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

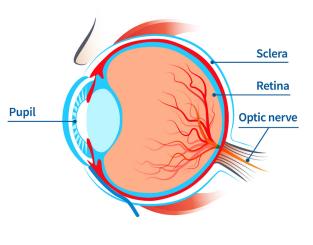
#### Part 2 of 3 in a series

(https://preventblindness.org/retinopathy-of-prematurity-rop)

Read Next: "What Do I Need to Know About My Child's Retinopathy of Prematurity (ROP) and Lifelong Vision Health"

#### 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.<sup>1</sup>



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 31<sup>st</sup> 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).

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#### 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.

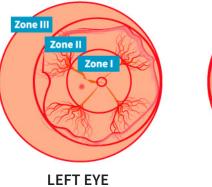


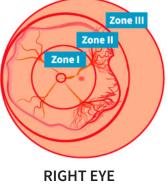
Zone

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Zone

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.





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

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:	Stage 2:	Stage 3:	Stage 4:	Stage 5:
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.	A raised "ridge" means there is an increase in abnormal blood vessels growing, piling on top of each other in the retina.	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.	Abnormal blood vessels pull part of the retina away from the back of the eye. This is called a partial retinal detachment.	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 Retinopathy of Prematurity (ROP) Diagnosed and Treated? (continued)

#### 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 important for 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.

#### 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.

<u>Cryotherapy (kry-oh-THER-uh-pee)</u>: 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-uhl) **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. Follow all recommended appointments at least once a year. This will help to monitor for any other vision problems.



"We all have similar experiences about our journeys with our children, and I think it's important that families continue to hear those experiences, and that they know that they are not alone."

 Nicole, Parent of Child with ROP & Family and Professional Training Director, SPAN Parent Advocacy Network

### Questions to ask the doctor:

You are a big part of your child's care team. Here are some questions that might be helpful to ask 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?



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

# Resources for families of children with ROP

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

**Hand to Hold** (https://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

(<u>https://infanthealth.org</u>) provides resources and education promoting patient-centered care for premature infants and their families.

#### SPAN Parent Advocacy Network

(<u>https://spanadvocacy.org/about</u>) 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.

Find more information on ROP, support for families of children in the NICU, and Early Intervention at: <u>https://preventblindness.</u> <u>org/family-resources-retinopathy-of-prematurity-rop</u>

#### 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. <u>https://doi.org/10.1542/peds.2018-3061</u>