

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

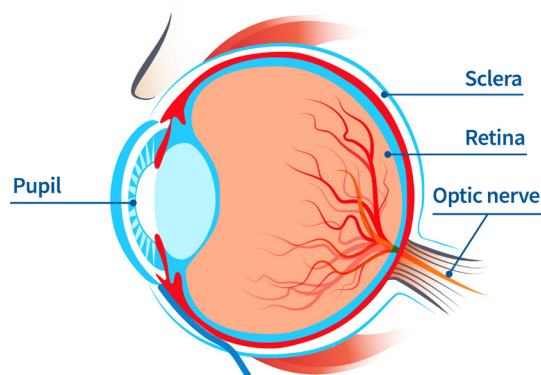
Part 3 of 3 in a series

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

What follow up is needed for ROP when your baby leaves the NICU?

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. Follow all recommended appointments at least once a year. This will help 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.

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 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.





“I highly recommend that parents connect with support organizations to find support and their community after they are at home, alone, caring for their baby.”

– Kelli, NICU mom and Founder and CEO, Hand to Hold

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

SPAN Parent Advocacy Network (<https://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.

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

This information developed in partnership with

