

Retinopathy of Prematurity (ROP) How is ROP Diagnosed and Treated?

Part 2 of a series (PreventBlindness.org/retinopathy-of-prematurity-rop)

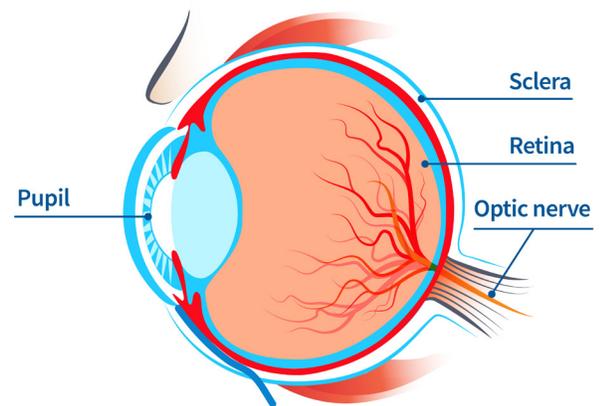
What is retinopathy of prematurity (ROP)?

Retinopathy (ret-in-AH-puh-thee) of prematurity (ROP) is an eye disease that occurs in some babies who:

- Are born prematurely (earlier than 30 weeks of pregnancy)
- Have low birth weight (less than 3 lb 5 oz or 1,500 g)
- Have complications after they are born and receive extra oxygen for more than a few days

ROP affects the back of the eye called the **retina**. The retina is the part of the eye that collects all of the light information from what we look at and sends this information through the **optic nerve** to the brain where the light information is processed as images. ROP occurs when blood vessels in the eye that have not finished growing before a baby is born begin to grow abnormally and in the wrong direction. Most ROP will resolve on its own without any damage to the retina or vision loss.

In severe cases, ROP can worsen, and abnormal blood vessels can form that may leak and even cause the layers of the retina to separate. Scar tissue can form and damage the retina by pulling the retina away from the back of the eye (retinal detachment) leading to vision loss or blindness.



For babies with ROP, it is difficult to know which cases will resolve or worsen. **Eye examinations conducted while the baby is in the Neonatal Intensive Care Unit (NICU), completion of examinations with specialists after the child leaves the NICU, and following treatment recommendations are important ways to prevent vision loss for babies at risk from ROP.**

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How is ROP diagnosed?

ROP can only be seen with special tools used by an ophthalmologist (of-thuhl-MOL-uh-jist) – a medical doctor who specializes in caring for eyes. The American Academy of Pediatrics (AAP) recommends that all babies who are born earlier than or equal to 30 weeks, weigh less than or equal to 1,500 grams at birth, or have other high-risk factors, receive an ROP eye exam.¹

A baby's first ROP exam in the NICU by an ophthalmologist should take place 4 weeks after birth unless they are born earlier than 27 weeks. For babies born earlier than 27 weeks, they will be examined at what would have been the 31st week of the pregnancy. A numbing drop is placed on the eye prior to the procedure to decrease pain. During the exam, the baby will get eye drops to widen their **pupils**, called dilation. Then, instruments will keep the eye open and in position, so it is easier for the doctor to check

all parts of their eyes. The doctor will then use lenses and a headlamp to look inside the eye at the retina so they can see where and how much of the retina may have abnormal vessels (retinopathy).

What to know about the ROP exam

These eye exams can be uncomfortable for your baby but should only last a few minutes. They are critical to protecting their vision and eye health. The dilating eye drops can sometimes make them sensitive to light and more irritable. Nurses at the bedside will monitor your baby closely and create a protective environment, such as turning down lights and providing sugar water, which will help your baby be as comfortable as possible both during and after the examination.

Scan the QR code with your smartphone's camera to learn more about ROP.



How serious is my baby's ROP?

The ophthalmologist will use a few terms to describe a baby's ROP diagnosis.

The Zone describes the location in the eye where the abnormal blood vessels are growing. A lower zone means that the abnormal vessels are closer to the center of the retina around the optic nerve (carries messages from the retina to the brain that becomes an image) and therefore a bigger risk to vision.

Zone I

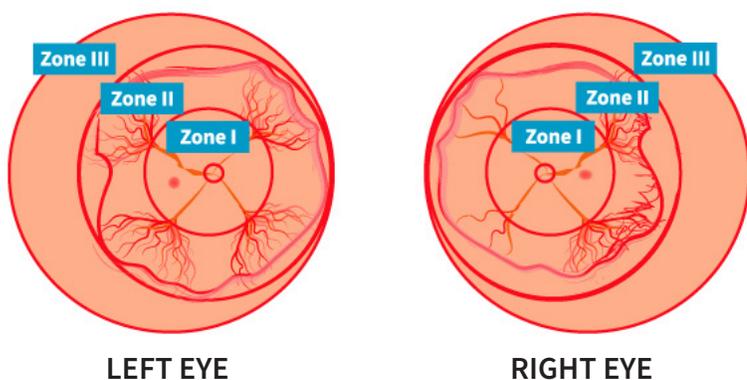
A small circular area at the center of the retina and includes the optic nerve. This zone also includes the **macula** which is the part of the retina that is responsible for central vision and color vision.

Zone II

A circular area around Zone I that includes all the outer part of the retina close to the nose.

Zone III

A half-moon-shaped area that runs along the retina's outer edge on the side closer to the ear.



The Stage describes how serious ROP is based on the presence and growth of abnormal vessels in the retina. The higher (later) the stage the more serious the disease.

Stage 1:

Presence of a line that separates the part of the retina where blood vessels were growing and the part of the outer retina where there are no blood vessels growing yet.

Stage 2:

A raised "ridge" means there is an increase in abnormal blood vessels growing, piling on top of each other in the retina.

Stage 3:

There is growth of new, abnormal blood vessels from the ridge seen in stage 2 or there may be bleeding from the abnormal blood vessels.

Stage 4:

Abnormal blood vessels pull part of the retina away from the back of the eye. This is called a partial retinal detachment.

Stage 5:

Abnormal blood vessel growth and scarring is so severe that the entire retina detaches from the back of the eye.

Plus disease describes cases of ROP where the blood vessels around the retina are significantly wider or more twisted than normal.

Pre-plus or plus disease can occur at any stage of ROP and means the baby will require treatment.

How is ROP treated?

Approximately 10% of ROP cases will be serious enough to require treatment that prevents permanent vision loss or blindness. Your provider will recommend when treatment is needed but is most likely if a child has plus disease or when there is Zone I with Stage 3 ROP or higher. Treatments for ROP include:

Injection of medication into the eye: This is the most common first treatment. The medication is given as a shot into the baby's eyes through the **sclera** (the white part of the eye). The medication helps block the growth of abnormal blood vessels. Babies that have received eye injections for ROP need to receive follow-up exams as the medicine only lasts for 4-6 weeks in the eye and the abnormal blood vessels could regrow after this time.

Laser therapy: This uses the heat of lasers to burn the outer area of the retina where there are no blood vessels. This will stop new, abnormal vessels from growing.

Cryotherapy (kry-oh-THER-uh-pee): This type of treatment uses an instrument to freeze the part of the retina that does not have adequate blood supply, stopping the abnormal vessels from growing more.

If ROP progresses to stage 4 or 5, **eye surgery** may be necessary to prevent the worsening of the retinal detachment. Eye surgeries to treat ROP include:

- **Scleral (SKLEER-uh) buckle surgery:** A flexible band is placed around the sclera which helps reduce the pulling of the retina from the back of the eye by the abnormal scar tissue.
- **Vitrectomy** (vi-TREK-tuh-mee): A process that allows the ophthalmologist to remove bleeding from in front of the retina or scar tissue resulting from ROP that caused the retina to tug away from the back of the eye.

What follow up is needed for ROP?

All babies with ROP need be checked about every 1-3 weeks until the ophthalmologist determines the ROP has fully resolved and/or the retina has fully grown blood vessels. Then, the baby's eyes can be checked less often. Some of these checks may happen after the baby goes home from the NICU. It is **very** important that you keep all scheduled follow-up appointments your doctor recommends. The earlier ROP is identified, the more helpful the treatment will be in preventing vision loss.

All children diagnosed with ROP, even if they didn't need treatment, should continue to see an ophthalmologist regularly, following all recommended appointments at least once a year, even into adulthood, to monitor for any other vision problems.

Questions to ask the doctor:

You are a critical part of your child's care team. Here are some questions that might be helpful to include when talking with the ophthalmologist:

- What is my child able to see?
- Will my child require medical treatment?
- Does the treatment have any complications?
- What are the chances that my child could go blind from ROP?
- How likely is it that my child's ROP will return after treatment?
- How frequently do I need to bring my child in for follow-up eye examinations?
- How will my child's vision be affected in the future?



A message from a parent of a child with ROP:

As the parent, you are the expert on your child, and you are your child's best advocate. Your parent "gut instinct" is priceless as you navigate your child's ROP journey. Follow your instincts, ask questions, take notes, and know it is ok to feel uncertain. Have your doctor explain everything about ROP so that you understand what is happening with your child's diagnosis and ask the doctor to explain what is happening during eye exams, treatment, and follow up visits.

Be part of the healthcare, eyecare, and education teams, and raise your voice! Use the resources in your school district, community, and state. Connect with community and state organizations for support and to find a "community" that will be the support you need for this journey!

– Nicole, parent of a child with ROP

Resources for families of children with ROP

The following resources provide information, education, and support for families of children in the neonatal intensive care unit (NICU), with ROP, and with visual impairment and blindness from ROP through their lifetime. The resources include peer support programs for parents while your baby is in the NICU in addition to Early Intervention and special education services as your child with ROP is in school.

These resources are from Prevent Blindness

[The National Center for Children's Vision and Eye Health at Prevent Blindness](https://NationalCenter.PreventBlindness.org)

(NationalCenter.PreventBlindness.org) offers resources on your child's developing sight, including approaches you can take to support vision and eye health throughout their life.

[Prevent Blindness](https://PreventBlindness.org) (PreventBlindness.org) offers information on a variety of children's vision conditions, financial assistance resources, advocacy training through storytelling, and support for individuals with vision loss and their care partners.

These organizations provide support and resources for families of children with ROP, other vision conditions, and infant health

[Hand to Hold](https://HandtoHold.org) (HandtoHold.org) provides resources and support to parents during and after their babies leave the NICU through virtual peer support groups, parent-to-parent mentoring, an app, counseling, educational materials, and podcasts.

[The National Coalition for Infant Health](https://InfantHealth.org) (InfantHealth.org) provides resources and education promoting patient-centered care for premature infants and their families.

[The American Academy of Ophthalmology \(AAO\)](https://AAO.org/eye-health/diseases/what-is-retinopathy-prematurity) (AAO.org/eye-health/diseases/what-is-retinopathy-prematurity) provides information on treatments for ROP and resources for finding an ophthalmologist in your area.

The National Eye Institute ([NEI.NIH.gov/learn-about-eye-health/eye-conditions-and-diseases/retinopathy-prematurity](https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/retinopathy-prematurity)) provides information about ROP and current research.

March of Dimes ([MarchofDimes.org](https://www.marchofdimes.org)) provides support for families of premature infants in the NICU, as well as advocacy, research, and lifelong support for issues related to prematurity, maternal and infant health.

HealthyChildren.org provides information for parents on newborn eyesight and warning signs of vision problems in children.

Blind Children's Resource Center ([BlindChildren.org](https://www.blindchildren.org)) is dedicated to helping visually impaired children be independent, functional members of society.

Infantsee® ([Infantsee.org](https://www.infantsee.org)) provides no-cost comprehensive eye and vision assessment for infants 6-12 months old regardless of a family's income or access to insurance. The website includes a parent center with helpful information on baby's developing eyes, what to expect at an appointment, and other ways to help with infant vision development.

These organizations provide support for families of children with special healthcare or learning needs

SPAN Parent Advocacy Network ([SpanAdvocacy.org/about](https://www.spanadvocacy.org/about)) empowers families as advocates and partners in improving education, health/mental health and human services outcomes for infants, toddlers, children, youth, and young adults. SPAN works in New Jersey and nationally to provide resources, support, leadership engagement and training, and advocacy for families of children and youth with special health care needs.

Parent Training Information Centers (PTIs) ([ParentCenterhub.org/find-your-center](https://www.parentcenterhub.org/find-your-center)) located in each state provide education and training to parents of children with disabilities up to age 26. PTIs help parents participate effectively in their children's education and development and partner with professionals and policy makers to improve outcomes for all children with disabilities.

Family Voices ([FamilyVoices.org](https://www.familyvoices.org)) is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities which provides support to families of CYSHCN. Family Voices offers state affiliates as well as opportunities to develop leadership skills for families, particularly those from underserved and underrepresented populations. Family Voices has [state affiliate organizations](https://www.familyvoices.org/affiliates) ([FamilyVoices.org/affiliates](https://www.familyvoices.org/affiliates)) to assist families.

Family-to-Family Health Information Centers (F2Fs) ([FamilyVoices.org](https://www.familyvoices.org)) located in each state are family-led organizations that provide engagement and support to families of children and youth with special health care needs (CYSCHN).

This information developed in partnership with



1. Fierson, W. M., American Academy of Pediatrics Section on Ophthalmology, American Academy of Ophthalmology, American Association for Pediatric Ophthalmology and Strabismus, & American Association of Certified Orthoptists (2018). Screening Examination of Premature Infants for Retinopathy of Prematurity. *Pediatrics*, 142(6), e20183061. <https://doi.org/10.1542/peds.2018-3061>.