



# Retinopathy of Prematurity (ROP)

## What Do I Need to Know About My Child's ROP and Lifelong Vision Health?

Part 3 of a series ([PreventBlindness.org/retinopathy-of-prematurity-rop](https://PreventBlindness.org/retinopathy-of-prematurity-rop))

### What is retinopathy of prematurity (ROP)?

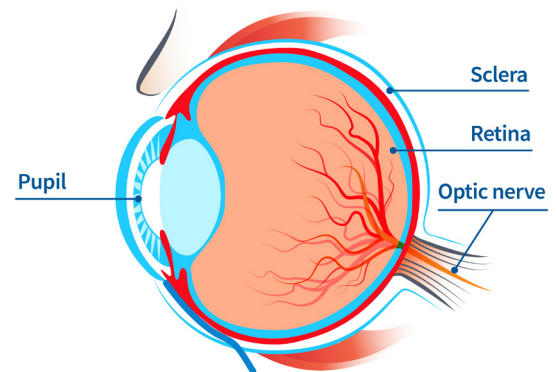
Retinopathy (ret-in-AH-puh-thee) of prematurity (ROP) is an eye disease that occurs in some babies who:

- 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

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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 and other vision issues which may appear later in childhood or adolescence.**

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#### What follow up is needed for ROP?

All babies with ROP need to 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 and follow all recommended appointments at least once a year, even into adulthood, to monitor for any other vision problems.

#### Will ROP affect my baby's vision later in life?

All children diagnosed with ROP, whether or not they needed treatment for it, will have an increased risk for other vision problems as they get older, including:

- Myopia (my-OH-pee-uh): Commonly called near-sightedness, it means being able to see up close, but having difficulty seeing at a distance
- Amblyopia (am-blee-OH-pee-uh): Often called lazy eye, this condition is caused by poor vision in one eye and can lead to vision impairment or blindness if not treated
- Strabismus (struh-BIZ-muhs): Often called crossed eyes, this condition occurs with one or both eyes do not line up with each other, appearing to look up, down, or to the side rather than straight ahead
- Glaucoma (glaa-KOH-muh): Harm to the optic nerve which can cause vision loss
- Color vision problems: Difficulty seeing certain colors
- Retinal detachment: The retina pulls away from the back of the eye

Many of these vision problems can be treated with eyeglasses, eye drops, patching (sometimes wearing an eye patch), specialized prescribed devices, or eye surgery.

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For babies with more serious ROP, early identification and treatment is the most important way to prevent vision problems later in life. While successful treatment can protect the center of the retina so the child has a better chance of seeing clearly directly in front of them, many will have some loss to their peripheral (side) vision (ability to see motion or objects outside the direct line of vision). Some babies with untreated ROP or retinal detachment might also experience symptoms such as:

- Nystagmus (ni-STAG-muhs): Eyes that make repetitive, uncontrolled movements (looks like “shaky” eyes)
- Leukocoria (loo-kuh-KAW-ree-uh): Pupil (the round opening of the eye that lets light into the eye) looks white rather than the usual black color
- Not following objects with their eyes or responding to light
- Trouble recognizing faces
- Blindness

## 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?

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



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### 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](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) ([PreventBlindness.org](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.

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



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**The National Eye Institute** ([NEI.NIH.gov/learn-about-eye-health/eye-conditions-and-diseases/retinopathy-prematurity](http://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](http://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](http://BlindChildren.org)) is dedicated to helping visually impaired children be independent, functional members of society.

**Infantsee®** ([Infantsee.org](http://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](http://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](http://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](http://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](http://FamilyVoices.org/affiliates) ([FamilyVoices.org/affiliates](http://FamilyVoices.org/affiliates)) to assist families.

**Family-to-Family Health Information Centers (F2Fs)** ([FamilyVoices.org](http://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

