



Rhabdomyosarcoma

What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide to make new cells, and die in an orderly way. During the early years of a person's life, normal cells divide faster to allow the person to grow. Once the person becomes an adult, most cells divide only to replace worn-out or dying cells or to repair injuries.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells continue to grow and form new, abnormal cells. In most cases, the cancer cells form a tumor. Cancer cells can also invade (grow into) other tissues, something that normal cells can't do. Growing out of control and invading other tissues are what makes a cell a cancer cell.

Cells become cancer cells because of damage to DNA. DNA is in every cell and directs all its actions. In a normal cell, when DNA is damaged the cell either repairs the damage or the cell dies. In cancer cells, the damaged DNA is not repaired, but the cell doesn't die like it should. Instead, this cell goes on making new cells that the body does not need. These new cells will all have the same damaged DNA as the first abnormal cell does.

People can inherit damaged DNA, but often the DNA damage is caused by mistakes that happen while the normal cell is reproducing or by something in our environment. In adults, sometimes the cause of the DNA damage is something obvious, like cigarette smoking. But often no clear cause is found.

Cancer cells often travel to other parts of the body, where they begin to grow and form new tumors. This process is called *metastasis*.

Different types of cancer can behave very differently. They grow at different rates and respond to different treatments. That is why people with cancer need treatment that is aimed at their particular kind of cancer.

Not all tumors are cancerous. Tumors that aren't cancer are called *benign*. Benign tumors can cause problems – they can grow very large and press on healthy organs and tissues. But they can't grow into (invade) other tissues. Because they can't invade, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

What are the differences between cancers in adults and children?

Cancers that develop in children are often different from the types that develop in adults. Childhood cancers are often the result of DNA changes in cells that take place very early in life, sometimes even before birth. Unlike many cancers in adults, childhood cancers are not strongly linked to lifestyle or environmental risk factors.

There are exceptions, but childhood cancers tend to respond better to treatments such as chemotherapy. Children's bodies also tend to tolerate chemotherapy better than adults' bodies do. But cancer treatments such as chemotherapy and radiation therapy can have long-term side effects, so children who have had cancer need careful attention for the rest of their lives.

Since the 1960s, most children and teens with cancer have been treated at specialized centers designed for them. These centers offer the advantage of being treated by a team of specialists who know the differences between adult and childhood cancers, as well as the unique needs of children with cancer and their families. This team usually includes pediatric oncologists (childhood cancer doctors), surgeons, radiation oncologists, pathologists, pediatric oncology nurses, and nurse practitioners.

These centers also have psychologists, social workers, child life specialists, nutritionists, rehabilitation and physical therapists, and educators who can support and educate the entire family.

Most children with cancer in the United States are treated at a center that is a member of the Children's Oncology Group (COG). All of these centers are associated with a university or children's hospital. As we have learned more about treating childhood cancer, it has become even more important that treatment be given by experts in this area.

When a child or teen is diagnosed with cancer, it affects every family member and nearly every aspect of the family's life. You can read more about coping with these changes in our document *Children Diagnosed With Cancer: Dealing With Diagnosis*.

What is rhabdomyosarcoma?

Sarcomas are cancers that develop from connective tissues in the body, such as muscles, fat, bones, the linings of joints, or blood vessels. There are many types of sarcomas.

Rhabdomyosarcoma (RMS) is a cancer made up of cells that normally develop into skeletal muscles. The body has 3 main types of muscles.

- **Skeletal** (voluntary) muscles are muscles that we control to move parts of our body.
- **Smooth** muscle is the main type of muscle in internal organs (except for the heart). For example, smooth muscles in the stomach and intestines push food along as it is digested. We do not control this movement.
- **Cardiac** muscle is the main muscle type in the heart.

About 7 weeks into the development of an embryo, cells called *rhabdomyoblasts* (which will eventually form skeletal muscles) begin to form. These are the cells that can develop into RMS. Because this is a cancer of embryonal cells, it is much more common in children, although it does sometimes occur in adults.

We might think of our skeletal muscles as being mainly in our arms and legs, but these skeletal muscle cancers can start nearly anywhere in the body, even in some parts of the body that don't normally have skeletal muscle.

Common sites of RMS include:

- Head and neck (such as near the eye, inside the nasal sinuses or throat, or near the spine in the neck)
- Urinary and reproductive organs (bladder, prostate gland, or any of the female organs)
- Arms and legs
- Trunk (chest and abdomen)

Types of rhabdomyosarcoma

There are 2 main types of RMS, along with some less common types.

Embryonal rhabdomyosarcoma

Embryonal rhabdomyosarcoma (ERMS) usually affects children in their first 5 years of life, but it is the most common type of RMS at all ages.

The cells of ERMS look like the developing muscle cells of a 6- to 8-week-old embryo. ERMS tends to occur in the head and neck area, bladder, vagina, or in or around the prostate and testicles.

Two subtypes of ERMS, botryoid and spindle cell rhabdomyosarcomas, tend to have a better prognosis (outlook) than the more common conventional form of ERMS.

Alveolar rhabdomyosarcoma

Alveolar rhabdomyosarcoma (ARMS) typically affects all age groups equally. It makes up a larger portion of RMS in older children and teens than in younger children (because ERMS is less common at older ages).

ARMS most often occurs in large muscles of the trunk, arms, and legs. The cells of ARMS look like the normal muscle cells seen in a 10-week-old fetus.

ARMS tends to grow faster than ERMS and usually requires more intense treatment.

Anaplastic rhabdomyosarcoma and undifferentiated sarcoma

Anaplastic rhabdomyosarcoma (formerly called *pleomorphic rhabdomyosarcoma*) is an uncommon type that occurs in adults but is very rare in children.

Some doctors also group undifferentiated sarcomas with the rhabdomyosarcomas. Using lab tests, doctors can tell that these cancers are sarcomas, but the cells don't have any features that help classify them further.

Both of these uncommon cancers tend to grow quickly and usually require intensive treatment.

Rhabdomyosarcoma in adults

Most rhabdomyosarcomas develop in children, but they can also occur in adults. Adults are more likely to have faster-growing types of RMS and to have them in parts of the body that are harder to treat. Because of this, RMS in adults is often harder to treat effectively.

This document focuses on RMS in children, but most of the information here (including much of the treatment information) applies to RMS in adults as well.

What are the key statistics about rhabdomyosarcoma?

About 3% of all childhood cancers are rhabdomyosarcoma (RMS). About 350 new cases of RMS occur each year in the United States. The number of new cases has not changed much over the past few decades.

Most rhabdomyosarcomas are diagnosed in children and teens, with more than half of them in children younger than 10 years old. These tumors are usually embryonal rhabdomyosarcomas (ERMS) and tend to develop in the head and neck area or in the genital and urinary tracts. Alveolar rhabdomyosarcoma (ARMS) affects all age groups and is found more often in the arms, legs, or trunk.

RMS is slightly more common in boys than in girls. No particular race or ethnic group seems to have an unusually high rate of RMS.

The prognosis (outlook) for people with RMS depends on many factors, including the type of RMS, the location and size of the tumor, the results of surgery, and whether the cancer has metastasized (spread). Children aged 1 to 9 tend to have a better outlook than infants or older children or adults. Statistics related to survival are discussed in the section “Survival rates for rhabdomyosarcoma by risk group.”

What are the risk factors for rhabdomyosarcoma?

A risk factor is anything that affects the chance of having a disease such as cancer. Different cancers have different risk factors.

Lifestyle-related risk factors such as body weight, physical activity, diet, and tobacco use play a major role in many adult cancers. But these factors usually take many years to influence cancer risk, and they are not thought to play much of a role in childhood cancers, including rhabdomyosarcoma (RMS).

Age and gender

RMS is most common in children younger than 10, but it can also develop in teens and adults. It is slightly more common in boys than in girls.

Inherited conditions

Some people have a tendency to develop certain types of cancer because they have inherited changes in their DNA from their parents. Some rare inherited conditions increase the risk of RMS (and usually some other tumors as well).

- Members of families with **Li-Fraumeni syndrome** are more likely to develop sarcomas (including RMS), breast cancer, leukemia, and some other cancers.
- Children with **Beckwith-Wiedemann syndrome** have a high risk of developing Wilms tumor, a type of kidney cancer, but they are also more likely to develop RMS and some other types of childhood cancer.
- **Neurofibromatosis type 1**, also known as *von Recklinghausen disease*, usually causes multiple nerve tumors (especially in nerves of the skin), but it also increases the risk of RMS.

- **Costello syndrome** is very rare. Children with this syndrome have high birth weights but then fail to grow well and are short. They also tend to have a large head. They are prone to develop RMS as well as some other tumors.
- **Noonan syndrome** is a condition in which children tend to be short, have heart defects, and can be slower than typical children in developing physical skills and learning things. They are also at higher risk for RMS.

These conditions are rare and account for only a small fraction of RMS cases. But they suggest that the key to understanding RMS might come from studying genes and how they work in very early life to control cell growth and development.

Exposures before birth

Some studies have suggested that being exposed to x-rays before birth might be linked with an increased risk of RMS in young children. Parental use of drugs such as marijuana and cocaine has been suggested as a possible risk factor as well. But the studies that have found these links have been small, and more research is needed to see if there is a true link among these factors and RMS.

Do we know what causes rhabdomyosarcoma?

Researchers do not know what causes most cases of rhabdomyosarcoma (RMS), but they are learning how normal cells become cancerous because of certain changes in their DNA. DNA is the chemical in each of our cells that makes up our genes – the instructions for how our cells function. It is packaged in chromosomes (long strands of DNA in each cell). We normally have 23 pairs of chromosomes in each cell (one set of chromosomes comes from each parent). We usually look like our parents because they are the source of our DNA. But DNA affects more than how we look.

Some genes control when our cells grow, divide into new cells, and die. Genes that help cells grow, divide, or stay alive are called *oncogenes*. Others that slow down cell division or make cells die at the right time are called *tumor suppressor genes*. Cancers can be caused by DNA changes that turn on oncogenes or turn off tumor suppressor genes.

For example, people with Li-Fraumeni syndrome have changes in the *TP53* tumor suppressor gene that cause it to make a defective p53 protein. The p53 protein normally causes cells with DNA damage to either pause and repair that damage or, if repair is not possible, to self-destruct. When p53 is not working, cells with DNA damage keep dividing, which can lead to further defects in other genes that control cell growth and development. This can lead to cancer.

Certain genes in a cell can be turned on when bits of DNA are switched from one chromosome to another. This type of change, called a *translocation*, can happen when a cell is dividing into 2 new cells. This seems to be the cause of most cases of alveolar

rhabdomyosarcoma (ARMS). In these cancers, a small piece of chromosome 2 (or, less often, chromosome 1) ends up on chromosome 13. This moves a gene called *PAX3* (or *PAX7* if it's chromosome 1) right next to a gene called *FOXO1*. The *PAX* genes play an important role in cell growth while an embryo's muscle tissue is being formed, but these genes usually shut down once they're no longer needed. The normal function of the *FOXO1* gene is to activate other genes. Moving them together probably activates the *PAX* genes, which may be what leads to the tumor forming.

Research suggests that embryonal rhabdomyosarcoma (ERMS) develops in a different way. Cells of this tumor have lost a small piece of chromosome 11 that came from the mother, and it has been replaced by a second copy of that part of the chromosome from the father. This seems to make the *IGF2* gene on chromosome 11 overactive. The *IGF2* gene codes for a protein that can make these tumor cells grow. Other gene changes are probably important in these tumors as well.

Changes in several different genes are usually needed for normal cells to become cancer cells. Scientists have found some other gene changes that set some RMS cells apart from normal cells, but there are likely still others that haven't been found yet.

Researchers now understand many of the gene changes that can lead to RMS, but it's still not clear what causes these changes. Some gene changes can be inherited. Others might just be a random event that sometimes happens inside a cell, without having an outside cause. There are no known lifestyle-related or environmental causes of RMS, so it's important to know that there is nothing children with RMS or their parents could have done to prevent these cancers.

Can rhabdomyosarcoma be prevented?

The risk of many adult cancers can be reduced with certain lifestyle changes (such as staying at a healthy weight or quitting smoking), but at this time there are no known ways to prevent most cancers in children.

The only known risk factors for rhabdomyosarcoma (RMS) – age, gender, and certain inherited conditions – can't be changed. There are no proven lifestyle-related or environmental causes of RMS, so at this time there is no way to protect against these cancers.

Even though we don't know how to prevent it, most children with RMS can be treated successfully.

Can rhabdomyosarcoma be found early?

At this time, there are no widely recommended screening tests for rhabdomyosarcoma (RMS). (Screening is testing for a disease such as cancer in people who don't have any symptoms.)

Still, RMS often causes symptoms that allow it to be found before it has spread to other parts of the body. For example, small tumors that start in the muscles behind the eye often make the eye bulge. Tumors in the nasal cavity often cause nasal congestion, nosebleeds, or bloody mucus. When small lumps form near the surface of the body, children or their parents often see or feel them.

Many cases of RMS start in the bladder or other parts of the urinary tract and can cause trouble emptying the bladder or blood in the urine or in diapers. Tumors starting around the testicles in young boys can cause painless swelling that is often noticed early by a parent. In girls with RMS of the vagina, the tumor might cause bleeding or a mucus-like discharge from the vagina.

It can be harder to recognize tumors in the arms, legs, and trunks of older children because they often have pain or bumps from sports or play injuries.

There are many other causes of the symptoms above, and most of them are not serious, but it is important to have them checked by a doctor. This includes having your child's doctor check out any pain, swelling, or lumps that grow quickly or don't go away after a week or so.

About 1 in 3 of these cancers is found early enough so that all of the visible cancer can be removed completely by surgery. But even when this happens, very small tumors (which cannot be seen, felt, or detected by imaging tests) could already have spread to other parts of the body, which is why other treatments are needed as well.

Families known to carry inherited conditions that raise the risk of RMS (listed in "What are the risk factors for rhabdomyosarcoma?") or that have several family members with cancer (particularly childhood cancers) should talk with their doctors about the possible need for more frequent checkups. It is not common for RMS to run in families, but close attention to possible early signs of cancer might help find it early, when treatment is most likely to be successful.

Signs and symptoms of rhabdomyosarcoma

Rhabdomyosarcoma (RMS) can start nearly anywhere in the body, so there are no symptoms that show up in all cases. The symptoms of RMS depend on where the tumor is, how large it is, and if it has spread to other parts of the body.

- When the tumor is in the neck, chest, back, limbs, or groin (including the testicles), the first sign might be a lump or swelling. Sometimes it can cause pain, redness, or other problems.
- Tumors around the eye can cause the eye to bulge out or the child to appear to be cross-eyed. Vision might be affected as well.
- Tumors in the ear or nasal sinuses can cause an earache, headache, or sinus congestion.

- Tumors in the bladder or prostate can lead to blood in the urine, while a tumor in the vagina can cause vaginal bleeding. These tumors might grow big enough to make it hard or painful to urinate or have bowel movements.
- Tumors in the abdomen or pelvis can cause vomiting, abdominal pain, or constipation.
- RMS rarely develops in the bile ducts (small tubes leading from the liver to the intestines), but when it does it can cause yellowing of the eyes or skin (jaundice).
- If RMS becomes more advanced, it can cause symptoms such as lumps under the skin (often in the neck, under the arm, or in the groin), bone pain, constant cough, weakness, or weight loss.

One or more of these symptoms usually leads parents to bring a child to the doctor. Many of these signs and symptoms are more likely to be caused by something other than RMS. For example, children and teens can have bumps or pain from play or sports injuries. Still, if your child has any of these symptoms and they don't go away within a week or so, check with your doctor so that the cause can be found and treated, if needed.

How is rhabdomyosarcoma diagnosed?

Certain signs and symptoms might suggest that a person has rhabdomyosarcoma (RMS), but tests are needed to find out for sure.

Medical history and physical exam

If your child has symptoms that could be from RMS (or another type of tumor), the doctor will want to get a complete medical history to find out more about the symptoms and how long your child has had them. The doctor will also examine your child to look for possible signs of RMS or other health problems. For example, the doctor might be able to see or feel an abnormal lump or swelling.

If the doctor suspects your child might have RMS (or another type of tumor), tests will be needed to find out. These might include imaging tests, biopsies, and/or lab tests.

Imaging tests

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

- To help find out if a suspicious area might be cancer
- To determine the extent of a tumor or learn how far a cancer has spread

- To help determine if treatment is working

People who have or may have RMS will get one or more of these tests.

Plain x-rays

X-rays are sometimes used to look for tumors, but their use is limited mainly to looking at bones because they don't show much detail in internal organs. A chest x-ray is sometimes done to look for cancer that might have spread to the lungs, although it isn't needed if a chest CT scan is being done.

Computed tomography (CT) scan

The CT scan uses x-rays to make detailed cross-sectional images of parts of the body, including soft tissues such as muscles. Instead of taking one picture, like a regular x-ray, a CT scanner takes many pictures as it rotates around your child while he or she lies on a table. A computer then combines these pictures into images of slices of the part of the body being studied.

This test can often show a tumor in detail, including how large it is and if it has grown into nearby structures. It can also be used to look at nearby lymph nodes, as well as the lungs or other areas of the body where the cancer might have spread.

Before the scan, your child may be asked to drink a contrast solution and/or get an intravenous (IV) injection of a contrast dye that will help better outline abnormal areas. Your child may need an IV line for the contrast dye. The dye can cause some flushing (a feeling of warmth, especially in the face). Some people are allergic and get hives. Rarely, more serious reactions like trouble breathing or low blood pressure can occur. Be sure to tell the doctor if your child has any allergies (especially to iodine or shellfish) or has ever had a reaction to any contrast material used for x-rays.

CT scans take longer than regular x-rays. A CT scanner has been described as a large donut, with a narrow table that slides in and out of the middle opening. Your child will need to lie still on the table while the scan is being done. Younger children may be given medicine to help keep them calm or even asleep during the test.

Magnetic resonance imaging (MRI) scan

Like CT scans, MRI scans give detailed images of soft tissues in the body. But MRI scans use radio waves and strong magnets to create the images instead of x-rays. A contrast material called *gadolinium* may be injected into a vein before the scan to help show details better. This contrast material usually does not cause allergic reactions.

This test might be used instead of a CT scan to look at the tumor and the tissues around it. MRI is especially useful if the tumor is in certain parts of the body, such as the head and

neck, an arm or leg, or the pelvis. MRI scans can help determine the exact extent of a tumor, because they can show the muscle, fat, and connective tissue around the tumor in great detail. This is important when planning surgery or radiation therapy. MRI is also very useful if your child's doctor is concerned about possible spread to the spinal cord or brain.

MRI scans take longer than CT scans – often up to an hour. Your child may have to lie on a table that slides inside a narrow tube, which is confining and can be distressing. The test also requires a person to stay still for several minutes at a time. Newer, more open MRI machines, which are less confining, might be an option, but the test still requires staying still for long periods of time. The MRI machine also makes loud buzzing and clicking noises that can be disturbing. Sometimes, younger children are given medicine to help keep them calm or even asleep during the test.

Bone scan

A bone scan can help show if a cancer has spread to the bones, and is often part of the workup for anyone with RMS. This test is useful because it provides a picture of the entire skeleton at once.

For this test, a small amount of low-level radioactive material is injected into a vein (IV). The amount of radioactivity used is very low and will pass out of the body within a day or so. Over a couple of hours, the substance settles in abnormal areas of bone throughout the body. Your child then lies on a table for about 30 minutes while a special camera detects the radioactivity and creates a picture of the skeleton. Younger children can be given medicine to help keep them calm or even asleep during the test.

Areas of active bone changes attract the radioactivity and show up as “hot spots” on the scan. These areas may suggest cancer in an area, but other bone diseases can also cause the same pattern, so other tests such as plain x-rays or MRI scans, or even a bone biopsy might be needed.

Positron emission tomography (PET) scan

For a PET scan, a radioactive substance (usually a type of sugar related to glucose, known as *FDG*) is injected into the blood. The amount of radioactivity used is very low and will pass out of the body in a day or so. Because cancer cells in the body are growing quickly, they will absorb large amounts of the sugar.

After about an hour, your child will lie on a table in the PET scanner for about 30 minutes while a special camera creates a picture of areas of radioactivity in the body. The picture is not detailed like a CT or MRI scan, but it provides helpful information about the whole body.

PET scans are not used routinely to help diagnose RMS, but they can sometimes be helpful in finding out if suspicious areas seen on other imaging tests (such as bone scans or CT

scans) are tumors. PET scans can also be repeated during treatment to monitor the cancer over time.

Some machines can do a PET and CT scan at the same time (PET/CT scan). This lets the doctor compare areas of higher radioactivity on the PET scan with the more detailed appearance of that area on the CT scan.

Ultrasound

Ultrasound uses sound waves and their echoes to make a picture of internal organs or tumors. For this test, a small, microphone-like instrument called a *transducer* is moved around on the skin (which is first lubricated with gel). It gives off sound waves and picks up the echoes as they bounce off the organs. The echoes are converted by a computer into an image on a screen.

Ultrasound can be used to see if tumors in the pelvis (such as prostate or bladder tumors) are growing or shrinking over time. (This test can't be used to look at tumors in the chest because the ribs block the sound waves.)

This is an easy test to have, and it uses no radiation. Your child simply lies on a table, and a doctor or technician moves the transducer over the part of the body being looked at.

To learn more about these and other imaging tests, see our document *Imaging (Radiology) Tests*.

Biopsy

The results of imaging tests might strongly suggest that someone has RMS, but a biopsy (removing some of the tumor for viewing under a microscope and other lab testing) is the only way to be certain. Usually several different kinds of lab tests are done on the biopsy sample to sort out what kind of tumor it is.

Biopsies can be done in several ways. The approach used depends on where the tumor is, the age of the patient, and the expertise and experience of the doctor doing the biopsy.

Surgical biopsy

The most common biopsy approach is to remove a small piece of tumor during surgery while the patient is under general anesthesia (asleep). In some cases, nearby lymph nodes are also removed to see if the tumor has spread to them. The samples are then sent to a lab and tested.

Needle biopsies

If for some reason a surgical biopsy can't be done, a less invasive biopsy using a thin, hollow needle may be done. There are 2 kinds of needle biopsies, each of which has pros and cons.

Core needle biopsy: For a core needle biopsy, the doctor inserts a hollow needle into the tumor to withdraw a piece of it (known as a *core sample*). If the tumor is just under the skin, the doctor can guide the needle into the tumor by touch. But if the tumor is deep inside the body, imaging tests such as ultrasound or CT scans might be needed to help guide the needle into place. The removed core sample is then sent to the lab for testing.

The main advantage of a core needle biopsy is that it does not require surgery, so there is no large incision. Depending on where the tumor is, adults and older children might not need general anesthesia (where they are asleep for the biopsy), but some younger children might. On the other hand, the specimen is smaller than with a surgical biopsy, and if the needle isn't aimed correctly, it might miss the cancer. If the specimen is not a good sample of the tumor, another biopsy will be needed.

Fine needle aspiration (FNA) biopsy: For this technique, the doctor uses a very thin, hollow needle attached to a syringe to withdraw (aspirate) a small tumor sample. An FNA biopsy is best suited for tumors that can be reached easily (such as those just under the skin), although it can also be used for tumors deeper in the body.

The downside of FNA is that the sample is very, very small. The pathologist must be experienced with this technique and be able to decide which lab tests will be most helpful on a very small sample. In cancer centers that have the experience to extract the most information from very small amounts of tissue, FNA can be a valuable – though certainly not foolproof – way to diagnose RMS, but it is not usually the preferred biopsy technique.

See *Testing Biopsy and Cytology Specimens for Cancer* to learn more about different types of biopsies, how the tissue is used in the lab for disease diagnosis, and what the results can tell you.

Bone marrow aspiration and biopsy

These tests aren't used to diagnose RMS, but they are often done after the diagnosis to find out if the tumor has spread to the bone marrow (the soft inner parts of certain bones).

The 2 tests are usually done at the same time. The samples are usually taken from the back of both of the pelvic (hip) bones, but in some patients they may be taken from other bones.

These tests might be done during the surgery to treat the main tumor (while the child is still under anesthesia), or they might be done as a separate procedure.

If the bone marrow *aspiration* is being done as a separate procedure, the child lies on a table (on his or her side or belly). After cleaning the skin over the hip, the doctor numbs the area and the surface of the bone with local anesthetic, which can briefly sting or burn. In most cases, the child is also given other medicines to help them relax or even be asleep during the procedure. A thin, hollow needle is then inserted into the bone, and a syringe is used to suck out a small amount of liquid bone marrow.

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

The samples of bone and marrow are sent to the lab, where they are looked at and tested for cancer cells.

Lumbar puncture (spinal tap)

Lumbar puncture is not a common test for RMS, but it might be done for tumors in the head near the covering of the brain (the meninges). This test is used to look for cancer cells in the cerebrospinal fluid (CSF), which is the liquid that bathes the brain and spinal cord.

For this test, the doctor first numbs an area in the lower part of the back near the spine. The doctor may also recommend that the child be given something to make him or her sleep so the spinal tap can be done without difficulty or causing harm. A small, hollow needle is then inserted between the bones of the spine to withdraw some of the fluid, which is then sent to the lab for testing.

Lab tests on the biopsy samples

A doctor called a *pathologist* looks at the biopsy samples under a microscope to see if they contain cancer cells. If cancer is found, the next step is to figure out if it is RMS. In rare cases, the pathologist can see that the cancer cells have small muscle striations, which confirms that the cancer is RMS. But most often, other lab tests are needed to be sure.

The pathologist might use special stains on the samples to identify the type of tumor. The stains contain special proteins (antibodies) that attach to substances in RMS cells but not to other cancers. The stains produce a distinct color that can be seen under a microscope. This lets the pathologist know that the tumor is a rhabdomyosarcoma.

Sometimes the tumor will also be tested for gene or chromosome changes, such as those discussed in the section “Do we know what causes rhabdomyosarcoma?”

If a diagnosis of RMS is made, the pathologist will also use these tests to help determine which kind of RMS it is. This is important because it affects how the cancer is treated. For example, alveolar rhabdomyosarcoma (ARMS), which tends to be more aggressive, typically requires more intense treatment than embryonal rhabdomyosarcoma (ERMS).

Blood tests

No blood test can be used to diagnose RMS. But certain blood tests may be helpful once a diagnosis has been made.

A complete blood count (CBC) measures the levels of white blood cells, red blood cells, and platelets in the blood. If the CBC result is abnormal at the time of diagnosis it could mean the cancer has spread to the bone marrow, where these blood cells are made.

Standard blood tests are done often to check a child's general health both before treatment (especially before surgery) and during treatment (such as chemotherapy) to look for possible problems or side effects. These tests often include a CBC to monitor bone marrow function and blood chemistry tests to measure how well the liver and kidneys are working.

How is rhabdomyosarcoma staged?

Once rhabdomyosarcoma (RMS) has been diagnosed and the type of RMS identified, doctors need to assess, as accurately as possible, how much cancer there is and where it has spread. The answers to these questions are expressed in a standard kind of shorthand known as *staging*.

The prognosis (outlook) for people with cancer depends, to a large extent, on the cancer's stage. The stage of a cancer is one of the most important factors in choosing treatment.

Your child's doctors will use the results of the imaging tests and biopsies (described in "How is rhabdomyosarcoma diagnosed?") and the direct examination of the organs during surgery to learn how far the cancer has spread. If there is any doubt about the extent of the cancer, more biopsies may be done on tissues at the edge of the tumor, nearby lymph nodes, and any suspicious lumps in other parts of the body.

To stage RMS, doctors first determine 3 key pieces of information:

- The type of RMS (embryonal or alveolar)
- The TNM stage
- The clinical group

These factors are then used to divide patients into risk groups, which then are used to guide treatment.

RMS is staged differently from most other cancers, and it can be confusing. If you have any questions about the staging or risk groups, ask the doctor or nurse to explain it to you in a way you understand.

The TNM stage

The TNM stage is determined before treatment starts, and is based on 3 key pieces of information:

- **T:** The characteristics of the main **tumor** (location and size)

- **N:** Whether the cancer has spread to nearby lymph **nodes** (bean-sized collections of immune system cells)
- **M:** Whether it has **metastasized** (spread) to distant parts of the body

These factors are combined to determine an overall stage:

Stage 1

The tumor started in a favorable area:

- The orbit (area around the eye)
- The head and neck area, except for parameningeal sites (areas next to the membranes covering the brain, such as the nasal passages and nearby sinuses, middle ear, and the uppermost part of the throat)
- A genital or urinary site, except the bladder or prostate gland
- Bile ducts (tubes leading from the liver to the intestines)

The tumor can be any size. It may have grown into nearby areas and/or spread to nearby lymph nodes, but it has not spread to distant parts of the body.

Stage 2

The tumor started in an unfavorable site:

- The bladder or prostate
- An arm or leg
- A parameningeal site (an area next to the membranes covering the brain, such as the nasal passages and nearby sinuses, middle ear, or the uppermost part of the throat)
- Any other part of the body not mentioned in stage 1

The tumor is 5 cm (about 2 inches) or smaller across and there is no evidence that it has spread to nearby lymph nodes or distant parts of the body.

Stage 3

The tumor started in an unfavorable site:

- The bladder or prostate
- An arm or leg

- A parameningeal site (an area next to the membranes covering the brain, such as the nasal passages and nearby sinuses, middle ear, or the uppermost part of the throat)
- Any other part of the body not mentioned in stage 1

And one of the following applies:

- The tumor is 5 cm across or smaller but has spread to nearby lymph nodes
- The tumor is larger than 5 cm across and may or may not have spread to nearby lymph nodes

In either case, the cancer has not spread to distant parts of the body.

Stage 4

The tumor can have started anywhere in the body and can be of any size. It has spread to distant parts of the body such as the lungs, liver, bones, or bone marrow.

Clinical group

The clinical group is based on the extent of the disease and how completely it is removed during initial surgery. The groups are defined as follows.

Group I

This group includes children with localized RMS (the cancer has not spread to nearby lymph nodes or to distant sites in the body) that is removed completely by surgery.

About 10% to 15% of RMS patients are in group I.

Group II

This group includes children who have had all of the visible cancer removed by surgery, but cancer cells have been found at the edges (margins) of the removed specimen (meaning that there may have been a small amount of cancer left behind), in the nearby lymph nodes, or in both places. In all cases, as much of the cancer has been removed as possible.

About 20% of RMS patients are in group II.

Group III

These children have tumors that could not be removed completely. Some tumor was left behind that could be seen with the naked eye. The cancer may have spread to nearby lymph nodes, but there is no sign that it has spread to distant organs.

About 50% of RMS patients are in group III.

Group IV

At the time of diagnosis, these children have evidence of distant cancer spread to places such as the lungs, liver, bones, bone marrow, or to distant muscles or lymph nodes.

About 15% to 20% of RMS patients are in group IV.

Risk groups

Using the information about the type of RMS, the TNM stage, and the clinical group, doctors classify patients into 3 risk groups. Information about risk groups helps doctors decide how aggressive treatment should be.

The risk groups are based on what has been learned from previous research on patients' outcomes. The groups discussed here are based on the most current information, but these may change in the future as safer and more effective treatments are developed.

Low-risk group

About 1 in 3 children with RMS falls into the low-risk group. It includes:

- Children with TNM stage 1 *embryonal* rhabdomyosarcomas (ERMS) that fall into clinical groups I, II, or III
- Children with stage 2 or 3 ERMS who are in clinical groups I or II

Intermediate-risk group

About half of children of RMS fall into the intermediate-risk group. It includes:

- Children with stage 2 or 3 ERMS who are in clinical group III
- Children with *alveolar* rhabdomyosarcoma (ARMS) that has not spread to distant parts of the body (stage 1, 2, or 3)

High-risk group

This group includes:

- Children with widespread (stage 4) RMS (ERMS or ARMS)

Survival rates for rhabdomyosarcoma by risk group

Survival rates are often used by doctors as a standard way of discussing a person's prognosis (outlook). Some people may want to know the survival statistics for those in similar situations, while others may not find the numbers helpful, or may even not want to know them. If you would rather not read about the survival rates, skip to the next section, "How is rhabdomyosarcoma treated?"

When discussing cancer survival statistics, doctors often use a number called the *5-year survival rate*. The 5-year survival rate refers to the percentage of patients who live *at least 5 years* after their cancer is diagnosed. Of course, many people live much longer than 5 years (and many are cured).

To get 5-year survival rates, doctors have to look at people who were treated at least 5 years ago. Improvements in treatment since then might result in a better outlook for patients being diagnosed with rhabdomyosarcoma (RMS) now.

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they can't predict what will happen in any person's case. For a person with RMS, the risk group is important in estimating their outlook. But many other factors can also affect a person's outlook, such as their age, the location of the tumor, certain gene changes in the cancer cells, and how well the cancer responds to treatment.

Here are *general* survival statistics based on risk groups. These numbers come from large clinical trials treating children with RMS in the 1980s and 1990s.

Low-risk group

Overall, the 5-year survival rate for children in the low-risk group is over 90%. Most of these children will be cured.

Intermediate-risk group

For those in the intermediate-risk group, the 5-year survival rates range from about 60% to about 80%. The rate varies based on tumor location, stage, and the age of the child (children aged 1 to 9 tend to do better than older or younger children).

High-risk group

If the cancer has spread widely, the 5-year survival rate is generally around 20% to 40%. Again, it's important to note that other factors, such as the patient's age and the site and type of tumor will affect these numbers. For example, children with embryonal rhabdomyosarcoma (ERMS) and limited spread (to only 1 or 2 distant sites) have a higher 5-year survival rate. Also, children 1 to 9 years of age tend to have a better outlook than younger or older patients.

Even when taking risk groups and other factors into account, survival rates are at best rough estimates. Your child's doctor is your best source of information on this topic, as he or she knows your situation best.

How is rhabdomyosarcoma treated?

This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.

The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.

Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.

General approach to treatment

Once rhabdomyosarcoma has been found and staged, the cancer care team will talk with you about treatment options. It's important to be sure you understand your child's options as well as their possible side effects to help make the decision that's the best fit for your child. If there is anything you don't understand, ask to have it explained. You can find some good questions to ask in the section "What should you ask the doctor about rhabdomyosarcoma?"

The treatment and prognosis (outlook) for patients with RMS depend to a large extent on the type of RMS and on how much of it can be removed with surgery. This is why it's very important for patients to be diagnosed and treated by doctors who have experience with RMS. Children with RMS are best treated in a cancer center where there is experience and expertise in treating childhood cancers, such as in centers who are members of the Children's Oncology Group.

For children and teens, a team approach is recommended that includes specialists at a children's cancer, as well as the child's pediatrician. For adults with RMS, the treatment team typically includes specialists at a major cancer center, as well as the patient's primary care doctor. Doctors on the treatment team might include:

- An orthopedic surgeon (a surgeon who specializes in muscles and bones) who is experienced in treating RMS
- A medical or pediatric oncologist (a doctor who treats cancer with chemotherapy and other drugs)

- A radiation oncologist (a doctor who treats cancer with radiation therapy)
- A pathologist (a doctor specializing in lab tests to diagnose and classify diseases)
- A physiatrist (a doctor who directs a person's rehabilitation and physical therapy after treatment)

The team will also include other doctors, physician assistants (PAs), nurse practitioners (NPs), nurses, psychologists, social workers, physical therapists and other rehabilitation specialists, and other health professionals. Going through cancer treatment often means meeting lots of specialists and learning about parts of the medical system you probably haven't been exposed to before. For more information, see our document [*Children Diagnosed With Cancer: Understanding the Health Care System*](#).

Before treatment, the doctors and other members of the team will help you understand the tests that will need to be done. The team's social worker will also counsel you about the problems you and your child might have during and after treatments such as surgery, and might be able to help you find housing and financial aid if needed.

The types of treatment that can be used for RMS include:

- Surgery
- Chemotherapy
- Radiation therapy
- High-dose chemotherapy and stem cell transplant (very rarely)

All children and adults with RMS will be treated with surgery to remove the tumor if it can be done without causing major damage or disfigurement. If this isn't possible, chemotherapy and/or radiation therapy may be used first to try to shrink the tumor. If it shrinks enough, surgery can be done at this point. The goal of surgery is to remove the tumor completely, but this isn't always possible.

Whether the tumor appears to have been removed completely or not, all patients with RMS need chemotherapy. Without it, it's very likely that the cancer will come back in distant parts in the body because small amounts of cancer have almost always reached other parts of the body when the cancer is first found.

If cancer is left behind after surgery or if the cancer has some less favorable traits and it hasn't spread to distant sites (as is the case most of the time), radiation therapy will also be given.

All of these treatments can have side effects, but many of them can be made less troublesome. Your medical team will help you take care of the side effects and help you understand and deal with the medical problems, stress, and other issues related to treatment.

Because many of these things can be more complex for cancer in children, many people will be involved in your child's overall care. As a parent, taking care of a child with cancer can be a very big job. It's important to remember that you will have a lot of help. It's also important for you to know that the health care professionals who treat children with RMS are using the experience and knowledge gained from many decades of detailed scientific study of treating this disease.

The next few sections describe in more detail the types of treatments used for RMS.

Surgery for rhabdomyosarcoma

Surgery is an important part of treatment for most rhabdomyosarcomas. It includes:

- The biopsy to diagnose the cancer
- The surgical treatment to remove the tumor(s)

The biopsy is generally the first surgery done for RMS. How it is done, how long recovery takes, and how it affects later treatment depends on many factors. The type of biopsy used is based on imaging test results, the location and size of the tumor, the patient's age and health, and the expertise of the doctor. (For a description of biopsy types, see "How is rhabdomyosarcoma diagnosed?")

Unless it is clear that the cancer has spread to distant parts of the body, surgery is usually the first step in treating rhabdomyosarcoma (RMS). Complete resection (removal) of the main tumor, along with some surrounding normal tissue, is the goal whenever possible. If there are cancer cells at the edges (margins) of the removed specimen (meaning that some cancer cells may have been left behind), the surgeon may operate again to try to remove the remaining cancer.

In some cases, surgery may be done even if it is clear that all of the cancer can't be removed because it may help other treatments (chemotherapy and radiation) to work better.

During surgery, nearby lymph nodes are often biopsied to determine if the cancer has spread to these areas, especially if the main tumor is near the testicles in older boys or is on an arm or leg.

Some types of surgery might need to be done by special surgeons. For example, removing tumors in the head and neck area may require surgical teams with ENT (ear, nose, and throat) surgeons, plastic surgeons, maxillofacial surgeons, and neurosurgeons.

If a tumor is large or is in a spot where removing it completely would severely affect the child's appearance or cause other problems, then surgery may be delayed until after a few courses of chemotherapy and possibly radiation therapy to try to shrink it, or surgery may not be done at all.

What to expect with surgery

The type and extent of surgery can vary a great deal based on the location and size of the tumor. RMS can appear in many parts of the body, so it's not possible to describe here all of the different types of operations that might be done. Your child's surgical team will discuss the planned surgery with you, but make sure you ask questions if there are any parts of it that aren't clear to you.

If the diagnosis of RMS was not confirmed by a biopsy before the main operation, the surgeon may first take only a small sample of the tumor. The sample is checked right away to see if it is cancer or not. If it can be determined that it is cancer while your child is still on the operating table, the surgeon may try to remove the entire tumor and also remove some of the nearby lymph nodes to check for spread of the cancer. If the surgeon suspects the disease has spread to another part of the body, a piece of the possible metastatic tumor may be removed and checked as well.

A bone marrow aspiration and biopsy may also be done, and a central venous catheter (a thin tube) may be inserted into one of the large veins in the chest. One end of the catheter stays in the vein, while the other end lies just under or outside the skin. This will let the health care team give chemo and other drugs and to draw blood samples without having to stick needles into the veins each time. The catheter usually stays in place for several months, and can make having chemo less painful. If such a device is used in your child, the health care team will teach you how to care for it to reduce the risk of problems such as infections.

Possible risks and side effects

Short-term risks and side effects: Depending on where the tumor is, surgery for RMS can be a long and complex operation. Serious short-term side effects are not common, but they can include reactions to anesthesia, excess bleeding, blood clots, and infections. Pain is common after the operation, and the patient might need strong pain medicines for a while after surgery as the site heals.

Long-term side effects: The long-term side effects of surgery depend mainly on where the tumor is and what type of operation is done. Physical changes after surgery can range from little more than a scar to changes in appearance or in how some parts of the body function, which may require physical rehabilitation.

For more on surgery as a treatment for cancer, see our document *A Guide to Cancer Surgery*.

Chemotherapy for rhabdomyosarcoma

All patients with rhabdomyosarcoma (RMS) will get chemotherapy at some point. Even if it appears that the cancer was removed completely by surgery, without chemotherapy it is likely to come back.

Chemotherapy (chemo) is the use of drugs to treat cancer. Chemo is *systemic* therapy, meaning that the drugs enter the bloodstream and go throughout the body to destroy cancer cells. This makes chemo useful for killing RMS cells that have spread to other parts of the body, even if they can't be seen.

After surgery, any tiny deposits of RMS that remain can often be destroyed by chemo. If larger areas of tumor remain after surgery (or if surgery couldn't be done for some reason), chemo (along with radiation) can often shrink these areas. In some cases it may shrink the tumor enough that surgery can remove the remaining tumor completely.

Drugs used to treat rhabdomyosarcoma

A combination of chemo drugs is used to treat patients with RMS. The drugs used depend to some extent on which risk group the child is in (described in the section “How is rhabdomyosarcoma staged?”). Some drugs can be taken by mouth, but most are given IV (injected into a vein).

The main chemo drugs used to treat children in the low-risk group are vincristine and dactinomycin (also known as *actinomycin-D*). This combination is often referred to as VA. Sometimes cyclophosphamide is added as well. This 3-drug combination is referred to as VAC.

The VAC regimen is the most common combination used for the intermediate-risk group. Irinotecan or topotecan may be added as well. Other drugs used to treat RMS include ifosfamide, etoposide, and doxorubicin.

The same drugs are also used for children in the high-risk group (which includes children with metastatic disease), but these drugs have not been shown to be as successful in this group. New drugs and drug combinations are continually being studied by researchers. It is hoped that they will improve the survival rate in the high-risk group.

Doctors give chemo in cycles, which is usually treatment on 1 or 2 days in a row, followed by days off to give the body time to recover. For RMS, chemo is typically given once a week for the first few months, and then less often. The total length of treatment usually ranges from 6 months to a year.

For more information about any of the chemo drugs mentioned here, see our *Guide to Cancer Drugs* on our website.

Possible side effects

Chemo drugs attack cells that are dividing quickly, which is why they often work against cancer cells. But other cells in the body, such as those in the bone marrow (where new blood cells are made), the lining of the mouth and intestines, and the hair follicles, also divide quickly. These cells are also likely to be affected by chemo, which can lead to side effects.

Children tend to have less severe side effects from chemo than adults and often recover from side effects more quickly. This is why doctors can often give them higher doses of chemo to kill the tumor.

The side effects of chemo depend on the type of drugs, the doses, and how long they are taken. Possible side effects can include:

- Hair loss
- Mouth sores
- Loss of appetite
- Nausea and vomiting
- Diarrhea
- Increased chance of infections (from having too few white blood cells)
- Easy bruising or bleeding (from having too few blood platelets)
- Fatigue (from having too few red blood cells)

These side effects tend to go away once treatment is finished. There are often ways to lessen these side effects. For example, drugs can be given to help prevent or reduce nausea and vomiting. Be sure to ask your doctor or nurse about medicines to help reduce side effects, and report any side effects your child has so they can be managed effectively.

Along with the risks above, some chemo drugs can have specific side effects (although these are relatively uncommon). For example:

Cyclophosphamide and ifosfamide can damage the bladder, causing blood in the urine. The risk of this happening can be lowered by giving the drugs with plenty of fluids and with a drug called *mesna*, which helps protect the bladder. These drugs can also damage the ovaries or testicles, which might affect fertility (the ability to have children).

Vincristine can damage nerves. Some patients may notice tingling and numbness, particularly in the hands and feet. This often goes away or gets better once treatment is stopped, but it could last a long time in some people.

Recent studies have shown that children under the age of 3 years are more likely to have liver damage from chemotherapy. Doctors now use lower doses for any child younger than 3 years old.

Some chemo drugs can also increase the risk of developing a second type of cancer, usually a form of leukemia, years after the RMS is cured. But this is rare, and the importance of chemotherapy in treating RMS far outweighs this risk.

For more on some of these possible long-term side effects, including fertility issues and second cancers, see the section “Possible late and long-term side effects of treatments for rhabdomyosarcoma.”

For more on chemotherapy, see the Chemotherapy section of our website, or our document *A Guide to Chemotherapy*.

Radiation therapy for rhabdomyosarcoma

Radiation therapy uses high-energy radiation to kill cancer cells. It is often an effective way to kill cancer cells that can't be removed with surgery. When radiation therapy is used to help treat rhabdomyosarcoma (RMS), it is typically given along with chemotherapy.

Radiotherapy is most useful if some of the main tumor is still left after surgery (group II or III) or if removing the tumor completely would mean loss of an important organ, like the eye or bladder, or would be disfiguring. It is not usually needed for children with embryonal rhabdomyosarcoma (ERMS) that can be completely removed by surgery (group I).

Usually radiation therapy is given to any area of remaining disease after 6 to 12 weeks of chemotherapy. An exception is when a tumor near the meninges (linings of the brain) has grown into the skull bones, into the brain itself, or into the spinal cord. In these patients radiation therapy is started right away (along with chemotherapy).

Radiation isn't given to the whole body to treat metastases, but it can be given to certain areas of known disease to reduce any symptoms the cancer is causing.

This type of treatment is given by a doctor called a *radiation oncologist*. Before treatments start, the radiation team takes careful measurements with imaging tests such as MRI scans to determine the correct angles for aiming the beams and the proper dose of radiation.

Radiation is usually given daily (5 days a week) over many weeks. Each treatment is much like getting an x-ray, although the dose of radiation is much stronger. For each session, your child will lie on a special table while a machine delivers the radiation from a precise angle. The treatment is not painful.

Each session lasts about 15 to 30 minutes, with most of the time spent making sure the radiation is aimed correctly. The actual treatment time each day is much shorter. Some younger children may be given medicine before each treatment to make them sleep so they won't move during treatment.

Newer radiation techniques

Some newer techniques can help doctors aim the treatment at the tumor more accurately while reducing the radiation exposure to nearby healthy tissues. These techniques may help increase the success rate and reduce side effects. Most doctors now use these approaches when they are available.

Three-dimensional conformal radiation therapy (3D-CRT): 3D-CRT uses special computers to precisely map the location of the tumor. Depending on where the tumor is, your child may be fitted with a plastic mold resembling a body cast to keep him or her in the same position during each treatment so that the radiation can be aimed more accurately. Radiation beams are then shaped and aimed at the tumor from several directions. Each beam alone is fairly weak, which makes it less likely to damage normal body tissues, but the beams converge at the tumor to give a higher dose of radiation there.

Intensity-modulated radiation therapy (IMRT): IMRT is an advanced form of 3D therapy. Along with shaping the beams and aiming them at the tumor from several angles, the intensity (strength) of the beams is adjusted to limit the dose reaching the most sensitive normal tissues. This lets doctors deliver a higher dose to the cancer areas. Many major hospitals and cancer centers now use IMRT.

Brachytherapy (internal radiation therapy): Another approach is to insert a radioactive source into or near the tumor for a short time. The radiation travels only a short distance, so the tumor gets most of the radiation. This approach may be especially useful in treating some bladder, vaginal, and head and neck area tumors. Some early studies suggest that this may be a good way to preserve the function of these organs in many children.

Other newer techniques, such as stereotactic radiotherapy and proton beam radiotherapy, are discussed briefly in the section “What’s new in rhabdomyosarcoma research and treatment?”

Possible side effects

The side effects of radiation therapy depend on the dose of radiation and where it is aimed, as well as a child’s age. Some effects are likely to last a short time, while others might have a longer lasting impact.

Short-term side effects can include fatigue and increased numbers of infections. Effects on skin areas that receive radiation can range from hair loss and mild sunburn-like changes to more severe skin reactions. Radiation to the abdomen or pelvis can cause nausea, vomiting, and diarrhea. In some cases there may be damage to the bladder, which might cause urinary problems. Radiation to the head and neck can cause mouth sores and loss of appetite.

Small children’s brains are very sensitive to radiation, so doctors try to avoid using radiation to the head whenever possible. If it is needed, it is aimed very carefully to try to limit how much reaches the brain. Side effects of radiation therapy to the brain can include headaches and problems such as memory loss, personality changes, and trouble learning at school. These problems tend to become most serious 1 or 2 years after treatment.

Other long-term problems can include the formation of scar tissue and the slowing of bone growth in areas that get radiation. Depending on the child’s age and what parts of the body get the radiation, this could result in deformities or a failure to grow to full height. Radiation can also raise the risk of cancer many years later (see “Possible late and long-term side effects of treatments”).

To limit the risk of serious long-term effects from radiation, doctors use the lowest dose of radiation therapy that is still effective.

For more on radiation therapy, see our document *Understanding Radiation Therapy: A Guide for Patients and Families*.

High-dose chemotherapy and stem cell transplants for rhabdomyosarcoma

A stem cell transplant (sometimes referred to as a *bone marrow transplant*) makes it possible to use much higher doses of chemotherapy than would normally be possible. Chemotherapy drugs kill rapidly dividing normal cells (such as those in the bone marrow, where new blood cells are made) as well as cancer cells. Higher doses of these drugs might be more effective in treating some cancers, but they can't be given because the severe damage to the bone marrow would cause life-threatening shortages of blood cells.

A stem cell transplant gets around this problem by taking out and saving some of the patient's own blood-forming stem cells (either from the blood or bone marrow) before high-dose chemotherapy and then putting them back into the blood after chemotherapy is over. The stem cells then travel to the bone marrow, which lets the normal marrow regrow.

Stem cell transplants are used to treat some aggressive childhood cancers, but so far it is not clear if they can help rhabdomyosarcoma patients. Because of the severe side effects they can cause, most doctors recommend they be used only as part of a clinical trial.

For more on stem cell transplants, see our document *Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants)*.

Rhabdomyosarcoma that progresses or recurs after initial treatment

Rhabdomyosarcoma (RMS) that continues to grow during treatment or that comes back once treatment is finished is often hard to treat. The treatment options will depend on a number of factors, including where the cancer comes back, the type of tumor, and previous treatments used.

For tumors that recur in the same spot as the original tumor, surgery may be used if it can be done. If radiation therapy wasn't part of the initial treatment, it may be tried as well.

In rare cases, surgery may be used for cancers that recur at distant sites, such as if there is a small recurrence in a lung.

Most often, chemotherapy is the best option for distant spread. This might include some of the drugs listed in the "Chemotherapy for rhabdomyosarcoma" section, as well as newer

drugs being studied. Because these tumors are hard to treat, clinical trials of newer treatments may be a good option in many cases.

Clinical trials for rhabdomyosarcoma

You may have had to make a lot of decisions since you've been told your child has rhabdomyosarcoma (RMS). One of the most important decisions you will make is deciding which treatment is best. You might have heard about clinical trials being done for RMS. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. These studies are done to learn more about promising new treatments or procedures.

Clinical trials are one way to get state-of-the-art cancer treatment. Sometimes they may be the only way to get some newer treatments. They are also the best way for doctors to learn better ways to treat cancer. Still, they are not right for everyone.

If you would like to learn more about clinical trials that might be right for your child, start by asking your doctor if your clinic or hospital conducts clinical trials. Children's cancer centers often conduct many clinical trials at any one time, and in fact most children treated at these centers take part in a clinical trial as part of their treatment.

You can also call our clinical trials matching service for a list of studies that meet your child's needs. You can reach this service at 1-800-303-5691 or on our website at www.cancer.org/clinicaltrials. You can also get a list of current clinical trials by calling the National Cancer Institute (NCI) at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials website at www.cancer.gov/clinicaltrials.

People have to meet certain requirements to take part in any clinical trial. If your infant or young child does qualify for a clinical trial, it's up to you whether or not to enter (enroll) the child into it. Older children, who can understand more, usually must also agree to take part in the clinical trial before the parents' consent is accepted.

To learn more about clinical trials, see our document *Clinical Trials: What You Need to Know*.

Complementary and alternative therapies for rhabdomyosarcoma

You might hear about ways to treat rhabdomyosarcoma or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to social media groups and websites might offer ideas for what might help. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

What exactly are complementary and alternative therapies?

Not everyone uses these terms the same way, and they are used to refer to many different methods, so it can be confusing. We use *complementary* to refer to treatments that are used *along with* your regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

Complementary methods: Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help a person feel better. Some methods that are used along with regular treatment are: art therapy or play therapy to reduce stress; acupuncture to help relieve pain; or peppermint tea to relieve nausea. Some complementary methods are known to help, while others have not been tested. Some have been proven not to be helpful, and a few have even been found to be harmful.

Alternative treatments: Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may be dangerous, or have life-threatening side effects. But the biggest danger in most cases is that your child could lose the chance to be helped by standard medical treatment. Delaying or interrupting medical treatments might give the cancer more time to grow and make it less likely that treatment will help.

Finding out more

It's easy to see why parents who have children with cancer think about alternative methods. You want to do all you can to help fight the cancer, and the idea of a treatment with few or no side effects sounds great. Sometimes medical treatments like chemotherapy can be hard to take, or they may no longer be working. But the truth is that most alternative methods have not been tested and proven to work in treating cancer.

As you consider your child's options, here are 3 important steps you can take:

- Look for "red flags" that suggest fraud. Does the method promise to cure all or most cancers? Are you told not to use regular medical treatments? Is the treatment a "secret" that requires you to take your child to certain providers or to another country?
- Talk to your child's doctor or nurse about any method you are thinking about.
- Contact us at 1-800-227-2345 or read our document [Complementary and Alternative Methods and Cancer](#) to learn more about this topic. You can also find out about the specific methods you are looking at by calling us or visiting the [Complementary and Alternative Medicine](#) section of our website.

The choice is yours

You always have a say in how your child is treated. If you want to use a non-standard treatment, learn all you can about the method and talk to your child's doctor about it. With

good information and the support of your child's health care team, you may be able to safely use the methods that can help your child while avoiding those that could be harmful.

More treatment information for rhabdomyosarcoma

For more details on treatment options – including some that may not be addressed in this document – other good sources of information include the National Cancer Institute (NCI) and the Children's Oncology Group (COG).

The NCI, part of the US National Institutes of Health, provides treatment information by phone (1-800-4-CANCER) and on its website (www.cancer.gov). More detailed information intended for use by cancer care professionals is also available on www.cancer.gov.

The COG is the world's largest organization devoted to childhood cancer research. The COG website, www.childrensoncologygroup.org, provides information to help support children and their families from the time of diagnosis, through treatment, and beyond.

What should you ask your doctor about rhabdomyosarcoma?

It's important to have honest, open discussions with your cancer care team. They want to answer all of your questions, no matter how minor they might seem. For instance, consider asking these questions:

- What kind of rhabdomyosarcoma does my child have?
- Has the tumor spread beyond where it started?
- Do we need other tests before we can decide on treatment?
- Which risk group does the cancer fall into, and what does that mean?
- How much experience do you have treating this type of cancer?
- Will we need to see other doctors?
- What are our treatment options?
- Are there any clinical trials we might want to consider?
- What do you recommend and why?
- What are the risks and side effects to the suggested treatments?
- Which side effects start shortly after treatment and which ones might develop later on?

- Will treatment affect my child's ability to grow and develop?
- Could treatment affect my child's ability to have children later on?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How will treatment affect our daily lives (school, work, etc.)?
- Based on what you've learned about the cancer, what is the outlook for cure?
- What will we do if the treatment doesn't work or if the cancer comes back?
- What type of follow-up and rehab will be needed after treatment?

You might have other questions as well. For example, you might want to:

- Ask about getting a second opinion as to the best treatment option.
- Find out if the treatment schedule can be arranged so that your child will miss as little school as possible.
- Ask how to explain what is happening with your child so that other family members and friends can understand.
- Ask about support groups that might help you benefit from the experience of other families who have been through this.

Also keep in mind that doctors are not the only ones who can provide you with information. Other health care professionals, such as nurses and social workers, may have the answers to some of your questions. You can find out more about speaking with your health care team in our document [*Talking With Your Doctor*](#).

What happens during and after treatment for rhabdomyosarcoma?

During and after treatment for rhabdomyosarcoma (RMS), the main concerns for most families are the short- and long-term effects of the tumor and its treatment, and concerns about the tumor still being there or coming back.

It's certainly normal to want to put the tumor and its treatment behind you and to get back to a life that doesn't revolve around cancer. But it's important to realize that close follow-up care is a central part of this process that offers your child the best chance for recovery and long-term survival.

Doctor visits and tests

Your child will probably have to return to the doctor often during chemotherapy for lab tests to look for low blood counts that could lead to bleeding or serious infection. The doctor will also check for other side effects from treatment. Your child may need blood transfusions to treat low blood counts or antibiotics to treat an infection.

Usually chemotherapy and follow-up testing will be done in the pediatric cancer center, but if the center is far from your home, the specialists involved in your child's care can work with your local doctor to try to reduce your need to travel.

Once treatment is finished, the health care team will discuss a follow-up schedule with you, including which tests should be done and how often. For several years after treatment, it's very important for your child to have regular follow-up exams with the cancer care team. The doctors will continue to watch for signs of disease, as well as for short-term and long-term side effects of treatment. Doctor visits will be more frequent at first, but the time between visits may get longer as time goes on.

Checkups after treatment of RMS include careful physical exams, lab tests, and sometimes imaging tests such as computed tomography (CT), magnetic resonance imaging (MRI), or positron emission tomography (PET) scans. If the RMS comes back (recurs), it is usually within the first few years after treatment. As time goes by, the risk of recurrence goes down, although doctor visits are still important because some side effects of treatment might not show up until years later.

If the tumor comes back, or if it does not respond to treatment, your child's doctors will discuss with you the various treatment options available (as discussed in "Rhabdomyosarcoma that progresses or recurs after initial treatment").

Some side effects from the treatment of RMS might not show up until many years later, including effects on fertility and a risk of developing another type of cancer at a later time. It's important to talk with your child's doctors to understand what these risks are. (See the section "Possible late and long-term side effects of treatments for rhabdomyosarcoma" for more details.)

Social, emotional, and other issues in treating rhabdomyosarcoma

Social and emotional issues might come up both during and after treatment. Factors such as the person's age when diagnosed and the extent of treatment can play a role here.

Most often, rhabdomyosarcoma (RMS) develops during a very sensitive time in a young person's life. RMS and its treatment can have a profound effect on how a person looks and how they view themselves and their body. It can also affect how they do some everyday tasks, including certain school, work, or recreational activities. These effects are often

greatest during the first year of treatment, but they can last a long time in some people. It's important that the treating center assess the family situation as soon as possible, so that any areas of concern can be addressed.

Many experts recommend that school-aged patients attend school as much as possible. This can help them maintain a sense of daily routine and keep their friends informed about what is happening.

Friends can be a great source of support, but patients and parents should know that some people have misunderstandings and fears about cancer. Some cancer centers have a school re-entry program that can help in these situations. In this program, health educators visit the school and tell students about the diagnosis, treatment, and changes that the cancer patient may go through. They also answer any questions from teachers and classmates. (For more information, see our document *Children Diagnosed With Cancer: Returning to School*.)

Centers that treat many patients with RMS may have programs to introduce new patients to children or teens who have finished their treatment. This can give patients an idea of what to expect during and after treatment, which is very important. Seeing another patient with RMS doing well after treatment is often helpful. Support groups also might be helpful.

Parents and other family members can also be affected, both emotionally and in other ways. Some common family concerns during treatment include financial stresses, traveling to and staying near the cancer center, the possible loss of a job, and the need for home schooling. Social workers and other professionals at treatment centers can help families sort through these issues.

During treatment, patients and their families tend to focus on the daily aspects of getting through it and beating the cancer. But once treatment is finished, a number of emotional concerns can come up. Some of these might last a long time. They can include things like:

- Dealing with physical changes that can result from the treatment
- Worrying about the cancer returning or new health problems developing
- Feeling resentful for having had cancer or having to go through treatment when others do not
- Worrying about being treated differently or discriminated against (by friends, classmates, coworkers, employers, etc.)
- Being concerned about dating, marrying, and having a family later in life

No one chooses to have RMS, but for many children and teens, the experience can eventually be positive, helping to establish strong self-values. Others may have a harder time recovering, adjusting to life after cancer, and moving on. It is normal to have some anxiety or other emotional reactions after treatment, but feeling overly worried, depressed, or angry can

affect many parts of a young person's growth. It can get in the way of relationships, school, work, and other aspects of life.

With support from family, friends, other survivors, mental health professionals, and others, many people who have survived cancer can thrive in spite of the challenges they've had to face. If needed, doctors and other members of the health care team can recommend special support programs and services to help after cancer treatment.

Although the psychological impact of this disease on children and teens is most obvious, adults with this disease face many of the same challenges. They should also be encouraged to take advantage of the cancer center's physical therapy, occupational therapy, and counseling services.

Possible late and long-term side effects of treatments for rhabdomyosarcoma

More children and teens with rhabdomyosarcoma (RMS) are now surviving this cancer. Doctors have learned that the treatment might affect children's health later in life, so watching for health effects as they get older has become more of a concern in recent years.

It's important to discuss what these possible effects might be with your child's medical team before starting treatment. Doctors try to limit these potential side effects as much as possible when planning treatment.

The long-term effects of surgery depend a great deal on the location and extent of the tumor(s). Some operations leave few physical changes other than a scar, while more extensive operations can lead to changes in appearance or in how some parts of the body function, which might require physical rehabilitation afterward.

Some chemotherapy drugs can damage cells in the ovaries or testicles, which might affect a patient's ability to have children later on. For parents, it's important to discuss this with your child's health care team before treatment. In some cases there may be ways to help preserve fertility. For more information, see our documents *Fertility and Women With Cancer* and *Fertility and Men With Cancer*.

The long-term side effects of radiation therapy can sometimes be serious, especially for young children. Bones and soft tissues that get radiation might not grow as well. Depending on the area getting radiation, this might cause problems such as curvature of the spine, a shortened arm or leg, limited motion of a joint, hardening of the surrounding soft tissue, or poor development of the facial bones. Other problems linked to radiation can include stiffening of the lungs, cataracts and poor vision in an involved eye, and later problems with sexual function. Young children's brains are especially sensitive to radiation to the head, which can lead to learning problems or other issues, so doctors do their best to avoid this when possible.

Children who get chemotherapy and/or radiation therapy also have a small, but definitely increased, risk of second cancers later in life. These include bone cancer, leukemia, or other soft tissue tumors. The bone cancers seem to be linked with radiotherapy, while the leukemias are more often seen after treatment with cyclophosphamide and related chemo drugs. These second cancers affect only a small number of RMS survivors, and these are children who most likely would not have survived without these treatments. For more information on second cancers, see our document *Second Cancers Caused by Cancer Treatment*.

There may be other possible complications from treatment as well. Your child's doctor should carefully review any possible problems with you before your child starts treatment.

Along with physical side effects, some childhood cancer survivors might have emotional or psychological issues. They might also have problems with normal functioning and school work. These can often be addressed with support and encouragement. If needed, doctors and other members of the health care team can recommend special support programs and services to help children after cancer treatment.

Long-term follow-up care for children and teens

To help increase awareness of late effects and improve follow-up care of childhood cancer survivors throughout their lives, the Children's Oncology Group (COG) has developed long-term follow-up guidelines for survivors of childhood cancers. These guidelines can help you know what to watch for, what screening tests should be done to look for problems, and how late effects can be treated.

It's very important to discuss possible long-term complications with your child's health care team, and to make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more, ask your child's doctors about the COG survivor guidelines. You can also read them on the COG website: www.survivorshipguidelines.org. The guidelines are written for health care professionals. Patient versions of some of the guidelines are available (as "Health Links") on the site as well, but we urge you to discuss them with your doctor.

For more about some of the possible long-term effects of treatment, see our document *Children Diagnosed With Cancer: Late Effects of Cancer Treatment*.

Keeping good medical records

As much as you might want to put the experience behind you once treatment is completed, it is very important to keep good records of your child's medical care during this time. This can be very helpful later on as your child changes doctors. Gathering these details during and soon after treatment may be easier than trying to get them at some point in the future. Be sure the doctors have the following information (and always keep copies for yourself):

- A copy of the pathology report(s) from any biopsies or surgeries.

- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD, etc.)
- If there was surgery, a copy of the operative report(s).
- If your child stayed in the hospital, a copy of the discharge summary the doctor wrote when the child was sent home.
- If chemotherapy was given, a list of the final doses of each drug your child received.
- If radiation therapy was given, a summary of the type and dose of radiation and when and where it was given.
- The names and contact information of the doctors who treated your child's cancer

It is also very important to keep health insurance coverage. Tests and doctor visits cost a lot, and even though no one wants to think of the tumor coming back, this could happen.

What's new in rhabdomyosarcoma research and treatment?

The treatment of rhabdomyosarcoma (RMS) has come a long way in the past few decades, largely due to the work of the Intergroup Rhabdomyosarcoma Study Group (now known as the Soft Tissue Sarcoma Committee of the Children's Oncology Group). However, more work needs to be done. Research on RMS is being done at many medical centers, university hospitals, and other institutions across the world.

Better classification of rhabdomyosarcomas

Newer molecular techniques may help doctors better categorize RMS and predict which patients will respond best to certain treatments. For example, rather than just looking at the cancer cells under a microscope, researchers have begun to use special genetic tests to help classify RMS.

About 1 out of 4 cancers that doctors would usually classify as alveolar rhabdomyosarcoma (ARMS) have been found to lack the typical gene change (the *PAX/FOXO1* fusion gene) seen in ARMS. Some early studies have shown that these cancers seem to act more like embryonal rhabdomyosarcoma (ERMS) than ARMS. ERMS generally requires less intensive treatment than ARMS. If this finding is confirmed in other studies, it may allow doctors to use less intensive treatments on these cancers and still achieve the same results.

Improving standard treatments

A major goal of current research is to treat all patients more effectively, while reducing the need for intensive treatments (and their side effects) when possible. For example, researchers are studying whether children who have a low risk of the tumor recurring can be treated without using potentially harmful treatments such as radiation therapy and the chemotherapy drug cyclophosphamide.

Because children's bodies are very sensitive to radiation, doctors are looking for ways to limit the doses as much as possible. Newer radiation therapy techniques allow doctors to aim the radiation more precisely, limiting the amount that reaches normal body tissues. Some of these techniques were described in the section "Radiation therapy for rhabdomyosarcoma."

Other ways to give radiation are also being studied. For example, in *stereotactic radiation therapy*, a special machine aims high doses of radiation at the tumor from many different angles, concentrating it on the tumor very precisely for short periods of time.

Proton beam radiation is another newer approach. Standard radiation beams give off the same amount of radiation at all points as they pass through the body. Proton beam radiation uses radioactive particles that travel only a certain distance before releasing most of their energy. Doctors can use this property to limit the radiation reaching normal body tissues. This new approach seems promising, but it's not yet clear if it's better than other newer forms of radiation therapy. It's also available in only a limited number of centers around the country at this time.

Doctors are studying adding newer chemotherapy drugs such as irinotecan and temozolomide to the standard chemotherapy regimens in those who have a higher risk of the tumor recurring.

For patients at a high risk of tumor recurrence, doctors are looking at maximizing the early treatment with drugs such as cyclophosphamide and ifosfamide by giving them more frequently (a concept called *interval compression*).

Newer treatment approaches

Drugs that target specific parts of cancer cells (as opposed to just attacking fast-growing cells, as chemotherapy drugs do) are now being studied for use in RMS. Some of these drugs are already being used to treat certain adult cancers. Examples of newer targeted drugs being studied for use against RMS include:

- IGF-1 receptor inhibitors, such as cixutumumab (IMC-1A2)
- Drugs that affect a tumor's ability to make new blood vessels, such as bevacizumab (Avastin) and sorafenib (Nexavar)

- Drugs that target the mTOR protein, such as temsirolimus (Torisel) and everolimus (Afinitor)
- Drugs that target the ALK protein, such as crizotinib (Xalkori)
- Drugs that target the cell's hedgehog pathway, such as LDE225
- Dasatinib (Sprycel)

Researchers are also testing other new ways to treat RMS. For example, some researchers are looking at exposing some of the body's immune system cells, called *dendritic cells*, to the abnormal PAX-FOXO1 protein that is found in many ARMS cells. The hope is that the dendritic cells will then cause the immune system to attack these cells, no matter where they are in the body.

Eventually, a combination of these approaches may prove to be the best way to treat RMS.

Additional resources for rhabdomyosarcoma

More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

Children with cancer

[Children Diagnosed With Cancer: Dealing with Diagnosis](#) (also in Spanish)

[Pediatric Cancer Centers](#) (also in Spanish)

[Children Diagnosed With Cancer: Understanding the Health Care System](#) (also in Spanish)

[Children Diagnosed With Cancer: Financial and Insurance Issues](#)

[Children Diagnosed With Cancer: Returning to School](#)

[Children Diagnosed With Cancer: Late Effects of Cancer Treatment](#)

Health Professionals Associated With Cancer Care

Talking With Your Doctor (also in Spanish)

Coping with cancer

[After Diagnosis: A Guide for Patients and Families](#) (also in Spanish)

[Family and Medical Leave Act \(FMLA\)](#) (also in Spanish)

[Nutrition for Children With Cancer](#) (also in Spanish)

What Happened to You, Happened to Me (children's booklet)

When Your Brother or Sister Has Cancer (children's booklet)

[When Your Child's Treatment Ends: A Guide for Families](#) (booklet)

Cancer treatment information

[A Guide to Cancer Surgery](#) (also in Spanish)

A Guide to Chemotherapy (also in Spanish)

[Understanding Radiation Therapy: A Guide for Patients and Families](#) (also in Spanish)

[Clinical Trials: What You Need to Know](#) (also in Spanish)

[Stem Cell Transplant \(Peripheral Blood, Bone Marrow, and Cord Blood Transplants\)](#) (also in Spanish)

Cancer treatment side effects

Caring for the Patient with Cancer at Home: A Guide for Patients and Families (also in Spanish)

Nausea and Vomiting

Anemia in People With Cancer

Fatigue in People With Cancer

Fertility and Women With Cancer

Fertility and Men With Cancer

Second Cancers Caused by Cancer Treatment

Books

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at www.cancer.org/bookstore to find out about costs or to place an order.

National organizations and websites*

Along with the American Cancer Society, other sources of information and support include:

Websites for parents and adults

American Childhood Cancer Organization (formerly Candlelighters)

Toll-free number: 1-855-858-2226

Website: www.acco.org

Offers information for children and teens with cancer, their siblings, and adults dealing with children with cancer. Also offers books and a special kit for children newly diagnosed with cancer, as well as some local support groups.

Amputee Coalition of America

Toll-free number: 1-800-AMP-KNOW (1-800-267-5669)

Website: www.amputee-coalition.org

Offers resources for specific groups with amputations, including parents and youth (see their “Limb Loss Resource Center” online); also lists some local support groups across the country.

Children’s Oncology Group (COG)

Website: www.childrensoncologygroup.org

Information from the world’s largest organization devoted to childhood cancer research to help support children and their families from the time of diagnosis, through treatment, and beyond. Also has a searchable database to find the COG center closest to you.

CureSearch for Children’s Cancer

Toll-free number: 1-800-458-6223

Website: www.curesearch.org

Provides up-to-date information about childhood cancer from pediatric cancer experts. Has sections on the website for patients, families, and friends to help guide them on how to support the child with cancer.

National Cancer Institute

Toll-free number: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Website: www.cancer.gov

Provides accurate, up-to-date information about cancer for patients and their families, including clinical trials information. Offers a special booklet for teen siblings of a child with cancer at: www.cancer.gov/cancertopics/when-your-sibling-has-cancer.

National Children's Cancer Society, Inc.

Toll-free number: 1-800-5-FAMILY (1-800-532-6459)

Website: www.children-cancer.org

Services include an online support network for parents of children with cancer, educational materials, and financial assistance for treatment-related expenses.

Websites for teens and children**Starlight Children's Foundation**

Toll-free number: 1-310-479-1212

Website: www.starlight.org

Website has animated stories and interactive programs to teach kids about chemo and procedures that may be done in the hospital; also has videos specifically for teens and provides a safe, monitored online support group for teens with cancer.

Group Loop (a subsite of the **Cancer Support Community** just for teens)

Toll-free number: 1-888-793-9355

Website: www.grouploop.org

An online place for teens with cancer or teens who know someone with cancer to connect with other teens – away from the pressures of classes, responsibilities, and treatment schedules. Has online support groups, chat rooms, information, and more.

Teens Living with Cancer

Website: www.teenslivingwithcancer.org

An online-only resource dedicated to teens coping with a cancer diagnosis and treatment. It focuses on teen issues and provides resources to support teens, their families, and friends.

SuperSibs! Powered by Alex's Lemonade Stand

Toll-free number: 1-866-333-1213

Website: www.supersibs.org

Supports, honors, and recognizes brothers and sisters of children diagnosed with cancer so they may face the future with strength, courage, and hope. (Alex's Lemonade Stand is restarting SuperSibs in 2014, so there may be some delays with resuming support services.)

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime day or night for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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