



# Retinoblastoma

If your child, adolescent, or young adult has been diagnosed with retinoblastoma or is suspected to have retinoblastoma, Memorial Sloan-Kettering Cancer Center is ready to help. [Our team of doctors, nurses, and other healthcare professionals](#) is dedicated to providing the most-effective, personalized treatment, while preserving the best possible quality of life.

## About Retinoblastoma

Retinoblastoma, the most common type of eye tumor seen in children, occurs most often in young children before the age of five and affects boys and girls in equal numbers. The tumor may be in one eye (referred to as unilateral retinoblastoma), or in both eyes (bilateral retinoblastoma).

Retinoblastoma tumors originate in the retina, the light-sensitive layer of the eye that enables sight. About 75 percent of retinoblastoma cases are unilateral, and 90 percent of retinoblastoma patients have no family history of the disease.

Retinoblastoma occurs most often before the age of five. There are approximately 350 new diagnosed cases per year in the United States, making it the seventh most common pediatric cancer.

Most retinoblastoma patients have a white pupil reflex or leukocoria instead of a normal black pupil or red reflex. This abnormal white pupillary reflex is sometimes referred to as a cat's eye reflex. Many times the parent is the first one to notice the cat's eye reflex. This white pupillary reflex may also be indicative of another disorder and does not always indicate retinoblastoma. An ophthalmologist can determine the correct diagnosis.

A crossed eye or strabismus is the second most common symptom of retinoblastoma. The child's eye may turn towards the ear (exotropia) or towards the nose (esotropia).

Children with retinoblastoma may also have the following symptoms:

- a painful red eye
- poor vision
- inflammation of tissue surrounding the eye
- an enlarged or dilated pupil
- different colored irises (a condition known as heterochromia)
- failure to thrive (trouble eating or drinking)
- extra fingers or toes (a condition known as hexadactylism)
- malformed ears
- delayed development or retardation

More than 95 percent of children treated for retinoblastoma in the US are cured. In addition, more than 90 percent of patients retain at least one eye and more than 80 percent of children treated keep 20/20 vision.

## Diagnosis & Treatment at Memorial Sloan-Kettering

Memorial Sloan-Kettering Cancer Center's experts on the retinoblastoma team can diagnose and treat children with this disease. Whether you come to us as soon as retinoblastoma is suspected or after a relapse of retinoblastoma treated elsewhere, we tailor our innovative treatments for each patient, based on the characteristics of your child and of his or her disease.

Learn more about how we diagnose and treat retinoblastoma.

## Diagnosis

At Memorial Sloan-Kettering, our ophthalmic oncologists have performed more than 12,000 examinations for retinoblastoma.

## Risk Factors

Ninety percent of all children who develop retinoblastoma are the first one in their family to have eye cancer. When retinoblastoma is passed from parent to child, the child usually develops retinoblastoma in both eyes.

## Treatment

We customize the treatment of retinoblastoma based on the age of a child, the involvement of one or both eyes, and whether or not the cancer has spread to other parts of the body.

# Diagnosis



David Abramson (right) and the retinoblastoma team examine every child thoroughly to diagnose the disease.

When there is a family history of retinoblastoma, newborn babies should be examined in the nursery at birth by an ophthalmologist. When there is no family history, it is frequently the parents who notice leukocoria (a white pupil reflex instead of a normal black pupil or red reflex) or strabismus (a crossed eye), the discovery of which leads the parents to bring their child in for an examination.

Unlike other types of cancer, a biopsy is rarely, if ever, done in cases of retinoblastoma. Although biopsy can accurately aid in diagnosis, there is concern about the possibility of spreading the cancer with biopsy.

Worldwide, many eyes thought to have retinoblastoma are enucleated (surgically removed) and found to have some other, non-malignant disorder. It is therefore critical that the ophthalmic oncologist making the diagnosis be experienced in the diagnosis of retinoblastoma and the diagnosis of conditions that look like retinoblastoma. At Memorial Sloan-Kettering, our ophthalmic oncologist has performed more than 12,000 examinations for retinoblastoma.

### Making an Appointment

If your child, adolescent, or young adult has been diagnosed with cancer, you can call our Department of Pediatrics to make an appointment at Memorial Sloan-Kettering.

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## ■ Ophthalmic Exam

The ophthalmic examination is best done under general anesthesia. Some very young and older patients can be examined without general anesthesia. If you have any questions about whether your child should have anesthesia, ask your ophthalmologist, anesthesiologist, or nurse.

The ophthalmologist views the retina with an indirect ophthalmoscope (a lighted instrument used to perform a magnified examination of the eye) to determine the presence of tumors. A metal clip known as a lid speculum is placed between the eyelids to help keep the child's eye open.

During the examination, the ophthalmologist uses a Q-tip or a metal scleral indenter (which looks like a pen with a flattened tip) to move the most forward portions of the retina (the sensory membrane located in the back of the eye) into view. Because the child is under anesthesia and his or her eye is numbed, they experience little or no discomfort from this process.

## ■ Fundus Drawings and Photographs

A drawing or photographs, called fundus (defined as the larger part of a hollow organ that is farthest away from the organ's opening) drawings or photos, are made of the tumors. The fundus drawing and photos serve as maps. Future examinations will be based on these original drawings and photographs; new drawings and photographs may be made at each follow-up visit.

Ultrasound examination, which uses sound waves to penetrate and outline structures in the eye, can confirm if retinoblastoma tumors are present and can determine their thickness or height. Black and white Polaroid photographs of the ultrasound images may be taken.

## ■ Testing for Metastatic Retinoblastoma

An examination called MRI (Magnetic Resonance Imaging) — which uses magnetic waves to image the eyes, the orbits, and the brain — may be performed to determine if there is any tumor outside the eye or in the brain.

Children who are diagnosed with retinoblastoma are also seen by a pediatric oncologist. The pediatric oncologist determines whether

there is cancer anywhere else in the child's body. A physical examination and sometimes blood tests, a spinal tap, and a bone marrow biopsy are performed.

## Risk Factors

Ninety percent of all children who develop retinoblastoma are the first one in their family to have eye cancer. When retinoblastoma is passed from parent to child, the child usually develops retinoblastoma in both eyes.

### ■ Chromosome 13

Although it is not exactly understood why retinoblastoma occurs, it is known that in all cases this cancer is caused by an abnormality in chromosome 13, in which a piece of the chromosome is nonfunctional or missing. (Chromosomes are the components of a cell that contain genetic information.)

Chromosome 13 is responsible for controlling retinal cell division. In children with retinoblastoma, retinal cell division continues unchecked, causing retinal tumors.

In 60 percent of retinoblastoma cases, the abnormality is only found in cells of the eye; in 40 percent of the cases, the abnormality is present in every cell of the body including the eye.

### ■ Genetic Testing

There are many options available for genetic testing of retinoblastoma. These tests can modify the risk or can predict whether or not a child in a family with bilateral retinoblastoma is at risk to develop the disease. Our genetic counselor, Katherine Beaverson, MS, CGC, is the world's only genetic counselor dedicated to retinoblastoma.

At the present time, the genetic test is most accurate if the lab can study a specimen of tumor from the surgically removed, or enucleated, eye of the patient together with a blood sample. If the patient has the inherited genetic abnormality, other members of the family may be screened or observed for development of the disease.

The most common situation is where neither parent has the gene for retinoblastoma but has a child born with retinoblastoma. If the parents are genetically normal, the chance of another child having retinoblastoma is one in 15,000 to 20,000.

### ■ Unilateral Retinoblastoma

If a parent had unilateral retinoblastoma, 7 to 15 percent of their offspring will have retinoblastoma. When a parent with unilateral retinoblastoma has a child who develops retinoblastoma, that child will develop bilateral retinoblastoma 85 percent of the time.

Every time the unilateral retinoblastoma parent has another child, the chance of that child developing retinoblastoma is 7 to 15 percent.

### ■ Bilateral Retinoblastoma

If a parent has been treated for bilateral retinoblastoma, almost half (45 percent) of their children will develop retinoblastoma in their eyes. At birth, the child may have tumors in the eye or elsewhere in the body. Other children may not have tumors at birth but will begin to develop them by 28 months and can continue to form them for up to seven years.

Many of these children do not have the tumor present at birth. In our experience, if the child is going to develop retinoblastoma, he or she will begin to develop tumors in the eyes by 28 months and can continue to form them until the age of seven years.

The majority of children with retinoblastoma born to a parent with bilateral retinoblastoma will also have bilateral retinoblastoma, but about 15 percent will develop unilateral retinoblastoma.

### ■ Cancer-Free Parents

The situation where neither parent has had retinoblastoma is the most common and the most difficult to explain. When this occurs, both parents are encouraged to have a dilated retinal exam.

One percent of the time, there is evidence of a cured or limited form of retinoblastoma in the eye of a parent who was never aware of having had retinoblastoma and was never treated for it. In this case, 45 percent of that parent's children will develop retinoblastoma.

#### Making an Appointment

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More confusing, and rarer, is the possibility that a parent has the gene for retinoblastoma but no evidence of retinoblastoma in their eyes. This is called the carrier state, meaning the parent carries the gene but not the disease. Again, 45 percent of their children will be affected with retinoblastoma.

## Treatment

For children with retinoblastoma in their eyes only, we use a mild form of chemotherapy to avoid or delay radiation therapy whenever possible. After the chemotherapy causes the retinoblastoma tumors to shrink, we use laser treatment, cryotherapy (freezing treatment), and plaque brachytherapy (a form of focused radiation therapy) to cure the remainder.

At Memorial Sloan-Kettering Cancer Center, the treatment of retinoblastoma is customized for each patient, and depends upon the age of the child, the involvement of one or both eyes, and whether or not the cancer has spread to other parts of the body. The main treatment options are as follows:

### ■ Enucleation

Enucleation is the most common treatment for retinoblastoma. During an enucleation, the eye is surgically removed. This is necessary because it is the only way to remove the cancer completely. It is not possible to remove the cancer from within the eye without removing the entire eye.

The removal of the eye is done under general anesthesia. In the operation, the entire eye is removed along with a long piece of optic nerve as one specimen, and is sent to a pathologist for examination under a microscope.

The eyebrow, lids, and muscles of the eye are all left in place. Blinking, tearing, and movement of the brow are not affected from this surgery. The operation takes less than an hour and is not painful. Children go home the same day and are usually examined in the office on the following day when post-operative instructions and care are explained.

### ■ Prosthetic Replacement

A ball of plastic, rubber, or coral is placed where the eye had been so there is no cavity or hole. After the socket heals, it will look like the tissue on the inside of the lip.

The child is fitted for a prosthesis or false eye approximately three weeks after the operation. The prosthesis is made of plastic to look exactly like the other eye. The prosthetic eye does not move as well as a natural eye and tends to move better up and down than it does side to side. And, of course, the prosthetic eye does not see. There is currently no way to transplant or replace an entire eye.

When both eyes are involved, sometimes the more involved or “worse” eye is enucleated, while the other eye may be treated with one of the vision-preserving treatments, such as external beam radiation, plaque therapy, cryotherapy, laser treatment, or chemoreduction.

### ■ External Beam Radiation Treatment

External beam radiation has been used since the early 1900's as a way to save the eye and the child's vision. Retinoblastoma is sensitive to radiation, and frequently the treatment is successful. The radiation treatment is performed on an outpatient basis five times per week over a three to four week stretch.

Custom-made plaster-of-paris molds are made to prevent the head from moving during treatment and sometimes sedatives are prescribed prior to treatment.

Tumors usually get smaller (regress) and look scarred after external beam radiation treatment but they rarely disappear completely. In fact, they may even become more obvious to the parent as they shrink, because the pinkish-grey tumor mass is replaced by white calcium.

Immediately after treatment, the skin may be sunburned or a small patch of hair may be lost in the back of the head from the beam exit position. Long-term effects can include cataracts, radiation retinopathy (bleeding and exudates of the retina), impaired vision, and there may be temporal bone suppression, characterized by bones on the side of the head which do not grow normally.

Radiation can also increase a child's risk of developing other tumors outside the eye for those



#### Perry's Story

When retinoblastoma spread to two-year-old Perry's brain, her parents brought her to Memorial Sloan-Kettering for treatment.

children who carry the abnormal retinoblastoma gene in every cell of their bodies.

## ■ Radioactive Plaques

Radioactive plaques are disks of radioactive material that were developed in the 1930's to radiate retinoblastoma. Today, the isotope iodine-125 is used and the plaques are custom-built for each child.

According to New York State radiation safety rules, the child must be hospitalized for this procedure, and he or she undergoes two separate operations (one to insert the plaque and another to remove it) over three to seven days. Following the use of radioactive plaque, long-term effects including cataracts, radiation retinopathy, and impaired vision may occur.

## ■ Laser Therapy

Laser therapy, which includes photocoagulation and laser hyperthermia (A type of treatment in which body tissue is exposed to high temperatures to damage and kill cancer cells), is a non-invasive treatment for retinoblastoma. Lasers very effectively destroy smaller retinoblastoma tumors. This type of treatment is usually done by focusing light through the pupil onto and surrounding the cancers in the eye.

A new delivery system of the laser, called a dioplexy probe, enables treatment of the cancer by aiming the light through the wall of the eye and not through the pupil. Our physicians at Memorial Sloan-Kettering were the first worldwide to use the dioplexy probe.

Laser treatment is done under local or general anesthesia, usually does not have any post-operative pain associated with it, and does not require any post-operative medications. Laser may be used alone in addition to external-beam radiation, plaques, or cryotherapy.

## ■ Cryotherapy

Cryotherapy freezes smaller retinoblastoma tumors and is performed under local or general anesthesia. A pen-like probe is placed on the sclera adjacent to the tumor and the tumor is frozen. Cryotherapy usually has to be repeated many times to successfully destroy all of the cancer cells.

Cryotherapy causes the lids and eye to swell for one to five days; sometimes the swelling is so much that the children are unable to open their lids for a few days. This can be frightening for the child and parents, but is usually harmless. Eye drops or ointment can be given to reduce the swelling.

## ■ Chemoreduction

Chemoreduction is the treatment of retinoblastoma with chemotherapy. Chemotherapy given intravenously to your child passes through the blood stream, and, if successful, causes the tumors to shrink within a few weeks. Chemotherapy, with one or more drugs, can be given once, twice, or more often.

At Memorial Sloan-Kettering, our physicians use only one chemotherapy drug for the treatment of retinoblastoma. This treatment provides the same effect as using two or three chemotherapy drugs, but with reduced toxicity.

Doctors at Memorial Sloan-Kettering introduced the concept of periocular chemotherapy, which is given around the eye using carboplatin to treat intraocular cases. This technique attains higher doses of chemotherapy in the eye and lower systemic (full body) doses. In some cases, this treatment may have to be given as many as 11 times.

Depending on the drugs used, the child may or may not be hospitalized during this process. After chemotherapy, the child is re-examined and any remaining tumors are treated with cryotherapy, laser, or radioactive plaque. Systemic chemotherapy alone rarely, if ever, cures intraocular retinoblastoma. Children may require as many as twenty treatments every three weeks.

## ■ Intra-Arterial Chemotherapy

Intra-arterial chemotherapy is a new treatment for advanced retinoblastoma in which the chemotherapy drug is injected directly into the ophthalmic artery (the blood vessel that leads to the eye). The patient is given general anesthesia by an anesthesiologist. A thin tube is inserted through a blood vessel (the femoral artery) in the groin (the top part of the leg) and threaded up to the ophthalmic artery, where the chemotherapy is then injected into the eye. This method of chemotherapy delivery is designed to minimize the drug's exposure to the rest of the body and to reduce side effects. The most common drugs used for this treatment are melphalan and

### Retinoblastoma: Our Clinical Trials

Browse a list of Memorial Sloan-Kettering's clinical trials for retinoblastoma that are currently enrolling patients.

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topotecan. The average number of treatment sessions is about three for each eye, each session being delivered at four-week intervals. After a successful treatment, the tumors will shrink. If needed, residual tumors may be treated with laser, cryotherapy, or plaque.

## ■ Metastatic Retinoblastoma

Although it is rare, retinoblastoma can spread (metastasize) to the brain, the central nervous system, and the bones. In these cases, chemotherapy is prescribed by a pediatric oncologist and is administered through the peripheral blood vessels or into the brain for months to years after initial diagnosis of metastatic disease.

The results have been very promising. A new intrathecal medication (delivered into the fluid that surrounds the brain and spinal cord) is available for patients whose retinoblastoma has spread to the surface of the brain.

## ■ Survivorship & Follow-Up Care

Most children with retinoblastoma in the United States — more than 95 percent — survive the cancer and have normal lives. Children with unilateral retinoblastoma have one eye whose sight is not affected even though they may have had one eye removed. It is important for children with vision in one eye to wear protective eyewear during sports and other activities.

Retinoblastoma is a life-threatening disease, but it is rarely a fatal one if treated appropriately. With the correct treatment and appropriate follow-up both for eyes and for cancers in other parts of the body, a child with retinoblastoma has a very good chance of living a long life.

The majority of children with bilateral retinoblastoma retain at least one eye with good vision, and many are able to retain the use of both eyes. However, all children with bilateral disease and the 15 percent of unilateral patients who have the familial form of retinoblastoma will be at much higher risk for other cancers not involving the eyes throughout their lives.

Five years after a retinoblastoma diagnosis, children with the inherited form of the disease are more likely to die from second tumors than from retinoblastoma. The most common second tumors are osteogenic sarcoma (a cancerous tumor which affects the bones), soft tissue sarcomas, and cutaneous melanomas (tumors of the skin, muscle, and connective tissue).

Although the reported incidences of these tumors vary widely, the risk appears to be about 1 percent a year. This risk is also increased by the use of external-beam radiation, although the amount of increase depends on the age at which the child was treated.

Follow-up appointments with an ophthalmologist and a pediatric oncologist are very important when a child is diagnosed with retinoblastoma. Frequency of examinations depends upon the age of the child, the ophthalmologist's suspicion of new tumors, whether one or both eyes are involved, and the type of treatment that the child has received. Parents are encouraged to talk to their nurse and to call with questions between visits.

## Our Approach & Expertise



David Abramson (right), Chief of the Ophthalmic Oncology Service, educates medical trainees.

The Retinoblastoma Program of the Ophthalmic Oncology Service at Memorial Sloan-Kettering Cancer Center has managed more patients than any other cancer center in the world. The Service has helped to advance the use of cutting-edge vision-saving techniques, including external beam radiation, radioactive plaques (a therapy in which radioactive discs are inserted directly into the affected eye), laser therapy, cryotherapy (a therapy in which smaller tumors are frozen), and chemoreduction (a therapy that uses chemotherapy to shrink the tumor).

With more than 12,000 examinations for retinoblastoma, our ophthalmic oncologist has unmatched experience in the diagnosis of retinoblastoma and of conditions that look like retinoblastoma.

Our multidisciplinary approach allows children to receive all their pediatric oncology care, ophthalmic oncology, and radiation oncology treatments under general anesthesia at Memorial Sloan-Kettering. Once a diagnosis has been made, our patients receive treatment in a suite of examination and treatment rooms dedicated exclusively to retinoblastoma.

### Nursing Care

Our dedicated team of nurses cares for your child during outpatient visits and inpatient hospital stays. Nurse practitioners work in collaboration with the primary physicians on your child's team to oversee care. This allows our nurses to assess your child's needs, triage symptoms, and if necessary, make referrals to other departments within Memorial Sloan-Kettering. Nurse practitioners and

#### Making an Appointment

If your child, adolescent, or young adult has been diagnosed with cancer, you can call our Department of Pediatrics to make an appointment at Memorial Sloan-Kettering.

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registered nurses can also help your child and family understand the details of the treatment plan and what to expect throughout the course of treatment.

### **Supportive Care**

Our social workers provide counseling, offer information, and assistance throughout the course of treatment, and can guide and direct you to resources you may need. Child life specialists, teachers, and session and physician office assistants all work together to meet your child's non-clinical needs.

### **■ Innovative Chemotherapy Treatments**

For children with retinoblastoma in their eyes only, we use a mild form of chemotherapy to avoid or delay radiation therapy whenever possible. We have introduced a new treatment for certain patients, in which chemotherapy is injected around the eye instead of being given intravenously. This can be more effective and also avoids some of the side effects of intravenous chemotherapy. This new treatment is discussed in greater detail in the journal [Ophthalmology](#).

### **■ Unique Treatment Approaches for Metastatic Retinoblastoma**

Retinoblastoma tumors that have metastasized outside the eye are often described as being incurable. However, at Memorial Sloan-Kettering we have successfully treated children with disease that has spread to their bones, bone marrow, and liver with intensive chemotherapy. The results have been very promising. A new intrathecal medication (given into the fluid that surrounds the brain and spinal cord) is available for patients whose retinoblastoma has spread to the surface of the brain. This procedure is discussed in the journal [Cancer](#).

#### **Our Publications**

Visit PubMed for our journal articles

[More »](#)

You may wish to have a formal consultation at the Retinoblastoma Program of Memorial Sloan-Kettering. Feel free to contact us at 212-639-2153; we will be happy to discuss your child's condition with you and organize a formal consultation if you want one.

## **Find a Retinoblastoma Expert**

Our multidisciplinary Pediatric Retinoblastoma Service provides comprehensive care to children, adolescents, and young adults diagnosed with retinoblastoma. Our pediatric physicians, nurse practitioners, nurses, and other specialists collaborate to maximize your child's chance of a cure. Our patients see the same team of healthcare professionals during their entire treatment process. This integrated care is personalized to each child's and family's needs.

As active members of the treatment team, nurse practitioners and nurses play an essential role in caring for children and young adults. Nurses bring extraordinary knowledge, experience, and expertise to patient care, and will help you and your child through your inpatient or outpatient experience at Memorial Sloan-Kettering.

Our social workers stay in close contact with families to meet any practical and psychosocial needs. Social workers provide counseling, information, and assistance throughout the course of treatment, and can direct you to additional resources. Our child life specialists, teachers, patient and program coordinators, and session and physician-office assistants also work together to help your child and family in the hospital and at home during treatment periods.

Find more information about our experts below. To make an appointment, please call the Department of Pediatrics at 212-639-5954.

Please visit <http://edit.mskcc.org/pediatrics/childhood/retinoblastoma/experts> to view and/or print this page.

## **Our Clinical Trials**

We have introduced a new treatment for certain patients, in which chemotherapy is injected around the eye instead of being given intravenously. This can be more effective and also avoids some of the side effects of intravenous chemotherapy. This new treatment is discussed in greater detail in the October 1999 issue of the journal [Ophthalmology](#) [[Abstract](#)].

Our team was the first to use a new laser delivery method known as a diopexy probe, which enables treatment of the cancer by aiming the light through the wall of the eye and not through the pupil.

For those patients whose retinoblastoma has spread to the surface of the brain, our team has had success using a new medication that is delivered directly into the fluid that surrounds the brain and spinal cord.

Recently, working in collaboration with physicians from Weill Cornell University Medical Center, our team used a technique known as preimplantation genetic testing in families at risk for having children with inherited retinoblastoma. After fertilizing 20 embryos from one couple using standard in vitro fertilization techniques, doctors tested each embryo for the mutation. Five of the embryos that were found to be free of the mutation were implanted in the mother's womb, resulting in the successful birth of a single, retinoblastoma-free child. The team has since repeated this success with another mother and child.

Here you can find a list of many of Memorial Sloan-Kettering's current clinical trials for neuroblastoma. To learn more about a study, choose from the list below.

Please visit <http://edit.mskcc.org/pediatrics/childhood/retinoblastoma/clinical-trials> to view and/or print this page.

## Support Programs & Services



Child life specialist Alyson Silver is one of the many members of our pediatric psychosocial support team.

At Memorial Sloan-Kettering, we understand that it can be overwhelming for a child and family to live with cancer or related diseases. Our experts are skilled in identifying and responding to the various symptoms and possible side effects associated with treatment, including the social and psychological aspects of therapies needed and recovery.

Many children have received treatment at Memorial Sloan-Kettering for the same disease as your child. You may find it helpful to speak to other patients or families who have had similar experiences. Please feel free to ask your child's care team to arrange for you to speak with some former patients and their families.

We also offer a broad range of support programs designed to help children, family members, and caregivers cope with the range of issues related to life during and after treatment.

### ■ Our Pediatric Psychosocial Support Team

Cancer can affect children in many ways. At Memorial Sloan-Kettering, our pediatric psychosocial care team offers support to our patients and their family members as they deal with a cancer diagnosis, complementing the efforts of our treatment teams.

Our psychosocial care team includes:

- social workers
- [child life specialists](#)
- [teachers](#)
- chaplains
- managers and support staff
- nurses
- physical and occupational therapists
- nutritionists
- psychiatrists
- [integrative medicine specialists](#)
- patient service coordinators
- patient representatives



#### Perry's Story

When retinoblastoma spread to two-year-old Perry's brain, her parents brought her to Memorial Sloan-Kettering for treatment.

In addition to our work with other experts at Memorial Sloan-Kettering, we also enlist the support of outside agencies, programs, and organizations to meet the needs of our families.

### ■ Our School Program

The Department of Pediatrics at Memorial Sloan-Kettering makes [our school program](#) a high priority. As one of 40 hospitals participating in a New York City Department of Education program called Hospital Schools, we have several full-time teachers who play an active role in educating our pediatric patients.

Our teachers, employed by the New York City Board of Education, help children and teens undergoing cancer treatment maintain their studies and prepare for exams. We work closely with each child's school and/or home instructor to enable a student to return to class after treatment with little or no loss of educational standing, and to prepare for required tests, including New York State Regents exams, SATs, and GEDs.

## ■ Child Life Services

Child life specialists are trained professionals who are experts in human growth and development. We have a variety of backgrounds and interests including education, psychology, fine arts, and art therapy. We combine our skills and certifications to create comprehensive [child life services](#) that educate and empower patients and family members throughout an illness. The goal of our Child Life Program is to help young patients and their families develop strategies for coping with and adjusting to treatment.

## ■ Recreational Programming

Our [programming](#) gives patients the chance to participate in many of the usual activities that children, adolescents, and young adults enjoy. Under the direction of child life specialists, we offer a range of age-appropriate activities daily in the Pediatric Day Hospital and the Inpatient Unit. These are designed to provide our patients and their siblings with social environments and supportive ways to spend time in the hospital.

## ■ Physical and Occupational Therapy

Children recovering from cancer treatment may need rehabilitation therapy. At Memorial Sloan-Kettering, our specially trained staff offers both outpatient and inpatient physical and occupational therapies for our pediatric patients.

## ■ Integrative Medicine

Our child and young adult patients may also benefit from the therapies offered by our [Integrative Medicine Service](#), which complements mainstream medical care by addressing the physical and emotional symptoms associated with cancer and its treatment. We offer music therapy, mind/body therapies, dance and movement therapy, yoga, and other services for our inpatients and outpatients in groups or at the bedside.

# Resources for the Blind & Visually Impaired

There are many organizations that offer information and services for cancer survivors, the blind, and the visually impaired. However, navigating the web is not always the easiest task. Therefore the following pages were created to serve as a base providing links to other useful sites that offer information and services for the blind and visually impaired. (The Resources for the Blind and Visually Impaired site was developed with support from the Leo Rosner Foundation.)

### [Informational Resources](#)

Great sources of information offering many services for the blind and visually impaired.

### [Assistive Technology & Products](#)

A listing of technology and products for the visually impaired.

### [Schools](#)

A listing of schools for the blind and visually impaired.

### [Camps](#)

Camps for cancer survivors and the visually impaired.

### [Libraries, Art & Theater](#)

A selection of libraries and programs in the arts designed for the blind and visually impaired.

### [Sports](#)

The United States Association for Blind Athletes and the New York Association for Blind Athletes provide athletic opportunities for the blind and visually impaired.

### **Text-Only Version**

[Access this section in a text-only version](#) 

# Informational Resources

The following links can serve as gateways to information and services for the blind and visually impaired. They offer a wide range of

resources, such as rehabilitation services and general education on living with blindness or visual impairment.

### **National Federation for the Blind**

The National Federation of the Blind is a large membership organization of blind individuals.

### **American Foundation for the Blind**

The American Foundation for the Blind is a national nonprofit that works to expand possibilities for the blind.

### **VISIONS**

VISIONS is a nonprofit agency that works to increase the independence of blind and visually impaired individuals. They offer information about rehabilitation services, publications on self-help, and a recreational and rehabilitation camp for both children and adults.

### **Blindline**

Blindline is a fully accessible website created by VISIONS in collaboration with the American Foundation for the Blind. It provides direct access to a New York State database of organizations and services for people who are blind or visually impaired as well as their family members, counselors, and other professionals.

### **Commission for the Blind and Visually Handicapped**

The Commission for the Blind and Visually Handicapped is part of New York State's Office of Children and Family Affairs. The organization offers a wide range of rehabilitation services to children and adults.

### **Lighthouse International**

Lighthouse International has been in existence for more than 100 years and aims to be a worldwide leader in helping those that are blind or visually impaired overcome their challenges vision loss.

### **Helen Keller Services for the Blind**

The Helen Keller Services for the Blind has been in existence for more than 110 years and offers many services, such as classes and workshops on rehabilitation, summer camps for children, and a large-print and braille library.

### **Jewish Guild for the Blind**

The Jewish Guild for the Blind is a nonprofit and nonsectarian agency that offers a broad range of programs that address low vision, psychiatric and rehabilitative services, managed long-term care, residential services, and educational training programs for independent living.

### **Scholarships for the Blind and Visually Impaired**

The Jewish Guild for the Blind has compiled an extensive list of the various scholarship opportunities offered for blind and visually impaired students

### **SightCare**

SightCare is a program of the Jewish Guild for the Blind that focuses on providing information on vision loss, educating those with vision loss, and providing training for those who provide rehabilitation services to people with vision loss.

### **National Association for Parents of Children with Visual Impairments (NAPVI)**

The National Association for Parents of Children with Visual Impairments (NAPVI) is a non-profit organization dedicated to offering support to the parents of children who have visual impairments. NAPVI has many chapter groups across the nation, including one in Bronx, NY.

## **Assistive Technology & Products**

### **Technologies for the Visually Impaired (TVI)**

Technologies for the Visually Impaired offers many electronic devices for the blind and visually impaired. Products include reading machines/notetakers, braille embossers, various computer software products, and video magnifiers.

### **MaxiAids**

MaxiAids offers many gadgets to aid independent living. Some of their products for the blind and visually impaired include canes, talking products (watches, clocks, scales, and personal organizers), magnifiers, and assorted large print products.

### **CTech**

CTech offers many electronic devices for the blind and visually impaired. Products include large print and speech software for

computers, portable magnifiers, video magnifiers, scan and read devices, and braille displays.

### **American Printing House for the Blind**

The American Printing House for the Blind promotes the independence of blind and visually impaired individuals by offering specialized products and services needed for education and life.

## Schools

### **New York City Department of Education's Blind Student Assistance**

A New York City Department of Education program, called Education Vision Services, is available to blind and visually impaired students ages five to 21.

### **New York State School for the Blind**

The New York State School for the Blind, located in Western NY, provides programs and services at no cost to legally blind children between the ages of five and 21.

### **Lavelle School for the Blind**

The Lavelle School for the Blind, located in Bronx, NY, was founded more than 100 years ago and offers educational programs for blind students.

### **New York Institute for Special Education**

The New York Institute for Special Education, located in Bronx, NY, offers various programs for students with special needs, including one for blind and visually impaired children between the ages of five and 21.

## Camps

### ■ **For Cancer Survivors**

#### **Camp Adventure (American Cancer Society)**

Camp Adventure, which takes place in Eastern Long Island, NY, is a week-long, sleep-away camp for children with cancer and their siblings, ages six to 18.

#### **Camp Good Days**

Camp Good Days, with various locations in Upstate NY, offers many different programs for survivors of cancer.

#### **Happiness is Camping**

Happiness is Camping, located in the Bronx, offers many summer camp sessions for children with cancer between the ages of six and 14.

#### **Camp Rising Sun**

Camp Rising Sun, located in Colebrook, CT, offers a week-long camp for children with cancer between the ages of six and 18.

### ■ **For the Blind and Visually Impaired**

#### **Camp Helen Keller (Helen Keller Services for the Blind)**

Camp Helen Keller is a six-week, summer day camp for blind or visually impaired children, ages four to 15.

#### **Camp Wanaqua (New York Institute or Special Education)**

Camp Wanaqua, located in New York City, is a summer camp for blind and visually impaired children, ages six to 13.

## Libraries, Art & Theater

### ■ **Libraries**

#### **National Library Service for the Blind and Visually Handicapped**

The National Library Service for the Blind and Visually Handicapped allows people to search for local libraries for the blind and visually impaired.

#### **Andrew Heiskell Braille and Talking Book Library**

The Andrew Heiskell Braille and Talking Book Library is a New York City public library for the blind and visually impaired.

## New York State Talking Book and Braille Library

The New York State Talking Book and Braille Library, located in Albany, NY, lends braille and recorded books to residents in Upstate New York.

### ■ Art

#### Art Beyond Sight

Art Beyond Sight provides information on art and museum education for the blind and visually impaired.

### ■ Theater

#### Theater by the Blind

Theater by the Blind is a critically acclaimed company made of both visually impaired and sighted individuals.

#### Recordings for the Blind and Dyslexic

Recordings for the Blind and Dyslexic offers many digitally recorded books for the blind. There are many national branches, including one in New York City.

## Sports

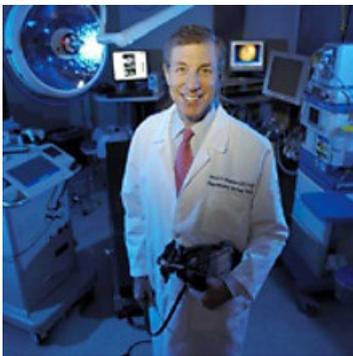
#### Unites States Association for Blind Athletes

The United States Association for Blind Athletes aims to increase athletic opportunities for blind and visually impaired individuals.

#### New York Association for Blind Athletes

The New York Association for Blind Athletes provides athletic opportunities and support for blind and visually impaired athletes in New York State.

## Building on a Legacy of Innovation & Collaboration: Better Treatments for Retinoblastoma



David Abramson is shown surrounded by the state-of-the-art technology he uses to treat children with retinoblastoma.

Less than 100 years ago, a diagnosis of retinoblastoma, a rare cancer affecting the retinas of young children, was a death sentence. It wasn't until the 1930s that doctors at Memorial Hospital for Cancer and Allied Diseases helped to establish some of the first retinoblastoma treatment successes. Now, more than 70 years later, the evolution of those early advances continues at Memorial Sloan-Kettering Cancer Center under the guidance of David H. Abramson, Chief of the Ophthalmic Oncology Service.

Each year in the United States, there are approximately 350 diagnoses of retinoblastoma — the most common eye cancer in children. For 90 percent of retinoblastoma cases, the affected child is the first in the family to have the disease, which, in these instances, is caused by a randomly occurring genetic mutation in chromosome 13. For the remaining ten percent, a mutation in the same gene is inherited (meaning that each child of a parent with retinoblastoma has about a 50 percent chance of inheriting the disease).

In the 1930s, a surgeon at Memorial Hospital named Hayes Martin teamed with an ophthalmologist named Algernon Reese to experiment with new treatment techniques.

Enucleation, the surgical removal of the affected eye, was then and remains now the primary treatment option for retinoblastoma, but Dr. Martin and Dr. Reese were able to save some children's eyes using radiation therapy. "This was a revolutionary concept then," said Dr. Abramson. "Before this, all of these children would have died." (With treatment, today more than 95 percent of children survive.)

Dr. Reese moved to Columbia Presbyterian Medical Center, where he trained and was succeeded by a young ophthalmologist named Robert Ellsworth. It was at Columbia, in the mid-1970s, that Dr. Abramson began to work with Dr. Ellsworth. The partnership would last for the next 20 years, during which they moved their eye cancer practice to New York Hospital.

In 2003, Dr. Abramson — who treats all cancers on, in, and around the eye — moved his practice to Memorial Sloan-Kettering Cancer Center, completing the circle that was begun some 30 years earlier. "At this point in my career," Dr. Abramson explained, "I felt that to make the next big advances in our field would require an immersion in the cancer world. I believed that we could take our

patients to the next level of treatment success.”

At Memorial Sloan-Kettering Cancer Center, Dr. Abramson and his team have helped to advance the use of cutting-edge vision-saving techniques, including radioactive plaques (inserting radioactive discs directly into the affected eye), laser therapy, cryotherapy (freezing smaller tumors), and chemoreduction (shrinking tumors with chemotherapy). Each patient is seen in a state-of-the-art suite of examination and treatment rooms dedicated to retinoblastoma. “There is literally no other space like it in the world,” said Dr. Abramson.

Most recently, working in collaboration with Zev Rosenwaks from Weill Cornell Medical Center, Dr. Abramson and his team used a technique known as preimplantation genetic testing in families at risk for having children with inherited retinoblastoma. After fertilizing 20 embryos from one couple using standard *in vitro* fertilization techniques, doctors tested each embryo for the mutation. Five of the embryos that were found to be free of the mutation were implanted in the mother’s womb, resulting in the successful birth of a single, retinoblastoma-free child. The team has since repeated this success.

“The last 100 years have been a wonderful story of retinoblastoma treatment evolution,” said Dr. Abramson, referring to the work that began with Drs. Martin and Reese. “But in the next ten years, there will be a revolution. These children will live in an entirely new world of hope.”

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