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Retinoblastoma Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- [Can Retinoblastoma Be Found Early?](#)
- [Signs and Symptoms of Retinoblastoma](#)
- [Tests for Retinoblastoma](#)

Stages of Retinoblastoma

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- [Retinoblastoma Stages](#)

Questions to Ask About Retinoblastoma

Here are some questions you can ask the cancer care team to help you better understand your child's diagnosis and treatment options.

- [Questions to Ask About Retinoblastoma](#)
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Can Retinoblastoma Be Found Early?

Retinoblastoma is a rare cancer, and there are no widely recommended screening tests for retinoblastoma. (Screening is testing for a disease like cancer in people with no signs or symptoms.) Still, many retinoblastomas are found early by parents, relatives, or a child's doctor.

During children's regular physical exams, doctors routinely check their eyes. Some of the things doctors look for include:

- Changes in how the eyes look (inside or outside)
- Changes in how the eyes move
- Changes in the child's vision

Any of these might be a sign of retinoblastoma, although they are more often caused by something else.

Sometimes, a parent or relative might notice that a young child's eye doesn't look normal, and it will prompt a visit to the doctor. It's important for parents to be aware of the possible signs and symptoms of retinoblastoma, and to report anything unusual to the doctor as soon as possible. Most often the cause is something other than retinoblastoma, but it's important to have it checked so that the cause can be found and treated right away, if needed.

For children at increased risk

For children in families known to carry an *RB1* gene change (which causes [heritable retinoblastoma](#)¹), or in families with a history of retinoblastoma who have not had [genetic testing](#)² for *RB1* gene changes, doctors recommend regular, thorough eye exams during the first years of life to detect tumors at an early stage. These children might need an eye exam soon after birth, and then frequently during the first years of life.

The *RB1* gene defect can be found by a special blood test, so most doctors now advise that children with parents or siblings with a history of retinoblastoma have this genetic test done during the first few weeks after birth. The results of the test then help define how often eye exams should be done. For example, children at risk because they have an *RB1* gene change might need an eye exam every month or so during the first year, and then every few months until at least age 4 or 5.

Children with the heritable form of retinoblastoma usually develop tumors in both eyes (bilateral retinoblastoma). Most heritable retinoblastomas develop and are diagnosed in infants only a few months old. Usually, if tumors develop in both eyes, it happens at the same time. But in some children, tumors develop in one eye first, then a few months (or even years) later in the other eye. So even if retinoblastoma is diagnosed in only one eye, these children will still need regular exams of the other eye for several years after treatment.

If a child has retinoblastoma that is thought to be hereditary, many doctors also recommend magnetic resonance imaging (MRI) scans of the brain at regular intervals for up to 5 years to check for a trilateral retinoblastoma (which includes a brain tumor such as a pineoblastoma). For more information, see [Tests for Retinoblastoma](#).

Hyperlinks

1. www.cancer.org/cancer/retinoblastoma/causes-risks-prevention/what-causes.html
2. www.cancer.org/cancer/cancer-causes/genetics.html

References

Hurwitz RL, Shields CL, Shields JA, et al. Chapter 27: Retinoblastoma. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 7th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2016.

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Signs and Symptoms of Retinoblastoma

Retinoblastomas nearly always occur in young children. They are often found when a parent or doctor notices that a child's eye looks unusual.

White pupillary reflex

This is the most common early sign of retinoblastoma. Normally when you shine a light in the eye, the pupil (the dark spot in the center of the eye) looks red because of the blood vessels in the back of the eye. In an eye with retinoblastoma, the pupil often appears white or pink instead, which is known as a white pupillary reflex (or leukocoria).

A parent might notice this white glare after a flash photograph is taken, especially if the pupils are different colors. It also might be noted by the child's doctor during a routine eye exam.

Lazy eye

Sometimes the eyes don't appear to look in the same direction, a condition often called lazy eye. (Doctors call this **strabismus**.) There are many possible causes of this in children. Most of the time lazy eye is caused by a mild weakness of the muscles that control the eyes, but it can also be caused by retinoblastoma.

Other possible signs and symptoms

Less common signs and symptoms of retinoblastoma include:

- Vision problems
- Eye pain
- Redness of the white part of the eye
- Bleeding in the front part of the eye
- Bulging of the eye
- A pupil that doesn't get smaller when exposed to bright light
- A different color in each iris (the colored part of the eye)

If the cancer spreads outside the eye, symptoms depend on where the cancer is. Some possible symptoms include:

- Loss of appetite and weight loss
- Headache
- Vomiting
- Lumps under the skin in the neck

Many of these signs and symptoms are more likely to be caused by something other than retinoblastoma. Still, if your child has any of these, check with your child's doctor so the cause can be found and treated, if needed.

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Hurwitz RL, Shields CL, Shields JA, et al. Chapter 27: Retinoblastoma. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 7th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2016.

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Tests for Retinoblastoma

Retinoblastomas are usually found when a child is brought to a doctor because he or she has certain signs or symptoms.

For most types of cancer, a biopsy is needed to make the diagnosis. During a biopsy,

the doctor takes a sample from the tumor and sends it to a lab to be looked at with a microscope.

But biopsies usually are not done to diagnose retinoblastoma, for 2 main reasons:

- Taking a biopsy specimen from a tumor in the eye can't be done easily without harming the eye and risking the spread of cancer cells outside the eye.
- Retinoblastoma can usually be diagnosed accurately without a biopsy by doctors who have experience with this disease, and it's unlikely to be confused with other eye problems in children.

Medical history and physical exam

If your child has signs or symptoms of retinoblastoma, the doctor will examine your child's eyes and get a complete medical history to learn more about your child's symptoms. The doctor may also ask about any family history of retinoblastoma or other cancers. This can be important when deciding if more tests and exams are needed. Your family history is also useful for determining whether other relatives could possibly pass the retinoblastoma (*RB1*) gene change on to their children or develop this cancer themselves (if they are young children), and if they might benefit from [genetic counseling and testing](#)¹.

If a retinoblastoma is suspected, the doctor will refer you to an **ophthalmologist** (a doctor who specializes in eye diseases), who will examine the eye closely to be more certain about the diagnosis. The ophthalmologist will use special lights and magnifying lenses to look inside the eye. Usually, the child needs to be asleep (under general anesthesia) during the exam so that the doctor can take a careful and detailed look.

If a diagnosis of retinoblastoma seems likely based on the eye exam, imaging tests will be done to help confirm it and to find out how far it might have spread within the eye and possibly to other parts of the body. Usually an ophthalmologist who specializes in treating cancers of the eye (called an **ocular oncologist**) will make the final determination. This doctor should also be part of the team of doctors treating the cancer.

Imaging tests

Imaging tests use x-rays, sound waves, magnetic fields, or radioactive substances to create pictures of the inside of the body. Imaging tests may be done for a number of

reasons, including:

- To help tell if a tumor in the eye is likely to be a retinoblastoma
- To determine how large the tumor is and how far it has spread
- To help determine if treatment is working

Children thought to have retinoblastoma may have one or more of these tests.

Ultrasound of the eye

[Ultrasound](#)² uses sound waves to create images of tissues inside the body, such as the inner parts of the eye. For this test, a small ultrasound probe is placed up against the eyelid or eyeball. The probe gives off sound waves and detects the echoes that bounce off the tissues inside and around the eye. The echoes are converted by a computer into an image on a screen.

Ultrasound is one of the most common imaging tests to confirm a child has retinoblastoma. This test can also be very useful when tumors in the eye are so large they prevent doctors from seeing inside the whole eye.

This test doesn't hurt and doesn't expose the child to radiation, but the child may need to be given medicine to help keep them calm or even asleep so the doctor can get a good look at the eye.

Optical coherence tomography (OCT) is a similar type of test that uses light waves instead of sound waves to create very detailed images of the back of the eye.

Magnetic resonance imaging (MRI) scan

An [MRI scan](#)³ creates detailed images using radio waves and strong magnets (instead of x-rays). MRI scans often are used for retinoblastomas because they provide very detailed images of the eye and surrounding structures, without using radiation. This test is also very good for looking at the brain and spinal cord.

Most children with retinoblastoma will have an MRI scan as part of their initial workup. For children with bilateral retinoblastomas (tumors in both eyes), many doctors continue to do MRI scans of the brain for several years after treatment to look for tumors of the pineal gland (sometimes called trilateral retinoblastoma).

Your child may have to lie inside a narrow tube for this test, which is confining and can be upsetting. This test also requires staying still for long periods of time. Young children

may be given medicine to help keep them calm or even asleep during the test.

Computed tomography (CT) scan

[CT scans](#)⁴ can help determine the size of a retinoblastoma tumor and how much it has spread within the eye and to nearby areas.

Normally, either a CT or an MRI scan is needed, but usually not both. Most doctors prefer to use MRI, because CT scans use x-rays, which might raise a child's risk for other cancers in the future. However, a CT scan can show deposits of calcium in the tumor much better than an MRI, which can be very helpful when the diagnosis of retinoblastoma is not clear.

Bone scan

A [bone scan](#)⁵ can help show if the retinoblastoma has spread to the skull or other bones. Most children with retinoblastoma don't need to have a bone scan. It's normally used only when there is a strong reason to think retinoblastoma might have spread outside the eye.

For this test, a small amount of low-level radioactive material is injected into the blood and travels to the bones. A special camera can detect the radioactivity and creates a picture of the skeleton.

Areas of active bone changes appear as "hot spots" on the scan. These areas may suggest cancer is in an area, but other bone diseases can also cause the same pattern. To help tell these apart, other tests such as plain x-rays or MRI scans of the bone might be needed.

For more details on imaging tests, see [Imaging \(Radiology\) Tests](#)⁶.

Genetic testing

When a child is diagnosed with retinoblastoma, it's important to know if it's the heritable (congenital) form or the non-heritable form of the disease. (See [What Causes Retinoblastoma?](#)⁷)

If tumors are found in both eyes (bilateral retinoblastoma), it can be assumed that the child has heritable retinoblastoma (even if there is no family history of the disease). This means they carry the mutant *RB1* gene in all of their cells. Some children with retinoblastoma in only one eye might also carry the mutant *RB1* gene in all of their

cells.

A blood test can be done to look for the *RB1* gene change in cells outside the eye. This test can usually tell if the child has the heritable form of retinoblastoma.

Knowing which form a child has is important, because children with heritable retinoblastoma have an increased risk for developing other cancers later in life, and are more likely to develop cancer if they get radiation therapy. These children will need close follow-up after treatment. (See [After⁸Treatment⁹](#).) They will also have a 1 in 2 chance of passing the *RB1* gene change on to each of their own children.

A child having the heritable form of retinoblastoma can also have implications for other family members, such as brothers or sisters, who might also carry the *RB1* gene change. Meeting with a genetic counselor can give you a better idea of what this risk might be and if other children in the family should be tested for the mutation.

Sometimes tests can't tell with certainty if a child inherited the *RB1* gene change. In these cases the safest plan is to monitor the child (and other children in the family) closely for retinoblastoma with frequent eye exams.

Other tests

Other tests are not often needed for retinoblastomas, but they might be helpful in some situations.

Biopsy

For most cancers, a biopsy (removing a tissue sample from the tumor and looking at it under a microscope) is needed to make a diagnosis. But trying to biopsy a tumor at the back of the eye can often damage the eye and may spread tumor cells, so this is almost never done to diagnose retinoblastoma. Instead, doctors make the diagnosis based on eye exams and on imaging tests, like those listed above. This is why it's very important that the diagnosis of retinoblastoma is made by experts.

Lumbar puncture (spinal tap)

Retinoblastomas can sometimes grow along the optic nerve, which connects the eye to the brain. If the cancer has spread to the surface of the brain, this test can often find cancer cells in samples of cerebrospinal fluid (CSF), which is the fluid that surrounds the brain and spinal cord. Most children with retinoblastoma don't need a lumbar puncture. It's used mainly when there is a reason to think retinoblastoma might have

spread into the brain.

Typically for this test, the child is given anesthesia so they will be asleep and not move during the procedure. This can help ensure the spinal tap is done cleanly. The doctor first numbs an area in the lower part of the back over the spine. A small, hollow needle is then placed between the bones of the spine to withdraw a small amount of the fluid, which is then sent to the lab for testing.

Bone marrow aspiration and biopsy

These 2 tests might be done to see if the cancer has spread to the bone marrow, the soft, inner part of certain bones. These tests are usually not needed unless the retinoblastoma has grown outside the eye and doctors suspect it might have also spread to the bone marrow.

The tests typically are done at the same time. The samples are usually taken from the back of the pelvic (hip) bone, but sometimes they may be taken from other bones. Usually the child is given anesthesia so they will be asleep during the procedure.

For a bone marrow **aspiration**, a thin, hollow needle is then inserted into the bone, and a syringe is used to suck out (aspirate) a small amount of liquid bone marrow.

A bone marrow **biopsy** is usually done just after the aspiration. A small piece of bone and marrow is removed with a slightly larger needle that is pushed down into the bone. Once the biopsy is done, pressure is applied to the site to help stop any bleeding.

The samples are then sent to a lab to be tested for cancer cells.

Hyperlinks

1. www.cancer.org/cancer/cancer-causes/genetics/what-happens-during-genetic-testing-for-cancer.html
2. www.cancer.org/treatment/understanding-your-diagnosis/tests/ultrasound-for-cancer.html
3. www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html
4. www.cancer.org/treatment/understanding-your-diagnosis/tests/ct-scan-for-cancer.html
5. www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-scans-for-cancer.html
6. www.cancer.org/treatment/understanding-your-diagnosis/tests/imaging-radiology-

[tests-for-cancer.html](#)

7. www.cancer.org/cancer/retinoblastoma/causes-risks-prevention/what-causes.html
8. www.cancer.org/cancer/retinoblastoma/after-treatment/follow-up.html
9. www.cancer.org/cancer/retinoblastoma/after-treatment/follow-up.html

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Retinoblastoma Stages

The stage of cancer describes how far it has spread. The outlook (prognosis) for children with retinoblastoma depends, to some extent, on the cancer's stage. The stage is also an important factor in choosing treatment.

Retinoblastoma is staged based on the results of eye exams, imaging tests, and any tests that were done, which are described in [Tests for Retinoblastoma](#).

A **staging system** is a standard way for your child's cancer care team to sum up how far a cancer has spread. Doctors use staging systems to predict the outlook for saving

the child's vision, as well as for survival and the likelihood that certain treatments will be effective.

When determining the best treatment options, doctors often divide retinoblastomas into 2 main groups:

- **Intraocular retinoblastoma:** The cancer is still within the eye.
- **Extraocular retinoblastoma:** The cancer has spread outside the eye. Extraocular cancers can be divided further into orbital retinoblastomas, which have spread only to the eye socket, and metastatic retinoblastomas, which have spread to distant parts of the body, such as the brain or bone marrow.

In the United States, most retinoblastomas are diagnosed before they have spread outside the eye, so **staging systems that apply only to intraocular retinoblastoma are used most often in this country.** There are 2 staging systems for intraocular retinoblastomas.

It's important to know that regardless of the stage, almost all children with intraocular retinoblastoma can be cured if they are properly treated. But the stage has a bigger impact on whether the affected eye (or the vision in the eye) can be saved.

International Classification for Intraocular Retinoblastoma

The International Classification for Intraocular Retinoblastoma is the staging system that most doctors now use. It divides intraocular retinoblastomas into 5 groups, labeled A through E, based on the extent of the cancer and on the chances that the eye can be saved using current treatment options.

Group A

Small tumors (no more than 3 millimeters [mm] across) that are only in the retina and are not near important structures such as the optic disc (where the optic nerve enters the retina) or the foveola (the center of vision).

Group B

All other tumors (either larger than 3 mm or close to the optic disc or foveola) that are still only in the retina.

Group C

Well-defined tumors with small amounts of spread under the retina (subretinal seeding) or into the jelly-like material that fills the eye (vitreous seeding).

Group D

Large or poorly defined tumors with widespread vitreous or subretinal seeding. The retina may have become detached from the back of the eye.

Group E

The tumor is very large, extends near the front of the eye, is bleeding or causing glaucoma (high pressure inside the eye), or has other features that mean there is almost no chance the eye can be saved.

The Reese-Ellsworth staging system

The Reese-Ellsworth system was developed in the 1960s, when most children were being treated with [external beam radiation therapy \(EBRT\)](#)¹. While this is no longer a common treatment, some doctors may still use this system to classify retinoblastomas that have not spread beyond the eye. This system can help determine the likelihood of preserving vision while still treating the tumor.

Terms such as favorable, doubtful, and unfavorable used in this staging system refer to the likelihood that the cancer can be treated while saving the affected eye, **not** to the likelihood of the child's survival. Indeed, more than 9 in 10 children with intraocular retinoblastomas are cured. The major challenge is saving the vision in the affected eye.

To explain the groupings below, it helps to define a few terms.

- The **optic disc** is the end of the optic nerve where it is attached to the retina. Retinoblastomas are diagnosed by looking at the retina through the front of the eye, so doctors can't measure their size directly using a ruler. Instead they compare the size of the tumor with the size of the optic disc, which is usually about 1.5 millimeters (1/16 inch) across. For example, a tumor estimated to be 3 times the size of the disc (3 *disc diameters* or 3 DD) would be about 4.5 millimeters (3/16 inch) across.
- The **equator** is an imaginary line that divides the front and back halves of the eyeball.

The Reese-Ellsworth staging system divides intraocular retinoblastoma into 5 groups. The higher the group number, from 1 to 5, the lower the chance of controlling the retinoblastoma or of saving the eye or any useful vision.

Group 1 (very favorable for saving [or preserving] the eye)

- 1A: one tumor, smaller than 4 disc diameters (DD), at or behind the equator
- 1B: multiple tumors smaller than 4 DD, all at or behind the equator

Group 2 (favorable for saving [or preserving] the eye)

- 2A: one tumor, 4 to 10 DD, at or behind the equator
- 2B: multiple tumors, with at least one 4 to 10 DD, and all at or behind the equator

Group 3 (doubtful for saving [or preserving] the eye)

- 3A: any tumor in front of the equator
- 3B: one tumor, larger than 10 DD, behind the equator

Group 4 (unfavorable for saving [or preserving] the eye)

- 4A: multiple tumors, some larger than 10 DD
- 4B: any tumor extending toward the front of the eye to the ora serrata (front edge of the retina)

Group 5 (very unfavorable for saving [or preserving] the eye)

- 5A: tumors involving more than half of the retina
- 5B: vitreous seeding (spread of tumors into the jelly-like material that fills the eye)

Other staging systems

Other staging systems that include both intraocular retinoblastomas and those that have spread beyond the eye (extraocular retinoblastomas) may be used by some doctors.

These can be especially useful in countries where these cancers are more likely to have spread by the time they are found. For example, the **American Joint Commission on Cancer (AJCC) staging system** takes into account 4 key pieces of information:

- **T:** The size of the main (primary) **tumor** and how far it has grown within and outside of the eye
- **N:** Whether or not the cancer has reached nearby lymph **nodes** (small, bean-shaped collections of immune cells, to which cancers sometimes spread) in the head or neck
- **M:** Whether or not the cancer has spread (**metastasized**) to distant parts of the body, such as the bone marrow, brain, skull, or long bones
- **H:** Whether or not the child has the [heritable form of retinoblastoma](#)²

This system can be used to describe the extent of retinoblastomas in detail, particularly for those that have spread outside the eye, which rarely happens in the United States.

The different staging systems used for retinoblastoma can be confusing. Be sure to ask your child's doctor if you have any questions about the stage of your child's cancer.

Hyperlinks

1. www.cancer.org/cancer/retinoblastoma/treating/radiation-therapy.html
2. www.cancer.org/cancer/retinoblastoma/causes-risks-prevention/what-causes.html

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Questions to Ask About Retinoblastoma

It's important to have honest, open discussions with your child's doctors. You should ask any question, no matter how small it might seem. Here are some examples.

If retinoblastoma has just been diagnosed

- How sure are you that my child has [retinoblastoma](#)¹?
- Is only one eye affected or are there tumors in both eyes?
- Do we know if this is the [heritable \(heditary\) form of retinoblastoma](#)²? How can we find out? If it is, what would this mean?
- Has the cancer spread outside the eye?
- What is the [stage](#) of the cancer, and what does that mean?
- Has my child's vision been affected?
- Do we need any other [tests](#) before we can decide on treatment?
- How much experience do you have treating this type of cancer?
- Do we need to see any other types of doctors?
- Who else will be on the treatment team, and what do they do?

When deciding on a treatment plan

- What are our [treatment options](#)³?
- Can my child's sight be saved? If so, how much?
- What do you advise for treatment and why?
- Should we get a [second opinion](#)⁴? How do we do that? Can you recommend a doctor or cancer center?

- Are there any [clinical trials](#)⁵ we should consider?
- How soon do we need to start treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What should we do to be ready for treatment?
- What are the risks and side effects of the suggested treatments?
- Which side effects start shortly after treatment and which ones might develop later on?
- Will treatment affect the growth of the area around my child's eye?
- Will treatment affect my child's ability to grow and develop?
- Could treatment affect my child's [ability to have children](#)⁶ later on?

During and after treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply, but getting answers to the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything we can do to help manage side effects?
- What symptoms or side effects should we tell you about right away?
- How can we reach you or someone on your team on nights, weekends, or holidays?
- Who can we talk to if we have questions about costs, insurance coverage, or social support?
- What are the chances of the cancer [coming back](#)⁷ after treatment? What are our options if this happens?
- Is there any risk of this type of tumor occurring in our other children or relatives?
- Should we consider [genetic counseling and testing](#)⁸?
- What type of [follow-up](#)⁹ will my child need after treatment?
- Does my child have a higher long-term risk of [other cancers](#)¹⁰?

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about recovery times so you can plan your schedules. You may also want to ask about nearby or online support groups, where you may be able to get in touch with other families who have been through similar situations.

Also keep in mind that doctors aren't the only ones who can give you information. Other health care professionals, such as nurses and social workers, may be able to answer

some of your questions. You can find out more about speaking with your health care team in [The Doctor-Patient Relationship](#)¹¹.

Hyperlinks

1. www.cancer.org/cancer/retinoblastoma/about/what-is-retinoblastoma.html
2. www.cancer.org/cancer/retinoblastoma/causes-risks-prevention/what-causes.html
3. www.cancer.org/cancer/retinoblastoma/treating.html
4. www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/seeking-a-second-opinion.html
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11. www.cancer.org/treatment/understanding-your-diagnosis/talking-about-cancer/the-doctor-patient-relationship.html

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