



What is Retinopathy of Prematurity (ROP)?

Part 1 of 3 in a series

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

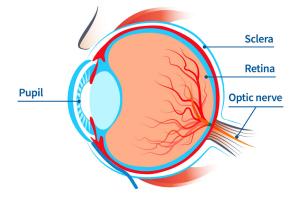
Read Next: "How is Retinopathy of Prematurity (ROP) **Diagnosed and Treated?**"

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 a thin layer of cells in the back of the eye. It collects all the light information from what we see. It then sends information through the optic nerve to the brain where it becomes an image. 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.

Important activities for your baby's vision throughout childhood and adolescence:

- Eye exams while your baby is in the NICU
- Eye exams with specialists after your baby leaves the NICU
- Following all treatment recommendations

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What is Retinopathy of Prematurity (ROP)?

(continued)

How Common is ROP?



Among babies who are born prematurely in the United States, about **14,000** children will be diagnosed with ROP each year.¹



About **1,300** children experience vision loss.¹

400 to 600

Children have severe visual impairment or blindness because of ROP each year.¹



Because Black and Hispanic babies are born early more often than White babies, they have higher rates of ROP.²



Almost 90% of babies with ROP will experience "regression" of the disease, meaning it improves on its own without treatment.¹

What causes ROP?

ROP happens more often in babies born early or small because the blood vessels of the retina begin to grow around 16 weeks into the pregnancy, and do not completely form until 36 and 40 weeks of pregnancy. Blood vessels in the eye that haven't finished growing before a baby is born might begin to grow abnormally and in the wrong direction once they are born - causing ROP. Being born early also requires more medical support, such as extra oxygen, which can also cause the blood vessels to grow abnormally fast.

What are the risk factors for ROP?

The earlier and smaller a baby is born, the more likely their chance of developing ROP that may need treatment. Other risk factors that may increase a newborn's likelihood of having severe ROP include:

- Breathing problems at birth that require prolonged and high amounts of oxygen
- Changing oxygen levels in the NICU (high to low and vice versa)
- Poor growth or weight gain after birth
- Being a multiple at birth (twins, triplets, etc.)
- Infections in the baby's mother around the time of delivery
- · Infections in the baby after birth
- Bleeding in the brain
- High blood sugar

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.



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What is Retinopathy of Prematurity (ROP)? (continued)



"As the parent, you are the expert on your child, and you are your child's best advocate. Follow your instincts, ask questions, take notes, and know it is ok to feel uncertain."

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

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.

<u>Prevent Blindness</u> (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.

<u>Hand to Hold</u> (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.

<u>SPAN Parent Advocacy Network</u> (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







- 1. American Association of Pediatric Ophthalmology and Strabismus (April 2023). Retinopathy of Prematurity. https://aapos.org/glossary/retinopathy-of-prematurity.
- 2. Bhatnagar A, Skrehot HC, Bhatt A, Herce H, Weng CY. Epidemiology of Retinopathy of Prematurity in the US From 2003 to 2019. *JAMA Ophthalmol*. 2023;141(5):479–485. doi:10.1001/jamaophthalmol.2023.0809

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