booklet can help you:

- Learn about your baby's eyes
- Understand your baby's eye screening
- Learn about tests and treatments
- Understand time-sensitive care

Timing is everything. Finding and treating ROP early is the best way to lower the chances it will cause serious problems.

Retinopathy of prematurity (ROP)

Retinopathy of prematurity (ROP) is an eye disease that can happen in babies who are premature or who weigh less than 3 pounds at birth.

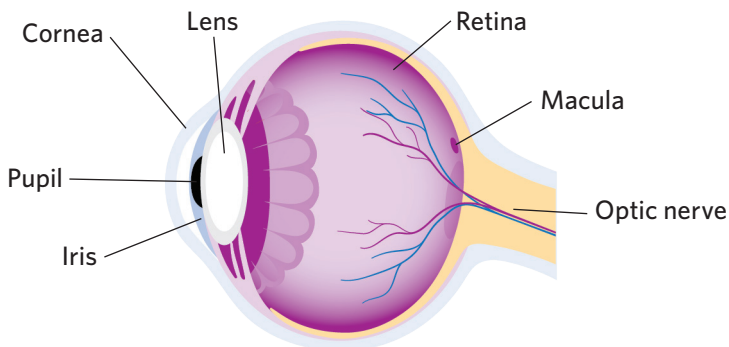
ROP happens when abnormal blood vessels grow in the retina (the light-sensitive layer of tissue in the back of your baby's eye). Some babies with ROP have mild cases and get better without treatment. But some babies need treatment to protect their vision and prevent blindness.

How the eye works

Think of the eye as a camera. The front of the eye focuses the image and adjusts the amount of light let in, while the retina (at the back of the eye) acts like the film. Without the film, the camera can't take a picture and without the retina, the eye cannot see. Like all the other structures in our body, the eye needs oxygen to work and the retina needs blood vessels to supply that oxygen.

By the time your baby is full-term, the retina is almost fully formed, meaning the blood vessels have grown all the way from the back of the eye to the front.

When your baby is born very prematurely, and for reasons not yet fully understood, the blood vessels sometimes stop where they are and start to grow abnormally instead of continuing to make their way to the front of the retina. This is called retinopathy of prematurity, or ROP for short.



The earlier your baby was born and the smaller the baby was at birth, the greater the chance that your baby will develop some degree of ROP. Most cases are mild and resolve on their own.

When ROP develops, one of three things can happen:

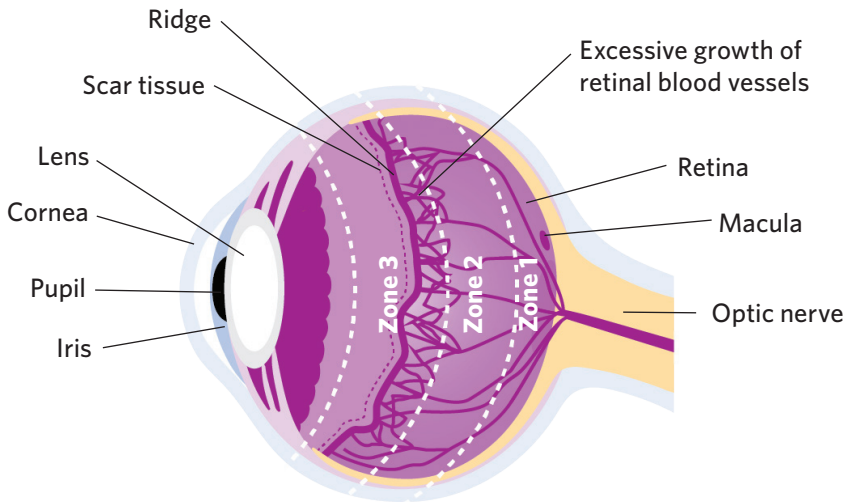
1. In most babies who develop ROP, the abnormal blood vessels will heal themselves completely, usually during the first year of life.
2. In some babies, the abnormal blood vessels heal only partially. Nearsightedness, lazy eye, or a wandering eye commonly develops. Glasses may be required in early life and sometimes a scar may be left in the retina, resulting in vision problems that are not entirely correctable with glasses.
3. In the most severe cases, which usually occur in the youngest, smallest, and sickest infants, the abnormal blood vessels form scar tissue, which pulls the retina out of its normal position in the back of the eye. This problem results in a severe loss of vision. Fortunately, there is treatment to minimize the loss; however, in about 1 out of 4 babies, despite treatment, the condition can lead to blindness.



ROP zones and stages

ROP is divided into three zones and five stages. The zone refers to the location in the eye. The stage refers to the severity of the disease.

ROP zones



ROP stages

Stage 1: Mildly abnormal blood vessel growth with a distinct line that separates normal from premature retina.

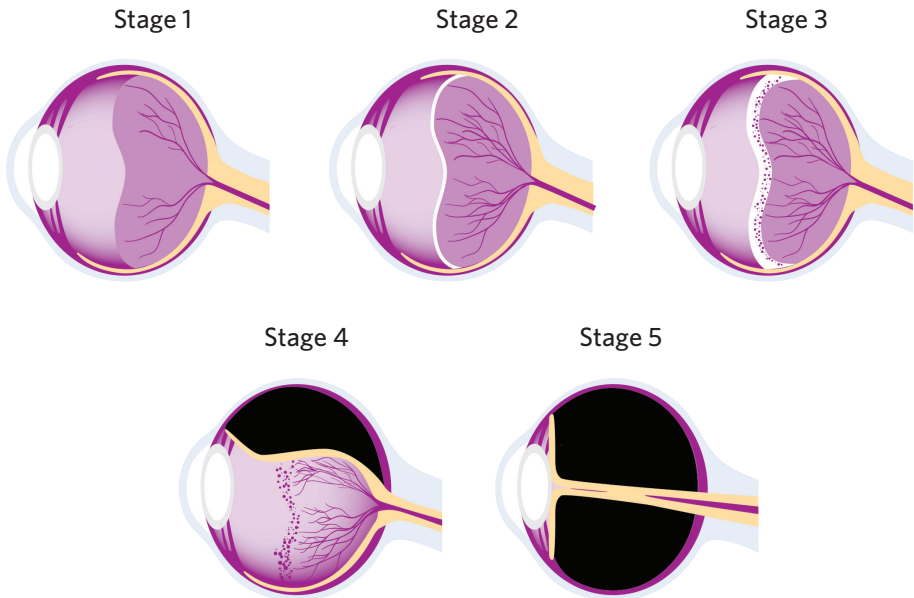
Stage 2: Moderately abnormal blood vessel growth with a distinct line that widens and thickens forming a ridge.

Stage 3: Severely abnormal blood vessel growth toward the center instead of along the retinal surface. "Plus disease" develops when blood vessels of the retina become enlarged or twisted.

Stage 4: Partial retinal detachment.

Stage 5: Complete retinal detachment.

Finding and treating ROP early is the best way to lower the chances it will cause serious problems. It is very important to make sure your baby gets their follow-up exams on schedule. Babies in any stage can get worse quickly and may require immediate treatment.





Babies at risk

ROP is more likely to develop in babies:

- Who are born prematurely, usually before 31 weeks.
- Who are small, usually under 3 pounds.
- Who have received donated blood (transfusions).
- With a low amount of red blood cells (anemia).
- With breathing problems (respiratory distress).
- Who have a condition that causes breathing to stop briefly (apnea).
- With a slow heart rate.
- With heart conditions.
- Who have an infection.
- Who are receiving high levels of oxygen or have had an increase in oxygen levels during treatment.

Tests and treatments

Timing is everything

ROP is a time-sensitive disease and for that reason, so is the screening. Babies are screened for the first time from 4-8 weeks after birth, depending upon their age at birth in weeks (40 weeks is full-term).

Screening is done every 1-2 weeks after that until your baby reaches full-term. Sometimes screening is done longer if ROP has been present or the vessels have not fully grown.

Screening

ROP can only be detected by an eye exam. Your baby's nurse will put drops in the baby's eyes to dilate the pupils for the examination. The drops do not hurt.

The eye doctor will begin the screening about an hour later and examine your baby's eyes with a special scope magnifying lens. Sometimes your baby gets angry about his/her eye being held open, but the exam does not hurt. Comfort measures such as swaddling or offering a pacifier during the exam may help.

During the eye exam, the eye doctor will check for:

- Abnormal blood vessels
- Bleeding in the eye
- Detached retina
- Formation of scar tissue

Treatment

Treatment depends on the severity of the ROP. If the condition is mild, it may not require treatment and it may go away on its own. If the condition is more severe, treatment may include:

- Injections of bevacizumab (Avastin): Medicine to help stop abnormal growth of blood vessels in the eye.
- Laser phototherapy: A laser beam is directed through the pupil to keep ROP from getting worse. This is the most common treatment.

More than one treatment may be needed. There may be additional treatment options your baby's doctor and care team may discuss with you.

Going home

- Be sure to provide your current contact information including your address and your phone number.
- You will receive information prior to discharge for any follow up appointments your baby may need.

Follow-up visits

- Remember this is a time-sensitive disease and, if needed, treatment is only possible for a short period of time.
- Arrive on time.
- There must be time for the drops to work before your eye doctor examines your baby's eyes.
- Do NOT miss the appointment.
- Call your baby's eye doctor's office if you are going to have difficulty making the appointment. Remember this is a time-sensitive disease.

Follow up care is important since babies who had ROP are also more likely to have other eye problems as they get older.

If your baby had ROP that caused damage, you may later notice:

- Their eyes wander, shake or make other unusual movements
- Their eyes don't follow objects
- Their pupils look white
- They have trouble recognizing faces

Discuss these or any other concerns with your baby's doctor.



Special care

- Many babies leave the NICU before they are full-term so it is very important to bring your baby to his/her time-sensitive follow-up appointments.
- ROP is a potentially blinding disorder but timing is everything!
- Once you graduate from ROP follow-ups, you will be advised when to see a pediatric ophthalmologist (eye doctor who specializes in infants and children). Your baby will need to be checked throughout his/her life because premature babies have a higher risk for problems such as crossed eyes, lazy eyes, and nearsightedness.
- At Studer Family Children's Hospital at Ascension Sacred Heart, we take great pride in the care we provide to our patients and their families. We want your baby to experience the very best in care, comfort, and compassion throughout their stay.
- Whenever you have questions, comments, concerns or something that needs to be addressed immediately, the first person you should speak with is your baby's doctor, nurse or another member of the healthcare team. When this is not possible, take your child to the Studer Family Children's Hospital emergency room.
- Studer Family Children's Hospital is available with convenient pediatric emergency locations across Northwest Florida. They are ready with equipment that is specially designed for a child's smaller anatomy and staffed 24/7 with team members who are specially trained in caring for children.

Choosing your baby's doctor is important
StuderFamilyChildrensHospital.com



Studer Family Children's Hospital at Ascension Sacred Heart

1 Bubba Watson Drive
Pensacola, FL 32504

Ascension and its logos are registered trademarks of Ascension. All third party trademarks are the property of their respective owners. All medications should be used as directed. If you have any questions, please ask your doctor or nurse. This information is not intended as a substitute for professional medical advice. Don't use this information to diagnose or develop a treatment plan for a health problem or disease without consulting a qualified healthcare provider. Follow the advice given to you by your healthcare provider. Discuss any questions you have with your healthcare provider.