Understanding Retinoblastoma in Children:
A Guide for Families

What is Retinoblastoma?

Retinoblastoma is a rare type of eye cancer that primarily affects young children, typically under the age of 5. It can occur in one or both eyes and originates in the retina, the light-sensitive lining inside the eye. Early diagnosis and treatment are crucial to prevent vision loss and other serious complications.

Signs and Symptoms

- White color in the pupil when light is shone in the eye (leukocoria)
- Eyes that appear to be looking in different directions (strabismus)
- Redness and swelling of the eye
- Poor vision

Treatment Options

Treatment for retinoblastoma depends on the size, location, and extent of the tumor, as well as whether one or both eyes are affected. The primary goal is to preserve life and vision. Here are some common treatments:

1. **Enucleation**: Surgical removal of the eye when the tumor is large or vision cannot be saved.
2. **Intravenous Chemotherapy**: Used to shrink tumors in both eyes.
3. **Intra-arterial Chemotherapy**: Delivers chemotherapy directly to the eye, minimizing systemic effects.
4. **Intravitreal Chemotherapy**: Injection of chemotherapy directly into the eye, used for vitreous seeding.
5. **Plaque Radiotherapy**: A small radioactive disc is placed near the tumor to destroy cancer cells.
6. **Laser Photocoagulation**: Uses laser beams to destroy blood vessels feeding the tumor.
7. **Cryotherapy**: Freezes and destroys small tumors.

Impact on Vision

Both the tumor and treatments can affect a child's vision. Enucleation results in vision loss in the affected eye, while other treatments may preserve some vision but can still cause side effects impacting sight.

Follow-Up and Monitoring

- **Monthly Follow-Ups**: Essential until the disease is completely cured to monitor for recurrence or complications.
- **Long-Term Monitoring**: Once stable, follow-ups can be less frequent but remain crucial.
- **Germline Mutation Considerations**: If a child has tumors in both eyes due to a germline mutation, they will require:
    - MRI scans twice a year until age 5 to monitor for additional tumors.
    - Lifelong follow-up for the risk of second cancers.

Risks and Prognosis

Retinoblastoma can metastasize, potentially leading to death. In the United States, the mortality rate is approximately 2%, while in some countries in South America, Africa, and Asia, it can be as high as 50%, often due to later diagnosis and limited access to treatment.

Support and Resources

Managing retinoblastoma can be challenging for families. Support groups and counseling services are available to help navigate these difficulties. Your healthcare team can provide information on local and national resources.

Contact Information

For more information or to schedule an appointment, please contact:

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This brochure was given to the patient/family and is intended to provide a general overview of retinoblastoma. For personalized medical advice, please consult your healthcare provider.