PATIENT RESOURCE

Fourth Edition

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Understanding Sarcoma

A TREATMENT GUIDE FOR ADULT AND PEDIATRIC PATIENTS AND THEIR FAMILIES

Soft Tissue Sarcoma
Liposarcoma
Leiomyosarcoma
Fibrosarcoma
Osteosarcoma
Chondrosarcoma
Ewing Sarcoma

WHERE INFORMATION EQUALS HOPE

Lilly

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Understanding Sarcoma

Fourth Edition

IN THIS GUIDE

> *See a sarcoma specialist, at least for a second opinion. Learn about sarcoma from reliable sources.*
>
> *~ Suzie Siegel, survivor*

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Learn About Your Sarcoma Diagnosis

Sarcomas are a group of rare cancers that most commonly form in the soft tissues (soft tissue sarcoma) or bones (bone sarcoma) (see Figures 1 and 2). Sarcomas originate in tissues of the supporting structures of the body, such as muscle, tendons, connective tissues, cartilage, nerves, fat and blood vessels. As a group of cancers, they compose about 1 percent of all cancers and are, thus, considered rare. They can occur in infants to the elderly; however, more primary bone sarcomas occur in the first two decades of life (see *Pediatric Sarcoma,* page 10). In adults, about 1 percent of all diagnosed solid tumors are sarcoma.

Diagnosing sarcomas can be difficult. Your doctor will likely order bloodwork and imaging scans, which may include computed tomography (CT), magnetic resonance imaging (MRI), positron emission tomography (PET), ultrasound or X-rays. A biopsy, however, will often be required to confirm a sarcoma diagnosis. Types of biopsies your doctor may use include needle biopsy (tissue removed with a needle), core needle biopsy (tissue removed with wide needle), incisional biopsy (a small piece of tissue is removed) or excisional biopsy (entire lump is removed) with the procedures being carried out in a hospital operating room or in the interventional radiology department by an interventional radiologist.

Identifying the sarcoma subtype requires a pathologist to review the biopsy. A pathologist with expertise in sarcoma is highly recommended to examine the appearance of the cells under a microscope and look for cells that appear more normal or abnormal. The way the cells look will also indicate the grade of the tumor, which is used in staging (see *Staging*, page 4).

Molecular testing is highly recommended. The pathologist will look for specific genetic abnormalities, including chromosomes that change places, extra copies of a gene and mutations (any change in the DNA sequence of a cell). Following are some of the molecular tests your doctor may order:

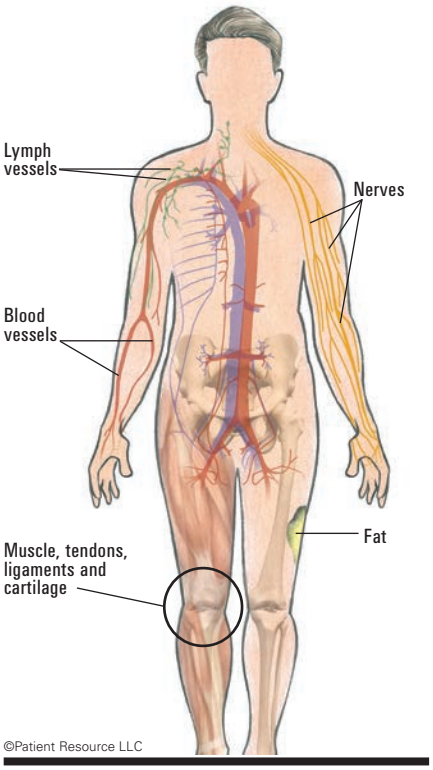
- Cytogenetics
- Flow cytometry
- Fluorescent in situ hybridization (FISH)
- Immunohistochemistry
- Light and electron microscopy

Because certain types of sarcoma may respond differently to certain treatments, these test results and whether the tumor is localized (contained to one area), regional (has spread to tissues near one area) or metastatic (spread to other tissues or organs) will help your doctor recommend a personalized treatment plan for you.

SOFT TISSUE SARCOMA

Soft tissue sarcomas are more common than bone sarcomas. There are more than 50 types of them (see Table 1), and they can form in any of the body's connective or supportive tissues, including blood vessels, lymph vessels, muscle, cartilage, nerves, tendons, fat, tissue around joints and fibrous tissue. Most soft tissue sarcomas begin in the arm or leg. About a third occur in the torso or abdomen, and the rest begin in the head or neck. These sarcomas are named according to where they develop in the body. For example, gastrointestinal stromal tumors (GISTs) develop in the stroma (supportive connective tissue) of the stomach and intestines; sarcomas that develop in fat tissue are called liposarcomas ("lipo" means "fat"); and sarcomas that develop in blood vessels are called angiosarcomas ("angio" means "vessel").

FIGURE 1
SOFT TISSUES AFFECTED BY SARCOMA

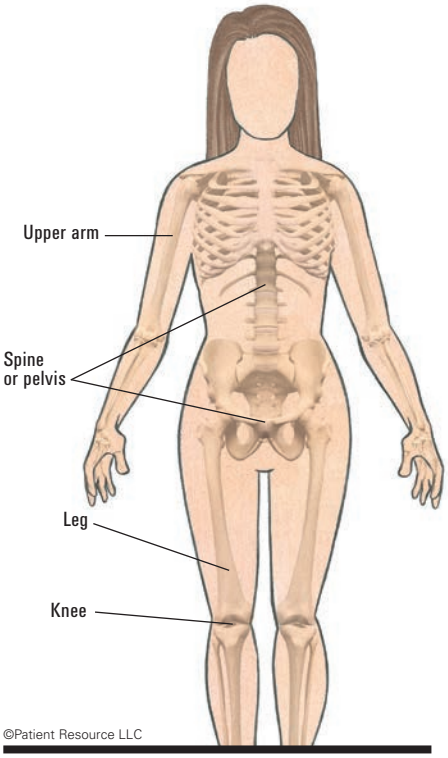


BONE SARCOMA

Bone sarcomas are primary cancers that originate in bone, in contrast to those cancers that spread from other organs to the bone. Primary malignant bone cancers are extremely rare and mostly occur in younger people. Following are the three most common types of primary bone sarcoma. See Table 2 for additional types.

Osteosarcoma, also called osteogenic sarcoma, is the most common bone cancer. It begins in bone cells that make new bone tissue. In children and adolescents, osteosarcoma usually develops during a growth spurt near the ends of long bones, such as in the leg (around the knee) and the upper arm. But osteosarcoma can occur in any bone, especially in older adults, and may be associated with hereditary conditions or other bony diseases.

FIGURE 2
COMMON LOCATIONS OF BONE SARCOMA



Chondrosarcoma, the second most common primary bone cancer, develops inside the bone and is made of cartilage. Cartilage is fibrous tissue mixed with a gel-like substance, making it softer than bone but harder than most tissues in the body. It can occur anywhere cartilage is found and most frequently develops in the pelvis, legs or arms. Chondrosarcoma occurs primarily in older adults.

Ewing sarcoma, the most common tumor in the Ewing family of tumors, occurs more often in children and young adults and is extremely rare after the age of 25. It usually develops in the pelvis and legs (see *Pediatric Sarcoma*, page 10).

SIGNS OF SARCOMA

Though you may experience pain or discomfort related to the sarcoma's location and the extent of the tumor, you may not experience any symptoms at all with a bone cancer. The cancer may be found merely by the presence of a mass or even incidentally on X-rays that are taken of the area for different purposes.

As soft tissue sarcomas grow, they may put pressure on nerves, nearby organs, muscles or blood vessels, which may cause pain. A common symptom of bone sarcoma is also pain, as well as swelling around the tumor site that progressively worsens. A painful limp may develop if the tumor is in the hip, thigh, knee, leg or foot. Pain may worsen when moving or during weight-bearing activities.

Managing your pain will be important regardless of the type of sarcoma you have. Treatments often referred to as supportive or palliative care are available to control cancer-related pain (see *Pain Management*, page 13). The better you feel, the more likely you are to complete your treatment as planned, which offers a greater chance for a successful outcome. Talk to your doctor about the pain management options that may be appropriate for you. ■

ADDITIONAL RESOURCES

- **American Society of Oncology:** www.cancer.net
  Sarcoma, Soft Tissue: Symptoms and Signs
- **Sarcoma Alliance:** www.sarcomaalliance.org
- **Sarcoma Alliance for Research through Collaboration (SARC):** www.sarctrials.org
- **Sarcoma Foundation of America:** www.curesarcoma.org
  FAQ

TABLE 1
SOME TYPES OF SOFT TISSUE SARCOMA

Type of Soft Tissue Sarcoma	Tissue of Origin	Typical Age (years)	Most Common Sites
Most common types			
Gastrointestinal stromal tumors	Stroma (supportive connective tissue) of the stomach and intestines	50 and older	Wall of the stomach, small intestine
Leiomyosarcoma	Smooth muscle tissue	Average, 60	Uterus, small intestine, stomach
Liposarcoma	Fat tissue	30-60	Thigh, behind the knee, retroperitoneum (behind the abdomen)
Synovial sarcoma	Tissue around joints	15-35	Near the foot, ankle, hand
Undifferentiated pleomorphic sarcoma (previously called malignant fibrous histiocytoma)	Uncertain	50-70	Leg; may also develop in the retroperitoneum (behind the abdomen) or head and neck
Other types			
Alveolar rhabdomyosarcoma	Skeletal muscle	Adolescents and young adults	Large muscles of the trunk, arm, leg
Alveolar soft-part sarcoma	Connective tissue	Young adults	Legs or extremities
Anaplastic rhabdomyosarcoma (previously called pleomorphic rhabdomyosarcoma)	Skeletal muscle	Over age 30	Large muscles of the trunk, arm, leg
Angiosarcoma	Inner lining of blood vessels	60-70	Skin, breast, liver, spleen, head and neck
Botryoid rhabdomyosarcoma	Skeletal muscle	Average, 7	Genital region, urinary tract
Desmoid tumors (aggressive fibromatoses)	Connective tissue that forms tendons and ligaments	10-40	Intra-abdominal mesentery (tissue that attaches organs to the wall of the abdomen), arm, leg
Desmoplastic small round cell tumor	Connective tissue that forms tendons and ligaments	Adolescents and young adults	Abdomen
Embryonal rhabdomyosarcoma	Skeletal muscle	Under age 10	Anywhere, but often in head and neck, and around the eye
Epithelioid sarcoma	Skin	20-39	Arm, hand, foot
Fibrosarcoma	Fibrous tissue	35-55	Thigh, knee, arm, trunk
Hemangiodendothelioma	Inner lining of blood vessels	20-40	Soft tissues or internal organs, such as liver or lung
Malignant peripheral nerve sheath tumors	Cells that surround a peripheral nerve (nerves that connect the central nervous system – spinal cord and brain) with other parts of the body	20-50	Upper part of the arm and leg, trunk

TABLE 2
SOME TYPES OF BONE SARCOMA

Type of Bone Sarcoma	Tissue of Origin	Typical Age (years)	Most Common Sites
Most common types			
Chondrosarcoma	Cartilage	40 and older	Pelvis, leg, arm
Ewing sarcoma	Bone	10-20	Pelvis, leg
Osteosarcoma	Bone	10-30	Leg (near the knee), upper arm (near the shoulder)
Other types			
Adamantinoma	Bone	20-50	Lower leg
Chordoma	Bone	40-70	Skull base, spine, tailbone
Malignant giant cell tumor of bone	Bone	20-60	Knee

Staging and Grading Help Guide Treatment Decisions

Staging is how doctors determine the extent of your sarcoma, where it is located and whether it has metastasized (spread) to nearby organs, tissues or lymph nodes, or to other parts of your body. The stage also assists in determining the prognosis (outlook) for the disease. The grade can indicate growth rate. Your doctor will consider the results of your physical examination, imaging studies, blood tests and a biopsy of the tumor. However, additional tests may be needed.

Your doctor will order various studies, which may include X-rays, CT (computed tomography), magnetic resonance imaging (MRI) and nuclear medicine (bone scans), which will assist in completing the staging of your cancer.

Your doctor may also suggest molecular laboratory tests on a tumor sample (after it is biopsied or removed) to identify specific genes, proteins and other factors unique to the tumor, including its molecular characteristics. Ask your doctor if the tissue samples from other tests you've had can be used for molecular testing to prevent additional procedures, if possible.

Because of the many subtypes of sarcoma, staging may be challenging. Your surgeon may present your case at a multidisciplinary sarcoma tumor board, which is a meeting of a group of physicians involved with sarcoma treatment. This team consists of many physicians "behind the scenes" but deeply involved in your care, such as sarcoma pathologists, musculoskeletal radiologists, pediatric and adult oncologists, radiation oncologists, rehabilitation physicians, and nonphysician personnel such as social workers, tumor registrars and chaplains. This team will discuss and evaluate your case in great detail and arrive at decisions best suited to you personally.

This is also a good time to get a second opinion from another sarcoma specialist. A second opinion will confirm the diagnosis and recommended treatment plan or introduce new information to consider.

STAGING SOFT TISSUE SARCOMAS

The staging and grading system most commonly used for soft tissue sarcomas is the American Joint Committee on Cancer (AJCC) TNM staging system.* Soft tissue sarcomas are staged and graded based on where they are found in the body, including soft tissues of the head and neck, trunk and extremities, abdomen and thoracic visceral organs and the retroperitoneum (the space behind the lining of the abdomen).

TNM staging uses the tumor (T), node (N) and metastasis (M) classification system, which takes into account the tumor's size and location, whether cancer cells are in nearby lymph nodes and if it has metastasized to other parts of the body. Soft tissue sarcomas commonly spread to the lungs. Numbers after T, N and M provide more details for each of these factors.

For both bone and soft tissue sarcomas, a grade (G) is given to indicate how rapidly the sarcoma will grow and spread. Knowing the grade will also help determine the prognosis (predicted outcome). The pathologist will examine sarcoma cells through a microscope and then assign a number to the grade according to how different these cells are from

TABLE 1

SOFT TISSUE SARCOMA OF THE HEAD & NECK

CLASSIFICATION

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T1	Tumor 2 cm (almost 1 inch) or less.
T2	Tumor more than 2 cm but not more than 4 cm (about 1 ½ inches).
T3	Tumor more than 4 cm.
T4	Tumor with invasion of adjoining structures.
T4a	Tumor with orbital invasion, skull base/dural invasion, invasion of central compartment viscera, involvement of facial skeleton, or invasion of pterygoid muscles.
T4b	Tumor with brain parenchymal invasion, carotid artery encasement, prevertebral muscle invasion, or central nervous system involvement via perineural spread.
Node (N)	
N0	No regional lymph node metastases or unknown lymph node status.
N1	Regional lymph node metastasis.
Metastasis (M)	
M0	No distant metastasis.
M1	Distant metastasis.

GRADE

Grade (G)	Definition
GX	Grade cannot be assessed.
G1	Total differentiation, mitotic count and necrosis score of 2 or 3.
G2	Total differentiation, mitotic count and necrosis score of 4 or 5.
G3	Total differentiation, mitotic count and necrosis score of 6, 7, or 8.

TABLE 2

SOFT TISSUE SARCOMA OF THE ABDOMEN & THORACIC VISCERAL ORGANS

CLASSIFICATION

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T1	Organ confined.
T2	Tumor extension into tissue beyond organ.
T2a	Invades serosa or visceral peritoneum.
T2b	Extension beyond serosa (mesentery).
T3	Invades another organ.
T4	Multifocal involvement (tumors at more than 1 site).
T4a	Multifocal (2 sites).
T4b	Multifocal (3-5 sites).
T4c	Multifocal (more than 5 sites).
Node (N)	
N0	No lymph node involvement or unknown lymph node status.
N1	Lymph node involvement present.
Metastasis (M)	
M0	No metastasis.
M1	Metastases present.

GRADE

Grade (G)	Definition
GX	Grade cannot be assessed.
G1	Total differentiation, mitotic count and necrosis score of 2 or 3.
G2	Total differentiation, mitotic count and necrosis score of 4 or 5.
G3	Total differentiation, mitotic count and necrosis score of 6, 7, or 8.

**Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.*

normal tissue cells, the number of tumor cells dividing and how much of the tumor has cells that are dying.

Grades range from low to high as GX (grade cannot be assessed), Grade 1 (G1), Grade 2 (G2) and Grade 3 (G3). Healthy cells are called well-differentiated (indicated by a lower grade). Low-grade tumor cells look more like normal cells and are less likely to grow and spread quickly. High-grade tumor cells (poorly differentiated cells) look more abnormal and tend to grow and spread faster. In general, the more differentiated the tumor, the better the prognosis.

The information your doctor gathers about the tumor, lymph nodes, possible metastasis and grade is used to assign a stage through a process called stage grouping. Roman numerals I to IV indicate the stages. Stage grouping is used for soft tissue sarcomas of the trunk and extremities (see Table 3) and retroperitoneum (see Table 4). However, stage grouping is currently unavailable for soft tissue sarcomas of the head and neck (see Table 1) and the abdomen and thoracic visceral organs (see Table 2) because more data is needed to offer any prognostic value.

TABLE 3

SOFT TISSUE SARCOMA OF THE TRUNK & EXTREMITIES

CLASSIFICATION

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
T1	Tumor 5 cm (almost 2 inches) or less in greatest dimension.
T2	Tumor more than 5 cm and less than or equal to 10 cm (almost 4 inches) in greatest dimension.
T3	Tumor more than 10 cm and less than or equal to 15 cm (approximately 6 inches) in greatest dimension.
T4	Tumor more than 15 cm in greatest dimension.
Node (N)	
N0	No regional lymph node metastasis or unknown lymph node status.
N1	Regional lymph node metastasis.
Metastasis (M)	
M0	No distant metastasis.
M1	Distant metastasis.

GRADE

Grade (G)	Definition
GX	Grade cannot be assessed.
G1	Total differentiation, mitotic count and necrosis score of 2 or 3.
G2	Total differentiation, mitotic count and necrosis score of 4 or 5.
G3	Total differentiation, mitotic count and necrosis score of 6, 7, or 8.

STAGE GROUPING

Stage	T	N	M	G
IA	T1	N0	M0	GX, G1
IB	T2, T3, T4	N0	M0	GX, G1
II	T1	N0	M0	G2, G3
IIIA	T2	N0	M0	G2, G3
IIIB	T3, T4	N0	M0	G2, G3
IV	Any T Any T	N1 Any N	M0 M1	Any G Any G

TABLE 4

SOFT TISSUE SARCOMA OF THE RETROPERITONEUM

CLASSIFICATION

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
T1	Tumor 5 cm (almost 2 inches) or less in greatest dimension.
T2	Tumor more than 5 cm and less than or equal to 10 cm (almost 4 inches) in greatest dimension.
T3	Tumor more than 10 cm and less than or equal to 15 cm (approximately 6 inches) in greatest dimension.
T4	Tumor more than 15 cm in greatest dimension.
Node (N)	
N0	No regional lymph node metastasis or unknown lymph node status.
N1	Regional lymph node metastasis.
Metastasis (M)	
M0	No distant metastasis.
M1	Distant metastasis.

GRADE

Grade (G)	Definition
GX	Grade cannot be assessed.
G1	Total differentiation, mitotic count and necrosis score of 2 or 3.
G2	Total differentiation, mitotic count and necrosis score of 4 or 5.
G3	Total differentiation, mitotic count and necrosis score of 6, 7, or 8.

STAGE GROUPING

Stage	T	N	M	G
IA	T1	N0	M0	GX, G1
IB	T2, T3, T4	N0	M0	GX, G1
II	T1	N0	M0	G2, G3
IIIA	T2	N0	M0	G2, G3
IIIB	T3, T4 Any T	N0 N1	M0 M0	G2, G3 Any G
IV	Any T	Any N	M1	Any G

STAGING BONE SARCOMAS

When doctors stage bone sarcomas, they use many of the same tests used for soft tissue sarcomas. They will also determine if the tumor is localized (seen only in the bone it started in and possibly tissues next to the bone, such as muscle, tendon or fat), or metastatic (has spread to other parts of the body). Depending on the type of bone sarcoma, one of two preferred staging systems will be used.

AJCC's TNM staging system considers the size and location of the tumor (T), whether cancer cells are found in nearby lymph nodes (N) and whether the cancer has metastasized (M) to other parts of the body. It also includes a grading system (GX-G3), which indicates the tumor's aggressiveness. Stages are indicated by Roman numerals I to IV.

The Musculoskeletal Tumor Society (MSTS) staging system, also known as the Enneking system, is based on the grade (G) of the tumor, the extent of the main (primary) tumor (T) and whether the tumor has metastasized (M) to nearby lymph nodes or other organs.

In the MSTS system, bone sarcomas are staged by how likely the tumor is to grow and spread (G1 or G2), whether the tumor has remained inside the bone (T1) or extended beyond the bone (T2), and if the tumor has spread to other organs (M1). Combining these factors gives an overall stage, which is indicated by Roman numerals I to III. ■

ADDITIONAL RESOURCES

- **American Cancer Society:** www.cancer.org
  Osteosarcoma Stages
  Soft Tissue Sarcoma Stages
- **American Society of Clinical Oncology:** www.cancer.net
  Osteosarcoma – *Childhood and Adolescence – Stages*
  Soft Tissue Sarcoma Stages and Grades
- **Sarcoma Alliance:** www.sarcomaalliance.org

Multiple Therapies Often Make Up Treatment Plan

Treatment advances in the past two decades, particularly in targeted therapy as well as limb-sparing surgical procedures, have led to better outcomes for people diagnosed with sarcoma. The availability of more treatments for both soft tissue and bone sarcoma means many people are able to live longer, better quality lives either disease-free or progression-free.

You are encouraged to seek care from a sarcoma specialist or at a dedicated sarcoma center. If that isn't possible, talk to your medical care team about reaching out to a sarcoma center for advice and planning, as most are happy to offer help.

Your medical team will recommend a treatment plan based on the type, stage and location of your sarcoma, as well as your overall health and other factors. It's important to talk with your doctor about all treatment options that may be available to you. Typically, a combination of treatments offers the best approach. Clinical trials should also be considered and may be of particular benefit for treating rare sarcomas.

SURGERY

For both soft tissue and bone sarcomas, a primary treatment is surgery. The most common surgical procedure used is wide local excision, which removes the entire tumor as well as a close margin of normal tissue surrounding it. Another name for this procedure is Wide en bloc Resection, which means removal of the entire tumor in one piece with a cuff of normal tissue surrounding it to ensure complete removal of every malignant cell without contamination of surrounding parts.

A pathologist (a doctor specializing in diagnosing disease) examines the margins under a microscope to check for cancer cells. If no cells remain, the margin is clean (also called negative or clear), and no further treatment is necessary. But if cancer cells are present (positive margin), then another surgery, radiation therapy and/or chemotherapy may be needed. The surgeon and pathologist work closely together to determine the adequacy of the margins.

Advances in surgical technologies and other treatment options have greatly reduced the number of amputations performed when sarcoma occurs in the arms or legs. Surgeons today prefer a limb-sparing procedure whenever possible to preserve the use and appearance of the limb. To replace tissue or bone lost in the limb from removing the tumor, bone or skin is grafted from elsewhere in the body. Radiation therapy may follow.

Amputation is not used as often as it once was, but it may be the best option if removing the tumor would also require removing essential nerves, muscles or blood vessels that would result in a poorly functioning or nonfunctional limb. Amputation may also be considered if the surgical area cannot fully be covered with soft tissue or the person cannot undergo reconstructive surgery.

In the likelihood that the sarcoma has spread to nearby lymph nodes, the surgeon will remove and examine them to check for cancer cells in a procedure called a lymphadenectomy.

In some cases of bone cancer, cryosurgery (also called cryotherapy) may be an option. Cryosurgery differs greatly from traditional surgery. Instead of removing the tumor through an incision, the surgeon inserts a hollow instrument through the skin into the tumor to deliver extremely cold liquid nitrogen (or argon gas) to kill sarcoma cells.

CHEMOTHERAPY

Chemotherapy involves using drugs to stop cancer by either killing cancer cells or preventing them from dividing and growing. It may be given orally (a pill) or intravenously through a small tube inserted into a vein (see Figure 1).

It may be given before or after the primary treatment, which is typically surgery or radiation therapy. Chemoradiation, a combination of chemotherapy and radiation therapy, may also be used. If surgery is not possible, chemotherapy may be used as a primary treatment. Because chemotherapy is systemic, which means the drugs travel throughout the entire body in the bloodstream, it may be used when the sarcoma has metastasized to several sites.

Chemotherapy is primarily used to treat Ewing sarcoma, osteosarcoma, embryonal or alveolar rhabdomyosarcoma in children or young adults, and sarcomas that have spread. When used for bone sarcomas, it is usually given before and after surgery. Several chemotherapy drugs can be used to treat sarcomas, alone or in combination with other drugs.

TARGETED THERAPY

This approach uses drugs or other substances to identify and attack specific types of cancer cells. Effective targeted therapy depends on two factors: identifying targets essential to cancer cell growth and survival,

TABLE 1
TYPES OF RADIATION THERAPY USED FOR SOFT TISSUE SARCOMA

Type of Radiation Therapy	Description
Brachytherapy	Radiation is delivered via radioactive "seeds" implanted near the tumor.
External-beam radiation therapy (EBRT)	Delivered from a machine outside the body, these types of radiation therapy are strong enough to kill cancer cells: **Three-dimensional conformal radiation therapy (3D-CRT)** delivers beams conforming to the shape of the tumor. **Intensity-modulated radiation therapy (IMRT)** uses computer images to deliver radiation matched to the size and shape of the tumor. **Proton-beam therapy** delivers very precise radiation using proton particles. **Stereotactic body radiation therapy (SBRT)** uses multiple beam angles to deliver a powerful dose of radiation to a specific area.
Intraoperative radiation therapy (IORT)	A single, powerful dose of radiation is delivered during surgery once the sarcoma has been removed.

FIGURE 1
INTRAVENOUS INFUSION

Some sarcoma treatments are administered by IV through a port or directly into your arm or hand.

and developing agents to attack those targets. For example, a type of targeted therapy pinpoints gastrointestinal stromal tumor (GIST) cells with a specific gene abnormality that is found in the majority of GISTs. The targeted therapy drug helps prevent recurrence after the tumor is removed. Molecular testing will determine if the GIST has this gene abnormality. This strategy may also be used as primary treatment for GISTs that cannot be surgically removed or that have spread. If the initial drug used stops working, other targeted drugs are available.

Another type of targeted therapy is a monoclonal antibody that binds to a kind of protein (RANK ligand) to prevent it from telling specific cells (osteoclasts) to break down bone. This drug helps shrink giant cell tumors of bone that have returned after surgery or that can't be surgically removed.

Targeted therapy may be a treatment option for sarcomas that are resistant to chemotherapy.

Considered a systemic treatment because the drugs travel in the bloodstream throughout the body, it typically doesn't damage healthy cells, which may result in fewer side effects. Targeted therapy may be given in pill form or intravenously through a small tube inserted into a vein (see Figure 1). Because healthy cells are usually spared, fewer side effects may occur.

RADIATION THERAPY

Radiation therapy uses high-energy X-rays or other particles to kill cancer cells or prevent their growth. With this kind of therapy, treatment is carefully planned and overseen by a specially trained doctor called a radiation oncologist.

FIGURE 2
RADIATION THERAPY

External-beam radiation therapy (EBRT) is the most common type for treating soft tissue sarcoma. A machine will direct high-energy radiation beams at cancer cells inside the body.

Newer radiation therapy techniques allow doctors to direct radiation more precisely. This means higher doses of radiation can be delivered while avoiding damage to healthy tissue, which may reduce side effects. Research has demonstrated lower rates of cancer recurrence with these newer radiation techniques.

The most common type of radiation therapy used for soft tissue sarcoma is external-beam radiation therapy (EBRT) (see Figure 2). Other types of radiation therapy also may be used (see Table 1). For osteosarcoma, radiation therapy is usually used only for tumors that cannot be surgically removed.

Radiation therapy may be integrated into the overall treatment plan in several ways.

- Before surgery, to shrink the tumor and make it easier to remove. This is known as neoadjuvant treatment.
- Following surgery, to kill cancer cells near the tumor site. This is known as adjuvant treatment.
- Instead of surgery as the primary treatment for a tumor that cannot be removed surgically or when the person cannot tolerate surgery because of health conditions.
- To help relieve symptoms from sarcoma that has metastasized (spread) to other parts of the body.

IMMUNOTHERAPY

Immunotherapy uses the body's own immune system to slow the growth of or kill cancer cells, much in the same way the immune system fights off bacteria or viruses. A category of immunotherapy drugs called cytokines is sometimes used to treat certain sarcomas. The drug works by delivering large amounts of laboratory-made cytokines into the immune system to promote specific immune responses.

Ongoing clinical trials are evaluating the effectiveness of other types of immunotherapy to treat sarcoma.

PALLIATIVE CARE

Palliative care is designed to relieve pain, distress and other physical and emotional side effects of cancer and its treatment and, in turn, improve quality of life. Often confused with hospice care, which helps enhance quality of life for people approaching the end of life, palliative care focuses on people whose illnesses are life-threatening or chronic. This includes people experiencing symptoms from sarcoma or its treatment. It is provided by a multidisciplinary team of doctors, nurses, social workers and others.

COMMONLY USED MEDICATIONS

CHEMOTHERAPY
- dacarbazine (DTIC)
- dactinomycin (Cosmegen)
- doxorubicin (Adriamycin)
- eribulin mesylate (Halaven)
- trabectedin (Yondelis)
- vinblastine (Velban)
- vincristine
- Combination treatment: MAID (mesna, doxorubicin, ifosfamide and dacarbazine)

IMMUNOTHERAPY
- interferon alfa 2-b (Intron A)
- interleukin-12

TARGETED THERAPY
- denosumab (Xgeva)
- imatinib (Gleevec)
- olaratumab (Lartruvo)
- pazopanib (Votrient)
- regorafenib (Stivarga)
- sunitinib (Sutent)

As of 12/11/18

For people with sarcoma, palliative care may involve drugs to manage pain or nausea, radiation therapy to help relieve bone pain or chemotherapy to help shrink a tumor causing pressure or a blockage. It is available from the time you're diagnosed throughout the duration of your treatment, so don't hesitate to discuss it with your doctor.

FOLLOW-UP CARE

Sarcoma that returns after treatment is called recurrent cancer. To monitor for a recurrence, follow-up visits are generally recommended every four months for the first two to three years, with longer intervals after that. Your doctor will establish a schedule for you. Depending on the type of sarcoma, your appointment may include a physical exam, blood tests, bone scan and imaging studies, such as computed tomography (CT), magnetic resonance imaging (MRI) and ultrasound. ■

ADDITIONAL RESOURCES

- **American Cancer Society:** www.cancer.org
  Treating Soft Tissue Sarcomas
  Bone Cancer
- **American Society of Clinical Oncology:** www.cancer.net
  Sarcoma, Soft Tissue: Treatment Options
- **National Cancer Institute:** www.cancer.gov
  Soft Tissue Sarcoma
- **Sarcoma Alliance:** www.sarcomaalliance.org
- **Sarcoma Alliance for Research through Collaboration (SARC):** www.sarctrials.org

Clinical Trials Lead to Promising Advances

Today's clinical trials are tomorrow's standard of care treatments, and they are a treatment option worthy of serious consideration for anyone who has cancer — and especially for those diagnosed with a rare cancer.

Hundreds of sarcoma clinical trials are currently taking place across the country to evaluate different aspects of sarcoma treatment, from new drug therapies to tests for identifying biomarkers. As a direct result of clinical trials such as these over the years, people are enjoying longer, better quality lives.

Each clinical trial is carefully designed and planned, then conducted according to rigorous standards to ensure consistent and safe treatment for every patient. Institutional Review Boards, the Data and Safety Monitoring Board and the FDA dictate strict safety measures to protect people who participate in clinical trials. Each study also has eligibility requirements, such as the subtype and stage of sarcoma, conditions specific to what the trial is studying, treatment history, age, overall health and other criteria.

It's important to know that if you choose to take part in a clinical trial, you will always receive the equivalent of the current standard of care treatment for your type and stage of cancer.

Benefits and Risks

Participating in a sarcoma clinical trial offers many potential benefits.

- Allows you access to leading-edge treatments that aren't yet commercially available.
- Provides an alternative if your current treatment no longer works as well as before or if the sarcoma is so rare that no standard treatment exists.
- Ensures even closer monitoring than usual by medical professionals as they gather required data on your progress.
- Gives you the opportunity to contribute to medical science by helping researchers find new and better treatments for future sarcoma patients.

Clinical trials may also pose potential risks and inconveniences. Nearly all cancer treatments have side effects, and therapies studied in clinical trials are no different. It's also possible the treatment won't be more effective than the current standard. In addition, clinical trials have a prescribed schedule that could conflict with yours, so before you commit, check your calendar to make sure you'll be available during the stated timeframe.

How to Search for a Clinical Trial

In addition to talking with your doctor about clinical trials, you can search for them on your own. Many online resources are available, but navigating through thousands of clinical trials may be overwhelming and confusing. Step-by-step instructions below will help guide you.

Before you begin, have your exact diagnosis, pathology report and a list of your previous treatments handy. If you don't find a clinical trial right away, keep checking because new trials are frequently added. You may choose to continue searching while you move ahead with your current treatment plan. If you're interested in a clinical trial that no longer accepts participants, your doctor may be able to appeal to the U.S. Food and Drug Administration (FDA) for expanded access known as "compassionate use."

[STEP 1] FILL IN YOUR INFORMATION

Enter Your Diagnosis
For example, enter "sarcoma." To get more results, do additional searches such as "pediatric sarcoma," "soft tissue sarcoma," "Ewing sarcoma," "advanced sarcoma," etc., and compare results.

Desired Location
If you prefer a clinical trial close to home, enter your address. If you have the ability to travel for treatment, enter additional locations.

Other Terms
Refine your search by adding a type of treatment, such as "targeted therapy," or a specific drug name. You may also add a Clinical Trial Identifier, which is an eight-digit code (preceded by "NCT") assigned to each trial.

Understanding Informed Consent

Choosing to participate in a sarcoma clinical trial is a significant decision. A process called Informed Consent helps you make sure the clinical trial you're considering is the right fit.

Once you confirm your interest with your doctor, you'll get detailed instructions and an Informed Consent form. The form will outline the clinical trial's purpose, how it will work, safeguards in place, potential benefits and risks, possible side effects, how you'll be monitored, number of appointments, patient rights and privacy information and more. The form should also state the treatment that is the current standard of care for your subtype and stage of sarcoma.

Take time to review the form thoroughly and discuss your questions or concerns with your doctor. Before you sign, contact your insurance provider(s) to find out which procedures, tests and appointments are covered and which (if any) you'll be expected to pay.

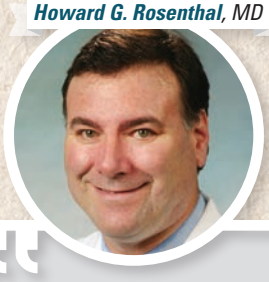
Once you've weighed the benefits and risks and have decided the clinical trial is right for you, sign and return the Informed Consent form. Understand that signing the form doesn't "lock you in" to the clinical trial. Participating in a clinical trial is voluntary. You have the right to withdraw from the study at any time and for any reason. Just let your doctor know your decision to switch to standard of care.

From the Physician's Desk

***Raphael E. Pollock**, MD, PhD, FACS*

Sarcoma clinical trials have led the oncology field in a number of areas. A clinical trial determined limb salvage surgery was just as effective as amputation, with far more manageable side effects.

***Howard G. Rosenthal**, MD*



We seek to educate our patients and their families about this rare cancer and the treatment options available. Our ultimate goal is to eradicate the patient's cancer and help him or her resume a normal, active lifestyle.

Consent Differs for Children

Parents must give consent for a child younger than 18 to participate in a clinical trial. However, it is important for children to be included in the process so they can better understand their treatment plan. The research will be explained in age-appropriate language using videos or other visuals (see *Pediatric Sarcoma,* page 10). ■

Find a Sarcoma Clinical Trial

→ Check out these online resources to search for clinical trials that may be available to you.

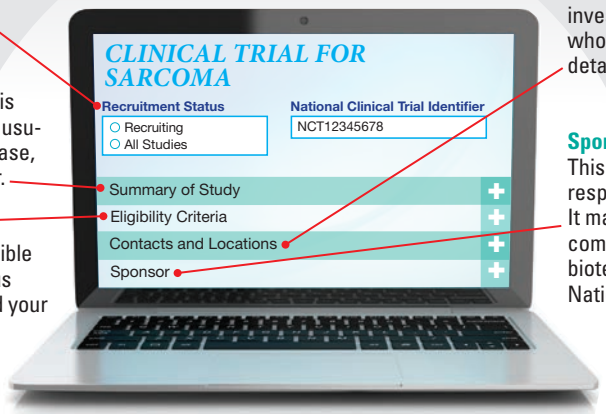
- **Accrual Net:** accrualnet.cancer.gov
- **Center for Information and Study on Clinical Research Participation:** www.searchclinicaltrials.org
- **CenterWatch:** www.centerwatch.com
- **ClinicalTrials.gov:** www.clinicaltrials.gov
- **Coalition of Cancer Cooperative Groups:** www.cancertrialshelp.com/cancer-trial-search
- **My Clinical Trial Locator:** www.myclinicaltriallocator.com
- **Sarcoma Alliance for Research through Collaboration (SARC):** www.sarctrials.org

[STEP 2] READ YOUR SEARCH RESULTS

Recruitment Status
This indicates whether the trial is actively seeking patients, not yet recruiting or is otherwise inactive. The status will change, so check for updates.

Summary of Study
Here you'll find details about the purpose of the clinical trial and the treatment being studied. This section may be difficult to interpret because it's usually written for a medical provider. If that's the case, print the information to discuss with your doctor.

Eligibility Criteria
This outlines the criteria you must meet to be eligible for the trial, such as the stage of disease, previous treatments you have had, sites of metastasis, and your age and overall health.



Contacts and Locations
This may include contact information for clinical trial investigators, staff or sponsors, who may be able to offer more details about the study.

Sponsor
This is the organization responsible for the clinical trial. It may be a pharmaceutical company, university, biotechnology company or the National Cancer Institute.

Childhood Cancer: Arm Yourself with Knowledge

Hearing that your child has cancer is shocking. Although little is known about what causes childhood cancer, it may be comforting to know that current research and advances are dramatically improving the way it is being treated and cured, which is bringing hope to many families.

After learning of the diagnosis, consider consulting with a doctor and/or treatment center with expertise in treating pediatric sarcoma. They, along with the resources in this guide, will be valuable sources of information. Understanding more about your child's diagnosis will better prepare you for the decisions ahead.

There are many types of pediatric sarcoma. They can begin in bones or soft tissues, which connect, support and surround organs and other areas. Soft tissues include blood vessels, fat, fibrous tissue, muscles, nerves, lymph vessels, synovial tissues (around joints), tendons and a mix of bone and cartilage.

The three most common pediatric sarcomas are Ewing sarcoma, osteosarcoma and rhabdomyosarcoma. Ewing sarcoma and osteosarcoma are staged with the American Joint Committee on Cancer (AJCC) staging system. Rhabdomyosarcoma has a grouping system and staging system. In general, the more cancer cells look like normal cells under a microscope, the more "favorable" they are and the greater the chance that treatment will be successful. Your doctor will be able to develop a plan of treatment most suited to your child once the appropriate diagnosis is made and staging studies (including X-rays and biopsy) are completed.

Following are brief descriptions for each type and treatment options.

Ewing sarcoma is a family of cancers that can form in the bones or nearby soft tissues. It most often develops in children and young adults between the ages of 10 and 20 and is more common in girls than boys. When it forms in the bone, it usually develops in the leg, pelvis, rib, arm or spine. In soft tissue, it more often develops in the thigh, pelvis, spine, chest wall or foot.

To plan treatment, doctors typically consider the stage and whether the Ewing sarcoma is localized, metastatic (spread to other areas) or recurrent (cancer that returns). The primary treatment is multidrug chemotherapy in combination with surgery and radiation therapy (see *Treatment Options,* page 6). Exploring clinical trials is highly recommended with this cancer because research is ongoing for newer treatment options (see *Clinical Trials Lead to Promising Advances,* page 8).

Osteosarcoma primarily affects and weakens bones anywhere in the body and can destroy tissue near bones. The disease begins when immature bone cells become cancer cells instead of developing into mature bone cells. Osteosarcomas most commonly start in the bones around the knee joint, including the femur (lower end of the thigh bone) or the tibia (upper end of the shin bone), or the humerus (upper arm bone between elbow joint and shoulder). It is rare for osteosarcoma to develop in soft tissues. It primarily affects teens and young adults in their twenties. Osteosarcoma has two main subtypes: central tumor (medullary tumor) or surface tumor (peripheral tumor). Each of these subtypes also has subtypes.

Doctors typically describe osteosarcomas as localized (only in the bone), metastatic (spread to other areas) or recurrent (cancer that returns). Surgery is the primary treatment, and clinical trials should be considered.

Rhabdomyosarcoma is a type of soft tissue sarcoma that forms in the immature cells that normally become striated muscle. These are muscles people can control. It can develop anywhere in the body, including the head and neck, urinary or reproductive organs, arms or legs, the trunk, lungs and other areas. It is slightly more common in boys than in girls and is most common in children under the age of 5.

This sarcoma has three subtypes: embryonal, alveolar and anaplastic. Embryonal is the most common and occurs most often in the head and neck area or in the genital or urinary organs. Alveolar tends to occurs in the arms or legs, chest, abdomen, genital organs or anal area. Anaplastic rarely occurs in children. Other less common types of sarcoma can form in tendons, nerves or blood vessels.

Surgery and combination chemotherapy (two or more chemotherapy drugs used together) are the main treatments for rhabdomyosarcoma. Every child treated for this type of sarcoma should receive chemotherapy to decrease the chance cancer will recur.

Most bone and soft tissue sarcomas in the pediatric population are treated in a limb preservation fashion, which is the removal of the tumor and parts of the limb that are affected by the cancer. This is followed by rebuilding or reconstructing the limb so that

Late Effects of Pediatric Sarcoma

Children who are treated for pediatric sarcoma may experience some side effects later in life — these are called late effects. They can happen months or even several years post-diagnosis. Ask for a list of symptoms to watch for and, if they occur, alert your health care team immediately. Establishing a follow-up plan with your doctor will ensure that the late effects are dealt with accordingly and in a timely manner. Below are some possible late effects of pediatric sarcoma treatment.

Changes in bodily function and capabilities. Children who undergo surgery and radiation to treat sarcoma may experience joint, bone and muscle changes, as well as delays in growth.

Exposure to viruses. If the child received any blood transfusions during sarcoma treatment, he or she will be tested for HIV, the hepatitis virus and HTLV-1, which have small transfusion-associated risks.

Gonadal dysfunction. Chemotherapy may affect sex hormone production. This, in turn, can lead to infertility, early menopause and brittle bones. Decreased sex hormone levels may also increase the risk for heart attack, fracture and obesity.

Heart or lung problems. Chemotherapy treatment may cause acute and late injuries to the cardiac muscle or lungs.

Immune function. After chemotherapy, a child's immune system may be weakened for up to nine months, leaving him or her more vulnerable to diseases and infections.

Kidney function. Certain chemotherapy drugs may affect kidney function.

Psychosocial problems. Cancer diagnosis and treatment can pose a significant life stress that can lead to issues in relationships, education, health care and professional and personal goal-setting.

the child regains function. Even in patients who have significant growth left, newer technologies allow surgeons to rebuild the limb in a functional and cosmetically pleasing fashion in the vast majority of cases.

SPECIAL CONSIDERATIONS

Treating children is not like treating adults. Children's bodies are still growing, and they have different physical and emotional needs. Talk to your child's health care team to help create a care plan, and consider these factors.

1. **Get a second opinion.** Seeing a different pediatric oncologist will either confirm the original diagnosis and treatment recommendations or offer new information to consider.
2. **Explore clinical trials.** Clinical trials are often recommended for treating childhood cancer. They may offer your child access to promising new treatments that aren't available outside of the trial. Children younger than 18 are legally unable to give "informed consent" to take part in a clinical trial, so parents must do so (see *Clinical Trials Lead to Promising Advances,* page 8). Children mature enough to understand will be involved in the "assent process." The research will be explained in kid-friendly language using videos or other visuals before the child is asked if he or she "assents" (agrees) to take part.
3. **Consider fertility preservation.** Some cancer treatments may cause infertility. If possible, talk to your child's doctor before treatment begins to determine the fertility preservation options that may be available. Options for boys and girls will depend on whether they have reached puberty. For girls, oocyte (unfertilized egg) freezing or ovarian tissue freezing followed by transplantation may be considered. For boys, sperm banking and testicular tissue freezing may be options.
4. **Prepare for side effects.** Side effects generally occur during treatment, while late effects may occur after treatment ends or even decades later. Ask your doctor about the potential side effects for each type of treatment, and keep in mind that not everyone experiences the same ones (see *Side Effects,* page 14). ■

ADDITIONAL RESOURCES

- **Cancer*Care* for Kids:** www.cancercareforkids.org
- **Sarcoma Alliance:** www.sarcomaalliance.org *Children with Sarcoma*

Guiding Your Child through Cancer and its Treatment

Children with cancer need special care. Although they may experience some of the same challenges as adults, they need your help to manage some of the problems that can occur.

They may feel their world has been turned upside down by a cancer diagnosis. Depending on their age, they may even have difficulty understanding the concept of cancer. You are a vital part of helping your child understand what is happening and cope. You may feel overwhelmed at times, but you are still the same mom or dad who has always supported them. Keep in mind that being flexible, patient and honest is very important from diagnosis through treatment and beyond.

Your physician and staff will care for your entire family as they understand siblings and family members will be affected by your child's diagnosis. Support groups, educational material and even other patients who have gone through similar situations can be sources of support.

- **Good nutrition is very important for children going through treatment.** Cancer and treating it can take a toll on the body and may make it difficult to get all of the nutrition needed to fight cancer and recover. Children's bodies are still maturing, and they need the nutrients from a healthy diet to continue growing. Good nutrition prevents weight loss, maintains strength and energy, enables them to tolerate side effects better, reduces the risk of infection and may help them recover faster.
- **Appetite loss may be a challenge.** Food may not sound good, especially if your child feels nauseated. There are many ways to encourage your child to eat. Be flexible with meals and mealtimes. Your child should eat whenever he or she is hungry. Consider offering several small meals and snacks instead of three large meals. If your child is having difficulty consuming enough calories, include high-calorie and high-protein foods. Even hamburgers, fries, pizza and ice cream are okay if your child wants them. The body requires a lot of calories when it is healing.
- **Make mealtimes fun**. Ideas include cutting sandwiches into shapes, making faces out of fruits and vegetables and using colorful plates, cups and straws. Change up normal meals. For example, have pizza for breakfast or pancakes for dinner. Take meals to the backyard or serve them on a blanket on your living room floor.
- **Support your child emotionally.** They may struggle with their feelings and may need your guidance to make sense of what is happening. Don't push your child to share his or her feelings. Find activities to boost your child's spirits, such as shopping, reading, watching movies or playing games. Watch for signs of depression. Call the doctor if you notice your child is frequently sad or appears depressed.
- **Encourage continued friendships with family members and friends.** Phone calls, texts, video chats and social media platforms make staying in touch easy, especially when an in-person visit may not be possible.
- **Explain possible changes in appearance that may be caused by treatment.** Physical changes caused by treatment may be upsetting to your child, especially if he or she is at a sensitive age. Teens often put a lot of value in appearance and may find some of the physical changes, such as hair loss, embarrassing. Ask your child's doctor if you should expect hair loss. If so, let your child pick out ball caps, hats, scarves or wigs ahead of time. Encourage your child to wear them and get used to them before they become necessary.
- **Prepare them for returning to school after being out for treatment**. Your doctor will determine if returning to school is medically appropriate for your child. It may be helpful to have a member of the medical team contact the school to explain necessary precautions, make a plan for managing side effects and answer any questions they may have. You may want to set up meetings with your child's teacher, school nurse and principal to prepare for your child's return. Although some children may be excited to return to school, others may be nervous or afraid. Socially, they may experience children who don't know how to act when a classmate is ill. Make a plan for how your child can respond to or ignore those moments. Some children may have difficulty concentrating or doing school work as a result of treatment side effects. You may need to work with the doctor and the school to determine the best course of action for your child.
- **Stay positive.** A positive attitude will go a long way to supporting your child. Trust your instincts and, remember, you are not alone. Your child's medical team will be there to help and provide resources for other services or support.

Survivor Finds Hope Helping Others

For the past 16 years, Suzie Siegel has managed leiomyosarcoma and the late effects of treatment, facing each challenge head on with the support of dear friends and skilled medical teams. She channels her energy into educating others and helping newly diagnosed patients cope.

Humor has gotten me through life, from poverty and crazy family dynamics to caring for family members and having a tough job as a journalist. I suffered from anxiety and depression before being diagnosed with a rare cancer called leiomyosarcoma. That didn't help.

A gynecologist at my college health center saw what appeared to be a tiny cyst in my vagina. An ultrasound indicated it was benign. After I graduated with a master's degree in women's studies, I moved home to Texas to help care for my father, who had Alzheimer's disease.

Within six months, I began bleeding between periods. A gynecologist thought my "cyst" was cancer. My student health insurance had run out, and I couldn't get private insurance. The doctor suggested I wait six weeks for a biopsy, when my insurance in the Texas risk pool would start. I began bleeding a lot and had a foul odor. The tiny cancer grew to 12 centimeters and poked outside of my body. I'm one of the few people who has actually seen their tumor while it was still growing. My doctor told me to hold on.

I kept busy. I sold my father's home; bought a new one in another city and moved in with my sister, her son, a St. Bernard and my father.

Finally, it came time for my biopsy. A pathologist who didn't specialize in sarcoma thought I had carcinosarcoma. A gynecologic oncologist tried to prepare me for a life-changing radical hysterectomy, in which my uterus, ovaries and part of my vagina would be removed. I was 43. I still had plans for my vagina. Nevertheless, I do best in a crisis. I told the doctor: I'm ready NOW.

After surgery, I had a lot of pain and felt traumatized. But a nurse told me about her own hysterectomy. She was kind but firm as she encouraged me to get up and accept the rough road ahead. With a walker, I made my way to the gift shop to get a birthday card for my elderly roommate who was dying. Thinking about others can help you not think about yourself.

Two pathology reports were needed to confirm that my cancer was actually pleomorphic leiomyosarcoma, a soft-tissue sarcoma of smooth muscle.

My surgeon had tried, but failed, to get clear margins against my bladder. I had two options. He could remove my bladder or I could do pelvic radiation. I chose the latter, which caused severe diarrhea one week and constipation the next. As a sitz bath soothed my vaginal-anal area, a friend sat on the edge of the bathtub with his guitar, taking requests.

After radiation, I went to a large sarcoma center to get a second opinion from a medical oncologist. Within a few months, my cancer metastasized to my right lung. My medical oncologist and gynecologic oncologist agreed on a chemotherapy that was experimental for leiomyosarcoma.

I did it for a year, until the 1-centimeter metastasis disappeared. After my father passed, I returned to Florida, where I had a larger support system. My friends have been wonderful, and we share a wicked sense of humor about my health problems.

About a year and a half after my first lung met, I got another tiny one. My medical and thoracic oncologists recommended surgery, which I had.

In my original surgery, nerves to my bladder were cut inadvertently. For eight years, I had to catheterize myself to fully empty my bladder. Eventually I needed to wear a diaper, and I was prone to antibiotic-resistant infections. Because I hated to lose my bladder, I got opinions from five urologists. I even talked to a tarot-card reader. She was a retired nurse, and she persuaded me to get a urostomy.

Scar tissue from that surgery led to partial bowel obstructions. Once again, I had to wear a diaper because of incontinence. The nausea and vomiting got so bad that I was ready for hospice, but my doctor's compassion convinced me to hold on. Finally, I had surgery to cut apart the adhesions. The obstructions returned a couple of years later, and he had to make a permanent colostomy for me.

Obstructions have come back again, as have resistant urinary tract infections. With each event, I focus on what I need to do next.

Contemplating the end of your existence is hard. Instead, I channel my anxiety into whether people like me and other pointless things. Some days I feel angry, frustrated and powerless. Telemarketers usually get the brunt of it.

I work almost every day on sarcoma advocacy. After my first surgery, I called a nonprofit that matched me with a peer-to-peer volunteer who had survived leiomyosarcoma. She greatly encouraged me. I then became a peer volunteer as well. I've used retirement savings to travel to cancer conferences. I tweet about sarcoma research and have more than 1,000 followers, and I write articles on sarcoma.

I encourage people who are newly diagnosed to see a sarcoma specialist, at least for a second opinion, and to learn about sarcoma from reliable sources. Being able to have a good conversation with your medical team is the first step to advocating for yourself. ■

Find Relief and Increase Your Comfort

Pain management has many benefits. Several options are available to help manage and relieve pain associated with the sarcoma itself, the location of the tumor, diagnostic procedures and treatment.

Studies show that people with cancer who have their pain under control are much more likely to finish their treatment on schedule. Your health care team must understand the type of pain you're experiencing, and that requires you to keep them informed. Keep a detailed diary that you can share with your doctor. Track when pain occurs, how long it lasts, what causes it and if anything makes it better. Speak up when you first begin to feel it. It's much easier to get ahead of it than treat full-blown pain.

People who feel better are often more active, which can positively affect overall health and emotional well-being. Be sure to talk with your treatment team about the pain relief options available to you.

CATEGORIES OF PAIN

Cancer-related pain is grouped into three categories.

1. **Acute pain** occurs suddenly. It may be related to a diagnostic procedure or treatment and usually resolves once the body recovers and heals.
2. **Chronic pain**, also called persistent pain, lasts for at least one month (typically longer) after treatment and is usually the direct effect of a tumor or cancer treatment.
3. **Breakthrough pain** includes severe flares of pain that "break through" during treatment, even with pain medication. Breakthrough pain can range from mild to severe, lasting minutes to hours.

PAIN MANAGEMENT OPTIONS

Your doctor may recommend one or more of the following strategies.

Pain medications, a practice known as pharmacotherapy, are a common way to alleviate pain. Mild pain can often be controlled with over-the-counter pain relievers, whereas more severe pain will likely require stronger medications prescribed by your doctor. Types of pain medications include the following.

- **Nonsteroidal anti-inflammatory drugs** (NSAIDs), or nonopioid analgesics, are intended to relieve mild-to-moderate pain. These drugs are typically available without a prescription.
- **Opioid analgesics,** or pain relievers, are prescribed to decrease both the perception of and reaction to pain.
- **Adjuvant analgesics,** including certain antidepressants and anticonvulsants, are designed to relieve pain related to damaged nerve cells or nerve swelling by changing how the affected nerves generate pain signals.
- **Bone-modifying agents** help reduce pain related to bone complications from metastatic cancer.

Percutaneous pain techniques include nerve blocks, ablative procedures (those that remove body tissue) and vertebroplasty/kyphoplasty or cementoplasty (filling the spinal bones with cement to stabilize them and/or reduce pain).

Targeted drug delivery may be an option if you cannot find pain relief with other pain medication (oral, intravenous, etc.) or if you cannot tolerate side effects. A targeted drug delivery system consists of a small pump and a catheter that deliver pain medication directly to the fluid surrounding the spinal cord (the intrathecal space). The system has been shown to be safe and effective for patients at all stages of the care continuum, especially during end-of-life care.

Intrathecal drug delivery, also called a "pain pump," sends pain medication directly to your spinal cord through the action of a small pump implanted in the body through an incision in your abdominal wall.

Neurosurgical procedures are designed to stop pain at its source by modifying specific brain and spinal cord fibers that carry pain signals. These procedures are performed by a neurosurgeon, a specialist in surgery on the brain, spinal cord and other parts of the nervous system.

Physiatry, or physical medicine and rehabilitation, helps relieve pain through customized therapy programs designed to enhance mobility, overcome disabilities, improve physical strength and manage pain and other symptoms. Anti-inflammatory injections are a part of this technique.

Integrative oncology addresses symptom control with complementary therapies combined with traditional cancer treatments only shown to be beneficial and safe. Those most commonly used for cancer-related pain include mind-body therapies, acupuncture, and manipulative and body-based therapies.

Palliative treatment uses radiation therapy, chemotherapy or surgery to improve your quality of life, rather than to cure the cancer. ■

ADDRESSING OPIOID CONCERNS

The opioid crisis is a growing problem that is often highlighted in the media. The fear of addiction may make you hesitate to take prescription medications. It's important to remember that opioids are only one option for cancer pain. Your doctor will likely consider a variety of nonopioid strategies first to relieve pain, depending on its type and severity. Your treatment team will evaluate your pain level on an ongoing basis to determine if other strategies will be needed to make you more comfortable.

Do not let the fear of addiction keep you from finding pain relief. If your doctor prescribes opioids, you will be monitored closely throughout treatment. Remember, this type of pain is the reason these medications exist.

PAIN MEDICATION QUESTIONS FOR YOUR DOCTOR Knowing what to expect when taking pain medication is important for controlling your pain and keeping you safe. Ask your doctor these questions about taking pain medication.

- What is the dosage, and how often is it taken?
- How long does it take for the medication to start working?
- How long will the pain relief last?
- Should the medicine be taken with food, other medications or supplements?
- What are the common and/or potentially serious side effects?
- What do I do if I take too much medication?
- What if I miss a dose?
- Whom do I call if I have concerns?

ADDITIONAL RESOURCES

- **Cancer*Care*:** www.cancercare.org
  Managing Cancer Pain: What You Need to Know
- **Cancer Pain Research Consortium:** www.cancerpainresearchconsortium.org
  Patient Resource Guide

Plan for Treatment-Related Side Effects

Sarcoma treatment side effects can differ from person to person, even between people with the same type and stage of sarcoma receiving the same treatment. Partnering with your health care team to manage them is crucial. The better you feel, the more likely you'll be to complete your scheduled treatment, which can improve your outcome.

Talk to your doctor before treatment begins about the side effects to expect, and find out how to prevent or minimize them (see Table 1). The key is to report side effects as soon as symptoms occur. By addressing them early, your doctor may head off potential complications that could interrupt your treatment. Your health care team will rely on you to communicate regularly so they can help you be more comfortable.

Surgical side effects most commonly include fatigue in the days and weeks following a surgical procedure. The healing of a wound requires a large number of calories (energy obtained from nutrition). Even though you may eat a normal amount following surgery, those calories go to healing of the surgical wound and immune system, thus depleting the rest of the body of calories, leading to fatigue. This process recovers over a period of time. Stiffness and weakness may also occur. Your doctor may prescribe physical therapy for these problems.

In addition to killing cancer cells, radiation therapy may cause damage to normal tissues, which can lead to side effects. Fatigue and skin problems are common. Side effects vary according to the area of the body being treated, the dosage and treatment schedule, your overall health and whether you are receiving any other treatment along with radiation therapy.

Drug therapies also result in certain side effects. Severe side effects are not common, but they can occur with some types of treatment, such as immunotherapy. Immune-related adverse events (IRAEs) can develop rapidly and become potentially life-threatening without medical attention. Cytokine release syndrome is an IRAE associated with adoptive T-cell therapies and monoclonal antibodies. Reactions are usually mild but can be severe and even life-threatening. Symptoms include headache, fever, nausea, rash, low blood pressure, rapid heartbeat and difficulty breathing. Remain alert to symptoms and report them for at least three months after you complete treatment.

If a side effect is very severe, you may need to stop your treatment for a period of

TABLE 1
STRATEGIES FOR MANAGING COMMON PHYSICAL SIDE EFFECTS

Side Effect	Related Treatment	Ways to Manage
Alopecia (hair loss)	Chemotherapy, radiation therapy, targeted therapy	Consider a cooling cap, and sleep on a satin pillowcase. Try hats, caps, scarves, a wig or go natural. Your doctor's prescription for a "cranial prosthesis" may make the wig eligible for insurance coverage.
Anemia (low red blood cell count)	Chemotherapy	Get plenty of rest and regular physical activity to manage fatigue and weakness.
Changes in appetite	Chemotherapy, radiation therapy, surgery	Eat smaller, more frequent meals. Eat when most hungry, and stock up on high-calorie snacks.
Cognitive dysfunction ("chemo brain")	Chemotherapy, radiation therapy	Take notes, keep lists and use a planner. Don't multitask. Ask loved ones for reminders and help with decision-making.
Constipation	Chemotherapy, radiation therapy	Take laxatives only after checking with your doctor. Eat high fiber foods, drink plenty of fluids and establish regular bowel habits.
Diarrhea	Chemotherapy, immunotherapy, radiation therapy, targeted therapy	Take antidiarrheal medication only after talking to your doctor. Report episodes severe enough to keep you housebound. Eat smaller, more frequent meals, avoid greasy foods and drink plenty of fluids.
Edema (swelling from fluid buildup in tissues)	Immunotherapy, targeted therapy	Contact your doctor about swelling, stiffness or a heavy feeling in your limbs, or rapid weight gain. Limit salt, wear loose clothing and prop your feet up.
Fatigue	Chemotherapy, immunotherapy, radiation therapy, surgery, targeted therapy	Engage only in activities most important to you, balancing activity with rest. Try power walking, working up to 30 minutes five times a week.
Infertility	Chemotherapy, immunotherapy, radiation therapy, surgery, targeted therapy	Ask your doctor before beginning treatment about the risk. Explore your fertility preservation options with a fertility specialist.
Lymphedema	Radiation therapy, surgery	Ask your health care team about lymphedema care and compression garments. Elevate a swollen limb.
Mouth sores	Chemotherapy, targeted therapy	Report symptoms promptly. Brush teeth often with a soft-bristle toothbrush. Eat soft foods and drink plenty of fluids.
Nausea, vomiting	Chemotherapy, immunotherapy, radiation therapy	Take antiemetics as prescribed. Eat smaller, more frequent meals and drink plenty of fluids to avoid dehydration. Avoid bad odors.
Neuropathy	Chemotherapy	Avoid tight clothes and shoes. Keep hands and feet warm. Avoid standing for long periods.
Neutropenia (low white blood cell count)	Chemotherapy, immunotherapy, radiation therapy	Wash your hands frequently to help prevent infection. Avoid crowds and people who are or have been sick. Ask your doctor about "neutropenic precautions."
Pain (abdominal, muscle, joint)	Immunotherapy, surgery, targeted therapy	Ask your doctor immediately about options for pain relief (see *Pain Management,* page 13).
Skin reactions	Chemotherapy, targeted therapy, radiation therapy	Use mild soap and thick moisturizer (no alcohol, dye or perfume). Talk to your doctor if a rash becomes painful or itchy.

SURVIVOR VOICE

"I don't believe your outcome is determined by your attitude, but I do believe having the right mentality can help you face terrible things."

~ ***Alison Olig**, pediatric sarcoma survivor*

time or permanently. However, prompt recognition and early management can often result in rapid resolution and allow you to stay on treatment longer. Thus, it is important to report any side effects to your doctor or nurse as soon as possible.

Make sure you and your caregiver know which symptoms require immediate medical attention and whom to contact. Always seek immediate treatment for medical emergencies such as shortness of breath, high fever, inflammation, swelling or severe abdominal pain. It's a good idea to post your doctor's contact information, including after-hours telephone numbers, in a convenient location. ■

ADDITIONAL RESOURCES

- **American Cancer Society:** www.cancer.org
  Cancer Treatment Side Effects
- **American Society of Clinical Oncology:** www.cancer.net
  Side Effects
- **Cancer*Care*:** www.cancercare.org
  Sarcoma Patient Support Group
- **Cancer Support Community:** www.cancersupportcommunity.org
  Emotional Distress
  Treatment Side Effects
- **National Cancer Institute:** www.cancer.gov
  Feelings and Cancer
- **Patient Resource:** www.patientresource.com/Treatment_Side_Effects.aspx
- **RT Answers:** www.rtanswers.org

Take care of your emotional well-being

A cancer diagnosis and treatment can be overwhelming, and you may feel a variety of intense emotions. Along with the suggestions below, you may consider talking with a therapist or mental health professional. Being emotionally healthy will help you better cope with cancer-related issues, so don't be embarrassed or hesitant to ask your health care team for a referral.

Anger is common before, during and even long after cancer treatment. To avoid expressing bottled up anger in unhealthy ways, find safe and healthy alternatives. Explain your feelings to a trusted friend. Yell at the top of your lungs while you are alone, hit a pillow with your fists or a foam bat, or participate in intense physical activity.

Anxiety, or persistently feeling nervous, stressed or worried, may make it difficult to cope with treatment, function day to day or for your body to properly heal. Explore relaxation techniques such as deep breathing, meditation, muscle relaxation, yoga or massage. Share your anxieties with a good listener. Eliminating caffeine may also be helpful.

Depression is most likely to occur for people with cancer during times of unrelieved symptoms, and it may also be a side effect of certain cancer therapies. It's extremely important to talk with your doctor about feeling sad, numb, hopeless, helpless, worthless or guilty if the feelings last more than a few days. Seek medical attention immediately if you have thoughts of death or suicide, or of hurting yourself or others.

Emotional overload is common because everything you're dealing with can seem overwhelming. Try taking charge of the things you can control, and be better prepared by learning all you can about your treatment plan. Ask loved ones to handle routine decision-making for you for now.

Fear is a common reaction to a cancer diagnosis and to undergoing cancer treatment, as you can't predict how you'll respond to either one. You may also fear possible changes in your appearance, sexuality or perceptions from others. Try learning all you can about your treatment plan to minimize surprises. Talk with others undergoing similar treatment and explore relaxation techniques.

Grief is an emotion many people with cancer don't expect, but you may mourn the loss of your health or of a future without the fear of cancer recurrence. Your diagnosis may also trigger grief from losing a loved one to cancer in the past. Give yourself permission to grieve, feel a full range of emotions and turn to loved ones for support.

Guilt may occur if you blame yourself for getting cancer because of health-related actions you did or didn't take, or if you feel you're upsetting or being a burden to loved ones. You may even feel guilty about having a negative attitude. Give yourself a break when your attitude isn't so positive. Share your feelings with other cancer survivors, or consider seeing a counselor.

Loneliness may occur if you feel no one understands, particularly since sarcoma is a rare cancer. You may also feel lonely if a friend or family member stops visiting or calling because he or she doesn't know how to act. Contact that person and suggest talking about anything other than cancer. Check out sarcoma support groups online, or contact someone in your spiritual community.

BASIC LIVING EXPENSES

American Childhood Cancer Organization ..... www.acco.org, 855-858-2226
Bringing Hope Home ..... www.bringinghopehome.org, 484-580-8395
Candlelighters Childhood Cancer Family Alliance ..... www.candle.org, 713-270-4700
Children's Cancer Recovery Foundation ..... www.childrenscancerrecovery.org, 717-688-7940
Cleaning for a Reason (free house cleaning service) ..... www.cleaningforareason.org, 877-337-3348
Compassion Can't Wait (for single parent families) ..... compassioncantwait.org, 310-276-7111
Family Reach Foundation ..... www.familyreach.org, 973-394-1411
Hugs and Kisses ..... www.hugsandkissesinc.org, 561-819-9471
Life Beyond Cancer Foundation ..... www.needhelppayingbills.com, 800-282-5223
The National Children's Cancer Society ..... www.thenccs.org, 314-241-1600
Stupid Cancer ..... www.stupidcancer.org, 877-735-4673
Team Continuum ..... www.teamcontinuum.net, 845-200-7094
Zichron Shlome Refuah Fund ..... www.zsrf.org, 718-438-9355

CANCER EDUCATION

Alex's Lemonade Stand Foundation for Childhood Cancer ..... www.alexslemonade.org
American Cancer Society ..... www.cancer.org
American Society of Clinical Oncology ..... www.cancer.net
CANCER101 ..... www.cancer101.org
Cancer*Care* ..... www.cancercare.org
CancerQuest ..... www.cancerquest.org
Centers for Disease Control and Prevention (CDC) ..... www.cdc.gov
The Gathering Place ..... www.touchedbycancer.org
Get Palliative Care ..... www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE) ..... www.cancergrace.org
The Hope Light Foundation ..... www.hopelightproject.com
LIVESTRONG Foundation ..... www.livestrong.org
National Cancer Institute ..... www.cancer.gov
National Comprehensive Cancer Network (NCCN) ..... www.nccn.org
National LGBT Cancer Network ..... cancer-network.org
NCI Contact Center (cancer information service) 800-422-6237
OncoLink ..... www.oncolink.org
Patient Power ..... www.patientpower.info
PearlPoint Nutrition Services ..... www.pearlpoint.org
Pine Street Foundation ..... pinestreetfoundation.org
Scott Hamilton Cares Foundation ..... www.scottcares.org
Triage Cancer ..... www.triagecancer.org
U.S. National Library of Medicine ..... www.nlm.nih.gov

CAREGIVERS & SUPPORT

4th Angel Patient & Caregiver Mentoring Program www.4thangel.org
CanCare ..... www.cancare.org
CANCER101 ..... www.cancer101.org
Cancer and Careers ..... www.cancerandcareers.org
Cancer*Care* ..... www.cancercare.org
Cancer Connection ..... www.cancer-connection.org
Cancer Hope Network ..... www.cancerhopenetwork.org
Cancer Information and Counseling Line 800-525-3777
Cancer Really Sucks! ..... www.cancerreallysucks.org
Cancer Support Community ..... www.cancersupportcommunity.org
Cancer Support Helpline 888-793-9355
Cancer Survivors Network ..... csn.cancer.org
Caregiver Action Network ..... www.caregiveraction.org
CaringBridge ..... www.caringbridge.org
Center to Advance Palliative Care ..... www.capc.org
The Children's Treehouse Foundation ..... www.childrenstreehousefdn.org
Cuddle My Kids ..... www.cuddlemykids.org
Family Caregiver Alliance ..... www.caregiver.org
Fighting Chance ..... www.fightingchance.org
Friends for Life Cancer Support Network www.friend4life.org, 866-374-3634
The Gathering Place ..... www.touchedbycancer.org
Guide Posts of Strength, Inc ..... www.cancergps.org
The Hope Light Foundation ..... www.hopelightproject.com
Imerman Angels ..... www.imermanangels.org
Lacuna Loft ..... www.lacunaloft.org
LIVESTRONG Foundation ..... www.livestrong.org
LivingWell Cancer Resource Center ..... www.livingwellcrc.org
Lotsa Helping Hands ..... www.lotsahelpinghands.com
MyLifeLine.org ..... www.mylifeline.org
The Lydia Project ..... thelydiaproject.org
Patient Empowerment Network ..... www.powerfulpatients.org
Patient Power ..... www.patientpower.info
SHARE Caregiver Circle ..... www.sharecancersupport.org/caregivers-support
Stronghold Ministry ..... www.mystronghold.org
Support Groups ..... www.supportgroups.com
Triage Cancer ..... www.triagecancer.org
Vital Options International ..... www.vitaloptions.org
Walk With Sally ..... www.walkwithsally.org
Well Spouse Association ..... www.wellspouse.org
weSPARK Cancer Support Center ..... www.wespark.org

CHEMOTHERAPY

Chemocare.com ..... www.chemocare.com
ChemoExperts ..... chemoexperts.com
The Chemotherapy Foundation ..... www.chemotherapyfoundation.com

CHILDHOOD CANCER

Alliance for Childhood Cancer ..... www.allianceforchildhoodcancer.org
American Childhood Cancer Organization ..... www.acco.org
ARCH National Respite Network and Resource Center ..... www.archrespite.org
Cancer*Care* for Kids ..... www.cancercareforkids.org
Candlelighters Childhood Cancer Family Alliance ..... www.candle.org
Children's Cancer & Blood Foundation ..... www.childrenscbf.org
Children's Cause for Cancer Advocacy ..... www.childrenscause.org
Children's Hospice International ..... www.chionline.org
Children's Organ Transplant Association ..... www.cota.org
CureSearch ..... www.curesearch.org
Curing Kids Cancer ..... www.curingkidscancer.org
Eagle Mount - Big Sky Kids Program (camps for children & young adults) ..... www.eaglemount.org
Jessie Rees Foundation ..... www.negu.org
Kids Kicking Cancer ..... www.kidskickingcancer.org
Kids Konnected ..... www.kidskonnected.org
Kids v Cancer ..... www.kidsvcancer.org
Make A Wish Foundation ..... www.wish.org
The National Children's Cancer Society ..... www.thenccs.org
National Pediatric Cancer Foundation ..... nationalpcf.org
Ronald McDonald House Charities ..... www.rmhc.org
Special Love for Children with Cancer ..... www.specialove.org
Starlight Children's Foundation ..... www.starlight.org
The Sunshine Kids Foundation ..... www.sunshinekids.org
SuperSibs! ..... www.alexslemonade.org/campaign/supersibs
Team Connor Childhood Cancer Foundation ..... teamconnor.org
The Ulman Cancer Fund for Young Adults ..... www.ulmanfund.org
Walk With Sally ..... www.walkwithsally.org
Wipe Out Kids' Cancer ..... www.wokc.org

CLINICAL TRIALS

AccrualNet ..... accrualnet.cancer.gov
ACT (About Clinical Trials) ..... www.learnaboutclinicaltrials.org
Center for Information and Study on Clinical Research Participation ..... www.searchclinicaltrials.org
CenterWatch ..... www.centerwatch.com
ClinicalTrials.gov ..... www.clinicaltrials.gov
Lazarex Cancer Foundation ..... www.lazarex.org
Lilly Oncology Clinical Trial Navigation Service 855-731-6039
Lilly Trial Guide ..... www.lillytrialguide.com
LIVESTRONG Foundation ..... www.livestrong.org
My Clinical Trial Locator ..... myclinicaltriallocator.com
National Cancer Institute ..... www.cancer.gov/clinicaltrials
NCI Contact Center (cancer information service) 800-422-6237
Sarcoma Alliance for Research through Collaboration (SARC) ..... www.sarctrials.org
TrialCheck ..... www.trialcheck.org

FERTILITY & CANCER

Alliance for Fertility Preservation ..... www.allianceforfertilitypreservation.org
American Society for Reproductive Medicine ..... www.reproductivefacts.org
LIVESTRONG Foundation ..... www.livestrong.org
RESOLVE: The National Infertility Association ..... www.resolve.org
SaveMyFertility ..... www.savemyfertility.org

FINANCIAL ASSISTANCE

BenefitsCheckUp ..... www.benefitscheckup.org
Bringing Hope Home ..... www.bringinghopehome.org
Cancer*Care* ..... www.cancercare.org/financial
Cancer Financial Assistance Coalition ..... www.cancerfac.org

HealthWell Foundation ..... www.healthwellfoundation.org
Hope Lodge ..... www.cancer.org/treatment/supportprogramsservices/hopelodge
Medicare.gov ..... www.medicare.gov
NeedyMeds ..... www.needymeds.com
Partnership for Prescription Assistance ..... www.pparx.org
Patient Access Network Foundation ..... www.panfoundation.org
Patient Advocate Foundation ..... www.patientadvocate.org
Patient Services, Inc. ..... www.patientservicesinc.org
RxAssist ..... www.rxassist.org
RxHope ..... www.rxhope.com
Social Security Administration ..... www.ssa.gov
Social Security Disability Resource Center ..... www.ssdrc.com
State Health Insurance Assistance Programs ..... www.shiptacenter.org
Stupid Cancer ..... www.stupidcancer.org

IMMUNOTHERAPY

The Answer to Cancer ..... www.theanswertocancer.org
Cancer Research Institute ..... www.cancerresearch.org
Society for Immunotherapy of Cancer ..... www.sitcancer.org

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline 866-276-7443

NUTRITION

American Cancer Society ..... www.cancer.org
Cancer*Care* ..... www.cancercare.org
LIVESTRONG Foundation ..... www.livestrong.org
OncoLink ..... www.oncolink.org
PearlPoint Nutrition Services ..... www.pearlpoint.org
Physicians Committee for Responsible Medicine ..... www.pcrm.org/health/cancer-resources

PAIN MANAGEMENT

American Chronic Pain Association ..... www.theacpa.org
American Society of Anesthesiologists ..... www.asahq.org
Cancer Pain Research Consortium ..... www.cancerpainresearchconsortium.org
LIVESTRONG Foundation ..... www.livestrong.org
The Resource Center of the Alliance of State Pain Initiatives ..... www.trc.wisc.edu
U.S. Pain Foundation ..... uspainfoundation.org

PRESCRIPTION EXPENSES

Cancer*Care* Co-Payment Assistance Foundation ..... www.cancercarecopay.org, 866-552-6729
Cancer Financial Assistance Coalition ..... www.cancerfac.org
Foundation for Health Coverage Education ..... www.coverageforall.org
GoodDays ..... www.mygooddays.org, 972-608-7141
HealthWell Foundation ..... www.healthwellfoundation.org, 800-675-8416
National Organization for Rare Disorders ..... rarediseases.org, 203-744-0100
NeedyMeds ..... www.needymeds.org, 800-503-6897
Partnership for Prescription Assistance ..... www.pparx.org
Patient Access Network Foundation ..... www.panfoundation.org, 866-316-7263
Patient Advocate Foundation Co-Pay Relief ..... www.copays.org, 866-512-3861
Patient Services, Inc. ..... www.patientservicesinc.org, 800-366-7741
RxAssist ..... www.rxassist.org
RxHope ..... www.rxhope.com
RxOutreach ..... www.rxoutreach.com, 888-796-1234
Singlecare ..... www.singlecare.com, 844-234-3057
Stupid Cancer ..... www.stupidcancer.org, 877-735-4673
Together Rx Access ..... www.togetherrxaccess.com, 800-444-4106

RADIATION ONCOLOGY

American Society for Radiation Oncology ..... www.astro.org
National Association for Proton Therapy ..... www.proton-therapy.org
Radcare.org ..... www.radcare.org
RadiologyInfo.org ..... www.radiologyinfo.org
RT Answers ..... www.rtanswers.org
Society of Interventional Radiology ..... www.sirweb.org

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Amgen Assist 360 ..... www.amgenassist360.com/patient, 888-427-7478
Bayer Patient Program 866-575-5002
Boehringer Ingelheim Cares Foundation Patient Assistance Program ..... www.boehringer-ingelheim.us/our-responsibility/patient-assistance-program, 800-556-8317
Bristol-Myers Squibb Access Support ..... www.bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation ..... www.bmspaf.org, 800-736-0003
Eisai Assistance Program ..... www.eisaireimbursement.com
Gleevec Patient Support Program ..... www.gleevec.com, 866-453-3832
Halaven Patient Assistance Program ..... www.eisaireimbursement.com/patient/halaven/financial-assistance, 866-613-4724
Intron A Patient Assistance Program www.merckhelps.com/intron%20%20a, 800-727-5400
Janssen CarePath ..... www.janssencarepath.com, 877-227-3728
Janssen Prescription Assistance ..... www.janssenprescriptionassistance.com
Johnson & Johnson Patient Assistance Foundation, Inc ..... www.jjpaf.org, 800-652-6227
Lartruvo Resources and Financial Assistance ..... www.lartruvo.com/resources-and-financial-support
Lilly Cares Foundation Patient Assistance Program ..... www.lillycares.com, 800-545-6962
Lilly PatientOne ..... www.lillypatientone.com/patient, 866-472-8663
Merck Access Program ..... www.merckaccessprogram.com/hcc/
Merck Helps ..... www.merckhelps.com, 800-727-5400
Novartis Financial Assistance ..... www.patient.novartisoncology.com/financial-assistance, 800-282-7630
Novartis Patient Assistance Now ..... patientassistancenow.com, 866-669-6682
Panretin Assistance ..... us.eisai.com/our-products/panrentin, 866-613-4724
Pfizer Oncology Together ..... www.pfizeroncologytogether.com/patient, 877-744-5675
Pfizer RxPathways ..... www.pfizerrxpathways.com, 844-989-7284
Sanofi Genzyme Patient Support Services ..... www.sanofigenzyme.com/en/patient-support/patient-services
Sanofi Patient Connection ..... www.sanofipatientconnection.com, 888-847-4877
Sancuso Patient Assistance ..... sancuso.com/patient/patient-assistance, 800-676-5884
Stivarga REACH Program ..... www.stivarga-us.com/getting-and-paying, 866-639-2827
Sutent Financial Assistance ..... www.pfizeroncologytogether.com/patient/sutent/patient-financial-assistance, 877-744-5675
Teva Cares Foundation Patient Assistance Programs ..... www.tevacares.org, 877-237-4881
Teva Oncology Core Reimbursement Assistance and Support ..... www.tevacore.com, 888-587-3263
Votrient Financial Resources ..... www.us.votrient.com/advanced-soft-tissue-sarcoma/patient-support/financial-resources, 888-669-6682
Xgeva Financial Resources ..... www.xgeva.com/financial-resources, 866-822-4832
Yondelis Janssen CarePath Savings Program ..... www.carepathsavingsprogram.com, 844-966-3354

SARCOMA

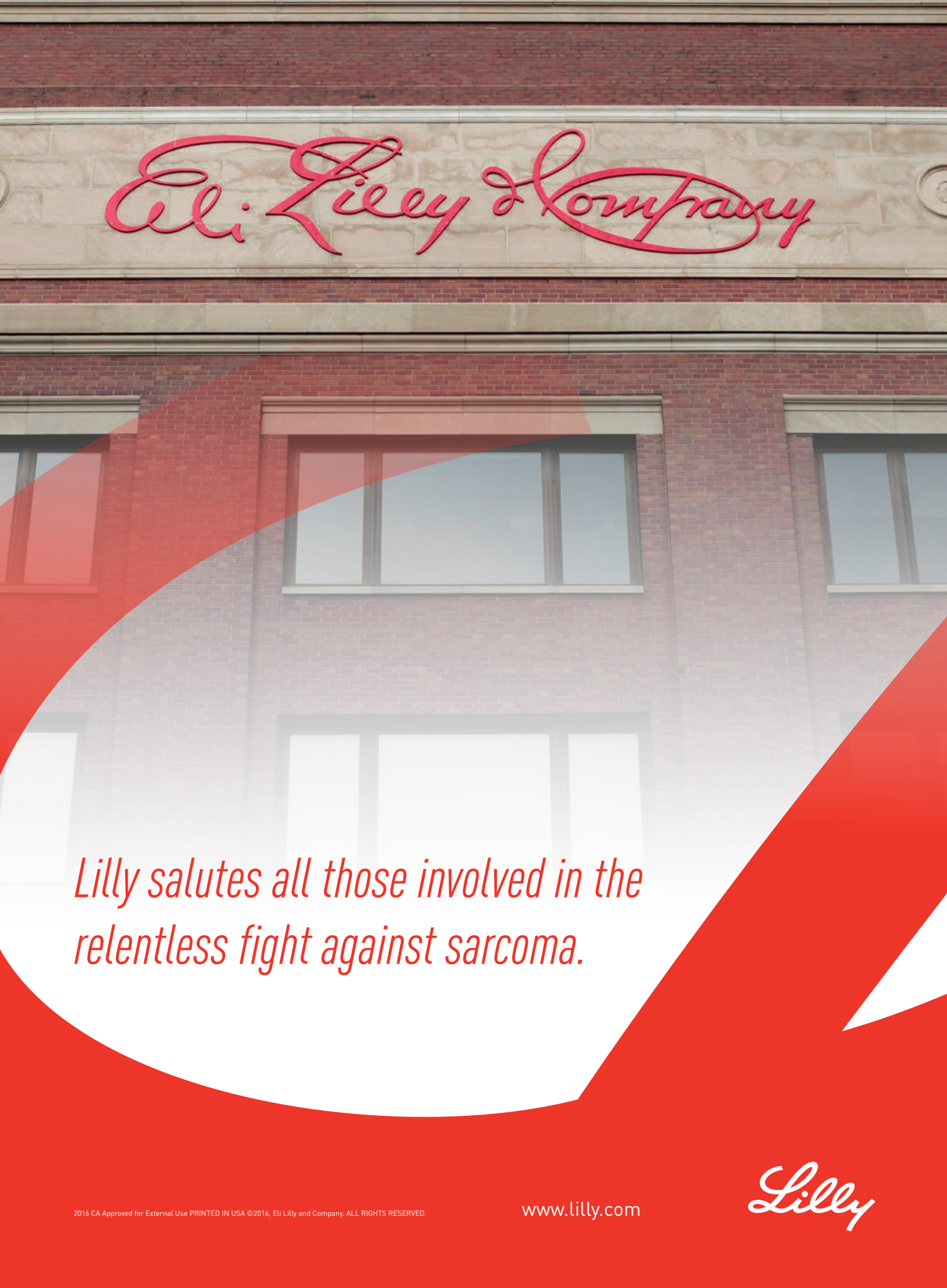
Be the Match ..... www.bethematch.org
Blood & Marrow Transplant Information Network ..... www.bmtinfonet.org
LMSarcoma Direct Research Foundation ..... www.lmsdr.org
National Bone Marrow Transplant Link ..... www.nbmtlink.org
National LeioMyoSarcoma Foundation ..... www.nlmsf.org
Northwest Sarcoma Foundation ..... www.nwsarcoma.org
Rein in Sarcoma ..... www.reininsarcoma.org
Sarcoma Alliance ..... www.sarcomaalliance.org
Sarcoma Alliance for Research through Collaboration (SARC) ..... www.sarctrials.org
Sarcoma Foundation of America ..... www.curesarcoma.org

STOPPING TOBACCO USE

American Cancer Society ..... www.cancer.org
BecomeAnEx ..... www.becomeanex.org
National Cancer Institute Smoking Quitline 877-448-7848
PLAN MY QUIT ..... www.planmyquit.com
QuitSTART ..... teen.smokefree.gov/sftapps.aspx
Quitter's Circle ..... www.quitterscircle.com
Smokefree.gov ..... smokefree.gov
SmokefreeTXT ..... smokefree.gov/smokefreetxt

YOUNG ADULTS

13thirty Cancer Connect 13thirty.org
Affordable Colleges Online ..... affordablecollegesonline.org/college-resource-center/students-with-cancer
Critical Mass: The Young Adult Cancer Alliance ..... criticalmass.org
For Pete's Sake Cancer Respite Foundation ..... www.takeabreakfromcancer.org
Hope for Young Adults With Cancer www.hope4yawc.org
Kids v Cancer ..... www.kidsvcancer.org
Lacuna Loft ..... www.lacunaloft.org
LIVESTRONG Foundation ..... www.livestrong.org
Look Good Feel Better For Teens ..... www.lookgoodfeelbetter.org
National Collegiate Cancer Foundation ..... www.collegiatecancer.org
The Samfund Support For Young Adult Cancer Survivors ..... www.thesamfund.org
Stupid Cancer ..... www.stupidcancer.org
The Ulman Cancer Fund For Young Adults ..... www.ulmanfund.org
Young Survival Coalition ..... www.youngsurvival.org



Lilly salutes all those involved in the relentless fight against sarcoma.

www.lilly.com

Lilly