

ASCO ANSWERS

RETINOBLASTOMA

WHAT IS RETINOBLASTOMA?

Retinoblastoma is a rare cancer that begins in the part of the eye called the retina. About 40% of children have the genetic form of retinoblastoma, meaning it is caused by a specific mutation (change) in a gene. When treating children with retinoblastoma, an important goal is preserving vision. Most children who begin treatment before the retinoblastoma has spread beyond the eye are cured; in fact, the cure rate is more than 90%.

WHAT IS THE FUNCTION OF THE RETINA?

The retina is a thin layer of nerve tissue that coats the back of the eye and enables the eye to see. Usually, retinoblastoma is unilateral (occurs only in one eye), but it can be bilateral (occurs in both eyes). Retinoblastoma can spread to the lymph nodes, bones, or the bone marrow (soft, sponge-like material inside large bones). Rarely, it involves the central nervous system (brain and spinal cord). Children with the genetic form of retinoblastoma are at increased risk for other cancers.

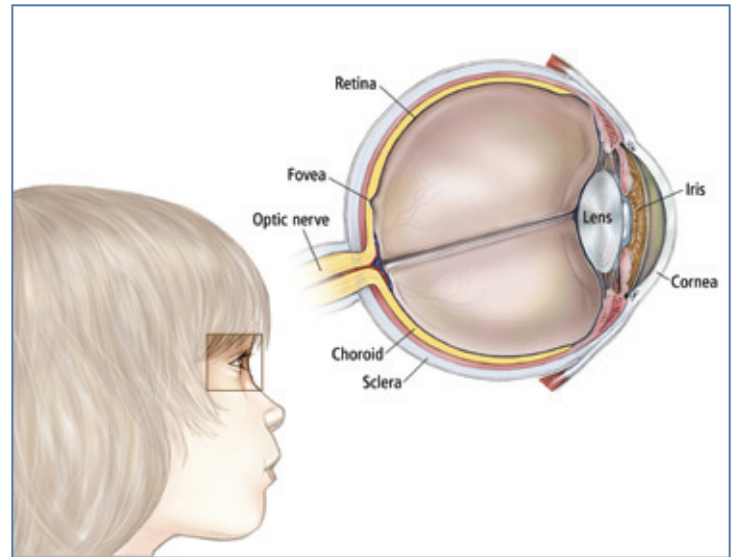


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Find additional cancer information at www.cancer.net.

WHAT DOES STAGE MEAN?

The stage is a way of describing the cancer, such as where it is located, if or where it has spread, and whether it is affecting the functions of other organs in the body. Retinoblastoma is described as intraocular (has not spread) or extraocular (has spread to tissues around the eye or other parts of the body). The International Classification System is used for staging; additional information is available at www.cancer.net/retinoblastoma.

HOW IS RETINOBLASTOMA TREATED?

Several types of treatment are used for retinoblastoma. Children with a tumor in one eye can often be cured with enucleation surgery to remove the eye. Children with a tumor in both eyes have enucleation if vision cannot be preserved using other treatment. A prosthesis (artificial eye) is then used to fill the eye area; children who need an artificial eye usually adapt well to the change in vision. Radiation therapy, cryotherapy (use of liquid nitrogen to freeze and kill cancer cells) or laser therapy (also called thermotherapy; the use of heat from a laser to shrink smaller tumors) are other treatment options. Chemotherapy may also be used to shrink tumors in the eye or eliminate any remaining smaller tumors after other treatments.

When making treatment decisions, consider a clinical trial; most children with cancer are treated as part of one. Talk with your child's doctor about all treatment options. The side effects of retinoblastoma treatment can often be prevented or managed with the help of your child's health care team.

HOW CAN I HELP MY CHILD COPE WITH RETINOBLASTOMA?

Helping your child understand a cancer diagnosis is a key part of the coping process. Children with cancer should be treated at a pediatric cancer center. These centers not only provide access to the latest treatments, they offer age-appropriate programs for social and emotional needs. Encouraging your child and other family members to share their emotions can be helpful in managing the diagnosis, treatment, and healing process.

QUESTIONS TO ASK THE DOCTOR

Regular communication is important in making informed decisions about your child's health care. Consider asking the following questions of your child's doctors:

- Does my child have the genetic form of retinoblastoma?
- Can you explain my child's pathology report (laboratory test results) to me?
- Would you explain my child's treatment options?
- What clinical trials are open to my child?
- What treatment plan do you recommend for my child? Why?
- Who is part of the treatment team, and what does each member do?
- What is the likelihood that the recommended treatment can save my child's vision?
- If enucleation is needed, how soon can my child receive an artificial eye, and what support services are available to help my child adjust to the partial/total loss of vision?
- How will this treatment affect my child's daily life? Will he or she be able to go to school and perform his or her usual activities?
- What short-term and long-term side effects may be associated with my child's cancer treatment?
- If I'm worried about managing the costs related to my child's cancer care, who can help me with these concerns?



Learn more about
retinoblastoma

- What follow-up tests will my child need, and how often will he or she need them?
- Where can I find emotional support for my child? For my family?
- Whom do I call for questions or problems?

Additional questions to ask the doctor can be found at www.cancer.net/retinoblastoma.

Cancer.Net™

Doctor-Approved Patient Information from ASCO®

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For more information, visit ASCO's patient website, www.cancer.net, or call 888-651-3038.

TERMS TO KNOW

Benign:

A tumor that is not cancerous

Biopsy:

Removal of a tissue sample that is then examined under a microscope to check for cancer cells

Chemotherapy:

The use of drugs to destroy cancer cells

Clinical trial:

A research study that tests a new treatment or drug

Lymph node:

A tiny, bean-shaped organ that fights infection

Malignant:

A tumor that is cancerous

Metastasis:

The spread of cancer from where the cancer began to another part of the body

Ocular oncologist:

A doctor who specializes in treating eye cancer

Ophthalmologist:

A doctor who specializes in diseases of the eye

Pediatric oncologist:

A doctor who specializes in treating children and teens with cancer

Prognosis:

Chance of recovery

Radiation therapy:

The use of high-energy x-rays to destroy cancer cells

Tumor:

An abnormal growth of body tissue