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

Third Edition
PARTICIPANT MUST:

- Have a confirmed diagnosis of advanced STS for which treatment with chemotherapy is deemed appropriate
- Be 18 years or older
- Consent to provide a sample from a previous biopsy or undergo another biopsy of the original or metastatic tumor before being treated
- Be able to walk and carry out work of a light or sedentary nature

PARTICIPANT MUST NOT:

- Have received any prior clinical trial medication in the last month or be currently enrolled in another investigational clinical trial
- Have received treatment with olaratumab, doxorubicin, or ifosfamide
- Have any abnormal function of the heart (cardiac dysfunction)
- Have had prior radiation to the whole pelvis or cardiac area
- Have a gastrointestinal stromal tumor or Kaposi STS
- Have any planned elective or required surgery
- Have urinary obstruction or bladder inflammation

FOR MORE INFORMATION:

Lilly Trial Guide: www.lillytrialguide.com/JGDR
www.clinicaltrials.gov/ct2/show/NCT03283696
Call the Lilly Oncology Clinical Trial Navigation Service at 1-855-731-6039
Monday-Friday, 9 AM-6 PM ET

The safety and efficacy of the agents under investigation have not been established. There is no guarantee that the agents will receive regulatory approval and become commercially available for the uses being investigated.

ENROLLING NOW
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I think my story can help others see that they can go through something and still keep a sense of humor and still live their lives.

~ Kristi Loyall

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Sarcomas are cancers that begin in bone or in the soft tissues, such as tendons, cartilage, muscle and fat, and can be found in any part of the body. This rare type of cancer is more often diagnosed in children, with sarcoma representing approximately 10 to 15 percent of all cancer diagnoses in people under the age of 20. In adults, about 1 percent of all diagnosed solid tumors are sarcoma.

To better understand sarcoma, it helps to have a basic understanding of cancer. Cancer is a collection of many different diseases, and it can develop almost anywhere in the body. Normally, cells divide in an orderly fashion. When they are worn out or damaged, they die, and new cells replace them. Cancer develops when genes begin to change, or mutate, within the structure of normal cells. These cells — now called cancer cells — grow and push against normal cells. If enough cancer cells are created, they may form a mass called a tumor.

Sarcomas are divided into two main groups: soft tissue sarcoma and bone sarcoma.

SOFT TISSUE SARCOMA

Soft tissue sarcoma can develop in the soft tissues anywhere in the body (see Figure 1). The soft tissues include cartilage, fat, muscle, blood vessels, fibrous tissue and other connective or supportive tissue. Most soft tissue sarcomas occur in the arms or legs.

More common than bone sarcoma, there are more than 50 types of soft tissue sarcoma (see common types in Table 1), and they are named according to where in the body they develop. 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”).

BONE SARCOMA

Bone sarcoma is a malignant (cancerous) tumor that starts in a bone (see Figure 2). Bone sarcoma is different from cancer that spreads to bone from another part of the body, such as the breast or lung. That is called metastatic cancer. Following are the three most common types of primary bone sarcoma (see Table 2).

- **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 at the same time as a growth spurt, and it begins 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.

- **Chondrosarcoma**, the second most common primary bone cancer, develops inside the bone and is made up 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. Chondrosarcoma can occur anywhere in the body where cartilage is present and most frequently develops in the pelvis, legs or arms. Chondrosarcoma occurs primarily in older adults.

- **Ewing sarcoma** is the most common tumor in the Ewing family of tumors. This rare bone sarcoma 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 12).

Other types of bone sarcoma, such as adamantinoma, chordoma and malignant giant cell tumor, occur in adults, but these tumors are rare.

**SYMPTOMS**

Soft tissue and bone sarcomas are accompanied by different symptoms.

For soft tissue sarcoma, symptoms depend on the location and may be very subtle at first. Pain is not typically a common symptom early on; rather, a person may note the presence of a slowly enlarging, painless mass that may or may not be related to a previous injury. Some sarcomas, including synovial sarcoma and various fibrous tumors, can cause pain. Or, if the tumor touches a nerve, it may cause pain as well. An abdominal mass is often found with a soft tissue sarcoma in the retroperitoneal area (the tissue that lines the abdominal wall), and pain occurs in about half of people with a soft tissue sarcoma in this site. People with soft tissue tumors usually found in the stomach or small intestine may have digestive symptoms, such as nausea, vomiting or a loss of appetite. They may also feel full after eating a small amount of food.

Pain around the tumor site that becomes progressively worse followed by swelling is a common symptom of bone sarcoma. If the tumor is in the lower extremities (hip, thigh, knee, leg or foot), it can cause a painful limp. Movement or weight-bearing activities of the involved extremity may make pain worse.
Managing the symptoms related to bone sarcoma is important and often referred to as supportive or palliative care. Many treatments are available to assist in controlling cancer-related pain issues (see Managing Pain, page 15). Keep in mind that when your pain is lessened, you will rest better and your body may be able to heal more quickly. Don't hesitate to talk to your doctor or other members of your treatment team about the pain management options available to you.

### ADDITIONAL RESOURCES
- Sarcoma Alliance: [www.sarcomaalliance.org](http://www.sarcomaalliance.org)
- Sarcoma Alliance for Research through Collaboration (SARC): [www.sarctrials.org](http://www.sarctrials.org)
- Sarcoma Foundation of America: [www.curesarcoma.org](http://www.curesarcoma.org)

### TABLE 1: TYPES OF SOFT TISSUE SARCOMA

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

### TABLE 2: TYPES OF BONE SARCOMA

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

There are no standard screening tests for sarcoma. Instead, your doctor will likely make the diagnosis through a combination of a clinical examination, imaging tests and confirmation by a biopsy. Your doctor will recommend specific tests required to make a correct diagnosis based on your age and medical condition, inherited disorders, type of cancer suspected, severity of symptoms and previous test results.

IMAGING TESTS
Imaging tests can be done to look for the cause of symptoms and to find a sarcoma tumor. They may also be done after a sarcoma is diagnosed to see if it has metastasized (spread) to other parts of the body.

X-ray. An X-ray of the area with the lump is often the first imaging test done, but it is usually not the only imaging test for diagnosing sarcoma. Rather, an X-ray is done to detect any abnormalities that may be sarcoma. If the findings on an X-ray suggest sarcoma, other imaging tests will be ordered. A chest X-ray may be done after an initial diagnosis to see if it has spread to the lungs.

Ultrasound. This test involves the use of sound waves to create a picture of internal organs. An ultrasound can sometimes determine if a lump is a cyst with fluid, which is likely to be benign (noncancerous) and not a sarcoma. An ultrasound can also be used to help guide a biopsy needle precisely into a tumor inside the body.

Computed tomography (CT). A CT is often performed if the doctor suspects sarcoma in the chest or abdomen. CT is an X-ray procedure in which three-dimensional images of structures in the body are created by a computer integrated with the X-ray. The detailed, cross-sectional images of the body can show if sarcoma has spread into the lungs, liver or other organs. Sometimes a special dye (called a contrast) is injected into a vein in the arm or is taken as a pill to provide better detail on the image. CT (like an ultrasound) can also be used to help guide a biopsy needle precisely into a tumor.

Magnetic resonance imaging (MRI). MRI is routinely done if a doctor suspects sarcoma. MRI can show the location of a tumor, the size of the tumor and sometimes even the type of tissue (like fat or muscle). All of these details are helpful for planning a biopsy. With MRI, radio waves and strong magnets are used to create detailed images of organs and tissues. These images are often better than CT images for evaluating sarcomas in the arms or legs. MRI is also used to see if sarcoma is present in the brain and spinal cord.

Positron emission tomography (PET). This specialized test may be ordered to see if sarcoma has spread. PET is not often used for sarcoma, but it can be helpful in certain cases.

Sometimes, PET and CT are integrated to collect images from both types of tests. The resulting combination of images provides more information about the structure of a tumor and how much energy it uses compared with normal tissues. This information can be helpful when trying to determine if abnormalities seen on the CT image are cancer or benign tumors.

BIOPSY
The most important procedure to confirm a diagnosis of sarcoma is a biopsy. A small amount of tissue from the tumor is removed, and a pathologist (a doctor trained to examine tissues and interpret the results) examines the tissue through a microscope to determine if cancer cells are present.

Several types of biopsy may be used to diagnose sarcoma. Doctors experienced with these tumors will choose one or more types of biopsy based on the size and location of the tumor. Samples are taken from the primary tumor, lymph nodes or other suspicious areas.

For a needle biopsy, a doctor inserts a hollow needle into the tumor to obtain tissue or cells for examination. Two types of needle biopsy may be done: core-needle or fine-needle. If the tumor is too deep to feel, the doctor can use CT or ultrasound to help guide the needle accurately into the tumor.

Surgical biopsies include an incisional biopsy, which almost always involves removing enough tissue to diagnose the exact type and grade of sarcoma, and an excisional biopsy, in which the surgeon removes the entire tumor.

MOLECULAR LABORATORY TESTING
Your doctor may suggest molecular laboratory tests on a tumor sample to identify specific genes, proteins and other factors unique to the tumor. Sometimes these special tests are needed to accurately determine whether a sarcoma is present and, if so, what type. Your doctor may also use the test results to recommend the best treatment because certain types of sarcoma may respond to different treatments. Ask your doctor if the tissue samples from other testing can be used for molecular testing to prevent additional procedures, if possible.

Bone Sarcoma Tests

If bone sarcoma is suspected, your doctor may also recommend the following tests.

Blood tests may help find bone cancer because people with osteosarcoma or Ewing sarcoma may have higher alkaline phosphatase and lactate dehydrogenase levels in the blood. High levels, however, do not always mean cancer. Alkaline phosphatase is normally high when cells that form bone tissue are very active, such as when children are growing or a broken bone is healing.

Bone scans use a radioactive tracer to show the inside of the bones. The tracer is injected into a vein and collects in areas of the bone. Healthy bone is detected by a special camera and appears gray. Areas of injury, such as those caused by cancer cells, appear dark.

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org
- How Are Soft Tissue Sarcomas Diagnosed?
- American Society of Clinical Oncology: www.cancer.net
- Bone Cancer: Diagnosis
- Sarcomas of Specific Organs: Diagnosis
- National Cancer Institute: www.cancer.gov
- Soft Tissue Sarcoma - Patient Version
What is the most important advice for someone who is newly diagnosed with sarcoma?

Given the rarity and the complexity of sarcoma, I highly recommend seeking care at a dedicated sarcoma center. In a typical hospital, a doctor may see one to three sarcoma patients a year. Although that physician may be highly skilled, the experience that comes from someone who sees 300-400 sarcoma patients a year is invaluable. Additionally, a sarcoma specialist understands how a patient’s treatment from the very beginning really sets the path. For example, decisions made early on, such as choosing how much tissue to take during a biopsy, how and where to make an incision or the type of treatment to administer, will affect the patient’s future treatment options. Getting to a sarcoma center is not always possible. In those cases, I encourage people and their caregivers to reach out to a sarcoma center for advice and planning purposes. Most are more than happy to offer help.

How do you approach each new patient’s case?

Two types of patients usually contact me. When I see people who have an undiagnosed or biopsied mass, I talk with them first about sarcoma in general. I go over staging, and I explain that every case we have is presented at our multidisciplinary planning board meeting. The board is made up of sarcoma-certified physicians who analyze every patient’s pathology and other test results to recommend the best possible treatment. What happens next is something I’m particularly proud of, and I know our patients appreciate it, too. We schedule doctors for the patients, not the other way around, and we have entry-level radiation and medical oncologists on site. It’s a patient-centric system that enables the patient to see many doctors and ancillary personnel in a couple of hours instead of over a couple of weeks. It is more effective, and it builds relationships, something I feel is essential. In fact, my cell number is on my business card. Patients don’t hesitate to use it, and I deeply enjoy helping them when they do.

The majority of my patients, however, come to me when their sarcoma has recurred. They typically find me on the Internet or through my activities as a medical advisory board member for several organizations. They often feel that since previous treatment wasn’t successful, I’m a bit of a last ditch effort. I find it more encouraging to share the basic philosophy that we are taking a disease process that is potentially lethal and trying to convert it to a chronic disease, one they can live with. Sometimes their previous recommendation was a surgical procedure that would leave them with a significant life-affecting outcome. Surgery is the mainstay of sarcoma treatment, but we can often craft a solution that doesn’t have a life-defining result. We’re able to do so because we use a team approach to surgery. It’s common for us to have five surgeons with five different specialties working on a case, which gives us the opportunity to do things together that we wouldn’t be able to do alone.

If patients choose to be seen elsewhere, I am always open to giving referrals or being involved in meetings to discuss inconsistencies in test results or treatment plans. The goal is always for the patient to be comfortable.

Do you often recommend clinical trials?

When we discuss treatment options, we discuss the clinical trials that are available depending on the patient’s treatment history. Currently, many clinical trials for recurrent sarcomas focus on systemic therapies. We also make sure people understand that they will always get the equivalent of standard of care if they participate in a trial.

Each oncology discipline has a distinct contribution to make, yet they are all interdependent. It’s interesting to note that although sarcoma is a rare disease, there are a number of areas where sarcoma clinical trials have led the oncology field. Neoadjuvant chemotherapy was first used successfully in 1976 on sarcoma tumors, and the first molecularly-targeted treatment was deemed successful in a sarcoma clinical trial. A clinical trial is also responsible for determining that limb salvage surgery was just as effective as amputation with far more manageable side effects.

To further the progress in trials, we have the Sarcoma Alliance for Research through Collaboration (SARC), an organization made up of about 45 sarcoma programs across the country that focuses on finding and conducting clinical trials. We coordinate with the European Organization for Research and Treatment of Cancer (EORTC), a similar organization in Europe that actually allows U.S. participants to take advantage of clinical trials happening in Europe. That isn’t common, but the intent is to make these observations and advances available to benefit patients everywhere, regardless of location. There is a lot of altruism in those groups, and in the industry overall.

What is on the horizon for sarcoma treatment?

Personalized medicine is just beginning in sarcoma treatment. Because it is such a rare disease, it isn’t easy to build research programs for it. However, with the AJCC staging updates introduced recently, we are getting closer to defining molecular staging criteria. We are also doing exciting work on nomograms (prediction tools), which allow us to share very accurate information about prognosis with patients based on clinical and pathological findings.

What drives you, professionally and personally?

I have numerous facets to my career that give me a wonderfully broad perspective. I operate two full days a week, see patients in clinic and am Director of the Sarcoma Research Laboratory at Ohio State. Our surgical fellows work alongside me in the clinic, and I supervise and actively mentor 16 surgeons in a collaborative environment. My most important accomplishments, however, are my three children. All three attend Ohio State University, two as undergrads and one in medical school. It gives me so much pleasure to see my kids reaching out and fulfilling themselves.
After sarcoma is diagnosed, your doctor stages the disease to determine the extent of the cancer, including where it is located and whether it has spread. This information will help your doctor recommend the most effective treatment plan.

As part of the staging process, you will likely have a number of tests and procedures. Your doctor may perform a physical examination and history and may order imaging studies, blood tests and a biopsy of the tumor and nearby lymph nodes. When examining the biopsy sample, the pathologist (a doctor who specializes in diagnosing diseases by looking at the tissue under a microscope) takes into account the number of cells that are actively dividing and how closely the cancer resembles normal tissue. The pathologist will be able to determine how fast the tumor may be growing, if the cancer is close to the surface of the skin (superficial) or deep in the body, and whether it has spread to lymph nodes or to other parts of your body. Lymph nodes are bean-shaped cells found in small collections throughout the body. They store special cells that can trap cancer cells or bacteria traveling through the body via the lymphatic system.

Your surgeon may decide to present your case at a multidisciplinary sarcoma tumor board. A tumor board is a meeting of a group of physicians who are members of the health care team involved with the treatment of sarcoma. The board will include the surgeon, medical oncologist, radiation oncologist, pathologist, radiologist, tumor registrar and other allied health personnel. This team will discuss and evaluate your case in great detail and arrive at decisions best suited to you personally.

STAGING SOFT TISSUE SARCOMAS

Soft tissue sarcomas are given a stage and grade depending on which part of the body is involved. Doctors typically use the American Joint Committee on Cancer (AJCC) TNM staging system to classify some soft tissue sarcomas, including all soft tissues of the head and neck, trunk and extremities, abdomen and thoracic organs, and the retroperitoneum (the space behind the lining of the abdomen).

The TNM 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), or spread, to other parts of the body. The most common sites of spread are the lungs or other bones. Numbers after T, N and M provide more details for each of these factors.

The grade (G) of your cancer is associated with how rapidly the sarcoma will grow and spread, as well as with your 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 normal tissue cells, how many tumor cells are dividing and how much of the tumor has cells that are dying.

Grades are listed from low to high as GX (the grade cannot be assessed), grade 1 (G1), grade 2 (G2) and grade 3 (G3). Cells that appear healthy are called well-differentiated (denoted by a lower grade). Low-grade tumor cells look more like normal cells and are less likely to grow and spread quickly, whereas 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.

To assign a stage, the information your doctor has gathered about the tumor, lymph nodes, metastasis and grade is combined in a process called staging group. The stage is described by Roman numerals from I to IV and the letters A or B.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>SOFT TISSUE SARCOMA OF THE HEAD &amp; NECK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CLASSIFICATION</strong></td>
<td><strong>DEFINITION</strong></td>
</tr>
<tr>
<td><strong>TUMOR (T)</strong></td>
<td></td>
</tr>
<tr>
<td>TX</td>
<td>Primary tumor cannot be assessed.</td>
</tr>
<tr>
<td>T1</td>
<td>Tumor 2 cm (almost 1 inch) or less.</td>
</tr>
<tr>
<td>T2</td>
<td>Tumor more than 2 cm but not more than 4 cm (about 1 ½ inches).</td>
</tr>
<tr>
<td>T3</td>
<td>Tumor more than 4 cm.</td>
</tr>
<tr>
<td>T4</td>
<td>Tumor with invasion of adjoining structures.</td>
</tr>
<tr>
<td>T4a</td>
<td>Tumor with orbital invasion, skull base/dural invasion, invasion of central compartment viscera, involvement of facial skeleton, or invasion of pterygoid muscles.</td>
</tr>
<tr>
<td>T4b</td>
<td>Tumor with brain parenchymal invasion, carotid artery encasement, prevertebral muscle invasion, or central nervous system involvement via perineural spread.</td>
</tr>
<tr>
<td><strong>NODE (N)</strong></td>
<td></td>
</tr>
<tr>
<td>N0</td>
<td>No regional lymph node metastases or unknown lymph node status.</td>
</tr>
<tr>
<td>N1</td>
<td>Regional lymph node metastasis.</td>
</tr>
<tr>
<td><strong>METASTASIS (M)</strong></td>
<td></td>
</tr>
<tr>
<td>M0</td>
<td>No distant metastasis.</td>
</tr>
<tr>
<td>M1</td>
<td>Distant metastasis.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>SOFT TISSUE SARCOMA OF THE ABDOMEN &amp; THORACIC VISCERAL ORGANS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CLASSIFICATION</strong></td>
<td><strong>DEFINITION</strong></td>
</tr>
<tr>
<td><strong>TUMOR (T)</strong></td>
<td></td>
</tr>
<tr>
<td>TX</td>
<td>Primary tumor cannot be assessed.</td>
</tr>
<tr>
<td>T1</td>
<td>Organ confined.</td>
</tr>
<tr>
<td>T2</td>
<td>Tumor extension into tissue beyond organ.</td>
</tr>
<tr>
<td>T2a</td>
<td>Invades serosa or visceral peritoneum.</td>
</tr>
<tr>
<td>T2b</td>
<td>Extension beyond serosa (mesenteric).</td>
</tr>
<tr>
<td>T3</td>
<td>Invades another organ.</td>
</tr>
<tr>
<td>T4</td>
<td>Multifocal involvement (tumors at more than 1 site).</td>
</tr>
<tr>
<td>T4a</td>
<td>Multifocal (2 sites).</td>
</tr>
<tr>
<td>T4b</td>
<td>Multifocal (3-5 sites).</td>
</tr>
<tr>
<td>T4c</td>
<td>Multifocal (more than 5 sites).</td>
</tr>
<tr>
<td><strong>NODE (N)</strong></td>
<td></td>
</tr>
<tr>
<td>N0</td>
<td>No lymph node involvement or unknown lymph node status.</td>
</tr>
<tr>
<td>N1</td>
<td>Lymph node involvement present.</td>
</tr>
<tr>
<td><strong>METASTASIS (M)</strong></td>
<td></td>
</tr>
<tr>
<td>M0</td>
<td>No metastasis.</td>
</tr>
<tr>
<td>M1</td>
<td>Metastasis present.</td>
</tr>
</tbody>
</table>

Currently, stage groupings exist for soft tissue sarcomas of the trunk and extremities and the retroperitoneum. More data must be collected before stage groupings are defined for soft tissue sarcomas of the head and neck and the abdomen and thoracic visceral organs.

The classification and grading (along with stage groupings, when available) of soft tissue sarcomas guide doctors in determining the most appropriate treatment plan for soft tissue sarcomas of the head and neck (see Table 1), abdomen and thoracic visceral organs (see Table 2), trunk and extremities (see Table 3) and the retroperitoneum (see Table 4). Other factors, such as the location of the sarcoma, also influence treatment planning and prognosis.

### TABLE 3

#### SOFT TISSUE SARCOMA OF THE TRUNK & EXTREMITIES

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

<table>
<thead>
<tr>
<th>Grade (G)</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>GX</td>
<td>Grade cannot be assessed.</td>
</tr>
<tr>
<td>G1</td>
<td>Total differentiation, mitotic count and necrosis score of 2 or 3.</td>
</tr>
<tr>
<td>G2</td>
<td>Total differentiation, mitotic count and necrosis score of 4 or 5.</td>
</tr>
<tr>
<td>G3</td>
<td>Total differentiation, mitotic count and necrosis score of 6, 7, or 8.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage Grouping</th>
<th>Stage</th>
<th>T</th>
<th>N</th>
<th>M</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
<td>G0</td>
<td>G1</td>
</tr>
<tr>
<td>IB</td>
<td>T2, T3, T4</td>
<td>N0</td>
<td>M0</td>
<td>G0</td>
<td>G1</td>
</tr>
<tr>
<td>II</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
<td>G2</td>
<td>G3</td>
</tr>
<tr>
<td>IIIA</td>
<td>T2</td>
<td>N0</td>
<td>M0</td>
<td>G2</td>
<td>G3</td>
</tr>
<tr>
<td>IIIB</td>
<td>T3, T4</td>
<td>N0</td>
<td>M0</td>
<td>G2</td>
<td>G3</td>
</tr>
<tr>
<td>IV</td>
<td>Any T</td>
<td>Any T</td>
<td>N1</td>
<td>M0</td>
<td>Any G, G1</td>
</tr>
</tbody>
</table>

### TABLE 4

#### SOFT TISSUE SARCOMA OF THE RETROPERITONEUM

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

<table>
<thead>
<tr>
<th>Grade (G)</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>GX</td>
<td>Grade cannot be assessed.</td>
</tr>
<tr>
<td>G1</td>
<td>Total differentiation, mitotic count and necrosis score of 2 or 3.</td>
</tr>
<tr>
<td>G2</td>
<td>Total differentiation, mitotic count and necrosis score of 4 or 5.</td>
</tr>
<tr>
<td>G3</td>
<td>Total differentiation, mitotic count and necrosis score of 6, 7, or 8.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage Grouping</th>
<th>Stage</th>
<th>T</th>
<th>N</th>
<th>M</th>
<th>G</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
<td>G0</td>
<td>G1</td>
</tr>
<tr>
<td>IB</td>
<td>T2, T3, T4</td>
<td>N0</td>
<td>M0</td>
<td>G0</td>
<td>G1</td>
</tr>
<tr>
<td>II</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
<td>G2</td>
<td>G3</td>
</tr>
<tr>
<td>IIIA</td>
<td>T2</td>
<td>N0</td>
<td>M0</td>
<td>G2</td>
<td>G3</td>
</tr>
<tr>
<td>IIIB</td>
<td>T3, T4</td>
<td>Any T</td>
<td>N1</td>
<td>M0</td>
<td>Any G, G1</td>
</tr>
<tr>
<td>IV</td>
<td>Any T</td>
<td>Any T</td>
<td>Any N</td>
<td>M1</td>
<td>Any G</td>
</tr>
</tbody>
</table>

### STAGING BONE SARCOMAS

To stage bone sarcomas, doctors use many of the same imaging tests and similar physical examinations used for staging soft tissue sarcomas. The first step is to determine if the bone sarcoma is localized (seen only in the bone it started in and possibly the tissues next to the bone, such as muscle, tendon or fat) or has spread to other parts of the body. Doctors then typically use one of two preferred staging systems.

- **The AJCC TNM staging system** is generally used to stage bone sarcomas. As noted earlier, this 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 that consists of three grades.

- **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.

As with soft tissue sarcomas, the grade of a bone sarcoma reflects how likely it is to grow and spread, based on how it looks under the microscope. Bone sarcomas are either low grade (G1) or high grade (G2). Low-grade tumor cells look more like normal cells and are less likely to grow and spread quickly, whereas high-grade tumor cells look more abnormal and tend to grow and spread faster.

In the MSTS system, the extent of the primary tumor is classified as either intracompartmental (T1), meaning it has basically remained within the bone, or extracompartmental (T2), meaning it has extended beyond the bone into nearby structures.

Bone sarcomas that have not spread to the lymph nodes or other organs are considered M0, and those that have spread are considered M1.

These factors are combined to give an overall stage, represented by Roman numerals I, II and III. Stages I and II are further divided into A for intracompartmental tumors or B for extracompartmental tumors.

After staging, you may consider getting a second opinion from a doctor who specializes in treating the type of sarcoma you have, especially if it was difficult for your physician to stage the disease. A second opinion will confirm the diagnosis and treatment plan or add new information to consider.
Some treatment options are similar for both soft tissue sarcoma and bone sarcoma, but sometimes the best treatment option depends on the type of sarcoma. Your doctor will create your treatment plan based on many factors, including the type, stage and location of your sarcoma, as well as your age and overall health.

Typically, a combination of these treatments is the best approach. In addition, clinical trials may be of particular benefit if your type of sarcoma is uncommon or rare.

Advancements in research have led to more available treatments and better outcomes, with many people living longer with no or stable disease. Be sure to talk to your doctor about all of your treatment options.

Surgery

Surgery is the main treatment for soft tissue and bone sarcomas. The most common surgical procedure for both types is known as wide local excision. In this procedure, the surgeon’s goal is to remove the entire tumor along with a portion of the normal tissue surrounding it (called the “margin”). The surgeon will try to remove as little normal tissue as possible consistent with achieving a negative margin. A pathologist (a doctor who specializes in diagnosing disease, including cancer) will examine the margin under a microscope to see whether cancer cells are present. If no cancer cells are present (referred to as negative, clear or clean margin), no further treatment is necessary. If cancer cells are found (referred to as positive margin), another surgery, radiation therapy and/or chemotherapy may be used to help control possible remaining cancer cells.

If sarcoma is in the arm or leg, techniques may be used, when possible, to avoid amputation of the limb. Advances in surgical techniques and other types of treatment options have led to a decrease in the number of amputations done for sarcoma. Today, surgeons prefer a limb-sparing procedure, which preserves the use and appearance of the limb. With a limb-sparing procedure, the surgeon may use bone or skin grafts from elsewhere in the body to replace lost tissue or bone in the limb.

However, sometimes amputation may offer the best treatment option, especially when the cancer is located where it would be difficult to surgically remove or for people who cannot have reconstruction or who have a surgical area that cannot be fully covered with soft tissue. Depending on the type of surgery you have, reconstruction may be necessary as part of the primary procedure. This may include the use of prostheses, grafts and metal rods or screws.

If the surgeon thinks that the sarcoma has spread to nearby lymph nodes, the lymph nodes will be removed and examined to see if cancer cells are present. Removal of lymph nodes is called lymphadenectomy.

In some cases of bone cancer, cryosurgery (or cryotherapy) may be an option. Cryosurgery differs greatly from traditional surgery. Instead of removing a sarcoma through an incision, the doctor inserts a hollow instrument through the skin into the tumor and extreme cold, produced by liquid nitrogen (or argon gas), is used to kill the sarcoma cells.

Radiation Therapy

Radiation therapy is used to destroy cancer cells and to keep them from growing. The most common treatment for sarcoma is external-beam radiation therapy (see Figure 1). Other types of radiation therapy may also be used as part of treatment (see Table 1). For osteosarcomas, radiation therapy is usually used only for bone tumors that cannot be removed with surgery.

Newer techniques of radiation therapy allow the radiation to be directed more precisely, which means higher doses of radiation can be given while avoiding damage to healthy tissue, which reduces side effects. Studies have shown that these newer techniques also lead to lower rates of recurrence. Radiation therapy may be integrated into the overall treatment plan in several ways:

- Before surgery, radiation therapy is given to shrink the tumor and make it easier to remove. Treatment given before surgery is known as neoadjuvant treatment.
- After surgery, radiation therapy is given to kill any cancer cells that may remain near the site of the tumor. Treatment given after surgery is known as adjuvant treatment.
- Instead of surgery, radiation therapy may be used as primary treatment for a person whose health is too poor to tolerate surgery, or who has a tumor that is unresectable (unable to be surgically removed) or to help relieve symptoms in a person whose sarcoma has metastasized (spread) to other parts of the body.

Chemotherapy

Chemotherapy drugs are used to stop the growth of cancer, by either killing cancer cells or preventing them from dividing and growing. Chemotherapy is considered a systemic treatment because the drugs travel in the bloodstream throughout the body and may be given orally (a pill) or intravenously through a small tube inserted into a vein (see Figure 2).

Chemotherapy may be given before (neoadjuvant) or after (adjuvant) the primary treatment, which is typically surgery or radiation therapy. Chemoradiation, a combination of
of chemotherapy and radiation therapy, may also be used. If surgery is not possible, chemotherapy may be used as a primary treatment. Because chemotherapy drugs travel throughout the entire body, they’re a useful option when the sarcoma has spread to several sites.

For sarcoma, chemotherapy is primarily used to treat Ewing sarcoma, embryonal or alveolar rhabdomyosarcoma in children or young adults, and sarcomas that have spread. When used for bone sarcomas, chemotherapy is usually given before and after surgery.

Several chemotherapy drugs can be used to treat sarcomas, and they may be used alone or in combination with other drugs. Your doctor will consider your particular type of sarcoma before recommending chemotherapy in your treatment plan.

TARGETED THERAPY

Targeted therapy may be a treatment option for people who have a sarcoma that is resistant to chemotherapy. Targeted therapy drugs block the signals that proteins and other molecules send along signaling pathways, which are systems in the body that direct basic cell functions like growth, division and death. Also considered a systemic treatment because the drugs travel in the bloodstream throughout the body, targeted therapy may be given orally (a pill) or intravenously through a small tube inserted into a vein (see Figure 2).

Effective targeted therapy depends on two factors: identifying targets that play an important role in the growth and survival of cancer cells, and developing agents that can attack those targets. For example, one type of targeted therapy targets gastrointestinal stromal tumor (GIST) cells with a mutation (abnormality) in the C-KIT gene; this mutation is found in more than 85 percent of GISTs.

Molecular testing is done to see if the C-KIT mutation is present in the GIST. If the mutation is not present, the drug will not be effective. But if it is present, the drug helps to prevent recurrence after the GIST has been surgically removed. This strategy may also be used as primary treatment for GISTs that are unresectable or that have metastasized. 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 protein called RANK ligand. RANK ligand normally tells cells called osteoclasts to break down bone, but when the drug binds to it, that action is blocked. This drug is used with giant cell tumors of bone that have either come back after surgery or cannot be removed with surgery and may help shrink tumors for a while.

Many clinical trials are being conducted to find additional targets in soft tissue and bone sarcomas and to develop targeted therapy drugs directed at them.

IMMUNOTHERAPY

Immunotherapy uses the body's own immune system to slow the growth of and kill cancer cells. To do so, the immune system uses substances made either by the body or in a laboratory to find and destroy cancer cells, much like it fights off foreign bacteria. One type of immunotherapy drug is known as a checkpoint inhibitor. This type of drug blocks specific proteins on the surface of immune T-cells. Blocking these proteins releases a natural brake on the immune system, allowing it to attack the cancer. Checkpoint inhibitors have been found to be effective in many other types of cancer, such as melanoma and lung cancer. Ongoing clinical trials are evaluating the use of checkpoint inhibitors in sarcoma.

PALLIATIVE CARE

Although sarcoma treatment focuses on curative intent, palliative care may be needed. Palliative care includes pain management and helps with other side effects of cancer and its treatment. It’s focus is to improve quality of life, and to support the emotional, spiritual and social needs of people with a serious illness.

Palliative care is often confused with hospice care. Both aim to improve quality of life, but palliative care can benefit anyone with a serious or life-threatening illness and is available at any time during treatment, whereas hospice care is reserved for care at the end of life. Palliative care focuses on relieving pain, other symptoms and the emotional distress that serious illness can bring. This care is provided by a multidisciplinary team that consists of doctors, nurses, social workers and others, all of whom work together to enhance your quality of life.

For people with sarcoma, palliative care may involve the use of drugs to relieve pain or nausea, radiation therapy to help relieve bone pain or chemotherapy to help shrink a tumor that is causing pressure or a blockage.

Because palliative care is available from the time you’re diagnosed throughout the duration of your treatment – as long as you’re experiencing disease-related symptoms – any time is a good time to talk to your doctor about it.

FOLLOW-UP CARE

After you are finished with treatment, follow-up care is recommended. Your doctor will establish a schedule that may consist of a history and physical examination, blood tests, bone scan and imaging studies, such as computed tomography (CT), magnetic resonance imaging (MRI) and ultrasounds. In general, follow-up visits are every four months for two to three years, then every six months for three years, then annually.

COMMON SARCOMA MEDICATIONS

<table>
<thead>
<tr>
<th>CHEMOTHERAPY</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>dacarbazine (DTIC)</td>
<td>doxorubicin (Adriamycin)</td>
</tr>
<tr>
<td>doxorubicin (Cosmegen)</td>
<td>etoposide (Etoposide)</td>
</tr>
<tr>
<td>dacarbazine (DTIC)</td>
<td>ifosfamide (Cytox, Ifex)</td>
</tr>
<tr>
<td>methotrexate (Otrexup, Rasuvo,</td>
<td>methotrexate (Otrexup, Rasuvo, Rheumatrex, Trexall)</td>
</tr>
<tr>
<td>trabectedin (Yondelis)</td>
<td>vinblastine (Velban)</td>
</tr>
<tr>
<td>imatinib (Gleevec)</td>
<td>vincristine</td>
</tr>
<tr>
<td>olaratumab (Lartruvo)</td>
<td></td>
</tr>
<tr>
<td>pazopanib (Votrient)</td>
<td></td>
</tr>
<tr>
<td>raloxifene (Ilfenat)</td>
<td></td>
</tr>
<tr>
<td>sunitinib (Sutent)</td>
<td></td>
</tr>
</tbody>
</table>

TARGETED THERAPY

- denosumab (Xgeva)
- imatinib (Gleevec)
- olaratumab (Lartruvo)
- pazopanib (Votrient)
- raloxifene (Ilfenat)
- sunitinib (Sutent)

COMMON SARCOMA MEDICATIONS

- dacarbazine (DTIC)
- doxorubicin (Adriamycin)
- etoposide (Etoposide)
- ifosfamide (Cytox, Ifex)
- methotrexate (Otrexup, Rasuvo, Rheumatrex, Trexall)
- trabectedin (Yondelis)
- vinblastine (Velban)
- vincristine
- Combination treatment: MAID (mesna, doxorubicin, ifosfamide and dacarbazine)

ADDITIONAL RESOURCES

- American Cancer Society: www.cancer.org
- American Society of Clinical Oncology: www.cancer.net
- Sarcoma, Soft Tissue: Treatment Options
- National Cancer Institute: www.cancer.gov
- Rein in Sarcoma Foundation: www.reininsarcoma.org
- Sarcoma Alliance: www.sarcomaalliance.org
Clinical trials are research studies that evaluate the safety and effectiveness of a medical strategy, treatment or device. They are also how the medical community determines a “standard of care,” the treatment that works best for certain illnesses or groups of people. In fact, many advances in cancer treatment that are helping save lives today are all products of research, and much of that research is done through clinical trials.

Depending on your diagnosis and other factors, a clinical trial may be a treatment option for you to consider. Although you may not know much about clinical trials yet, this information, along with input from your doctor, will help you understand more about the three types of clinical trials and what they may mean for you.

1 Treatment Trials evaluate whether a new type of treatment (drug, surgery, radiation therapy) or a combination of treatments is better than the currently approved treatments being used.

2 Quality-of-Life Trials study ways to improve the quality of life for people being treated for cancer and cancer survivors who experience cancer-related and treatment-related symptoms. This type of trial may evaluate the effects of such things as nutrition, group therapy or counseling.

3 Prevention, Screening and Diagnostic Trials assess ways to reduce the chance of getting cancer in general. In these trials, which may be treatment or non-treatment trials, many participants do not have cancer, but some have had cancer and are at risk of it returning (recurring) or a second cancer developing. Sometimes these trials consist of simply completing questionnaires and providing medical information.

Each trial is carefully thought out, planned and performed in an extremely consistent manner so that all patients are treated exactly the same, from medical treatment and dosing schedule to the frequency of follow-up appointments. Institutional review boards or ethics committees carefully set up safeguards to make sure that all patients in the clinical trial remain safe throughout the process. Whether you’re at a small rural hospital or a large facility in a metropolitan area, your medical team is responsible for diligently following all of the same protocols and safety measures for your treatment plan.

**Benefits and Risks**

Clinical trials present several potential benefits, such as the opportunity to access leading-edge treatments that aren’t yet available on a widespread basis. They may be an alternative if your current treatment isn’t working as well as it once was, or if you have a rare type of sarcoma that hasn’t been studied as much as others. You will also be more closely monitored in a clinical trial because your regular oncologist and the clinical trial medical team will be attending to your needs. Even after the treatment ends, you will continue to be in close contact with the medical team.

At the same time, trials can present potential risks or inconveniences. Almost every type of cancer treatment has side effects, and the treatments used in clinical trials are no different. Ask your medical team about what to expect so you are not surprised by any effects. In addition, a clinical trial may require more frequent tests or medical visits, for example. Make sure you are aware of the necessary schedule associated with the trial to be sure you can accommodate it.

Cost is a common concern regarding clinical trials. Talk with your doctor or study team to learn more about the specific costs to you if you agree to participate in a clinical trial. You may find you can have access to an innovative treatment and be an integral part of cancer research without incurring a great deal of expense. Following are resources where you can search for clinical trials and learn more about them:

- **ClinicalTrials.gov**: clinicaltrials.gov
- **Patient Resource**: www.patientresource.com Understanding Cancer/Search Clinical Trials
- **Sarcoma Alliance**: www.sarcomaalliance.org
- **Sarcoma Alliance for Research through Collaboration (SARC)**: www.sarctrials.org Search SARC Clinical Trials
- **U.S. Food & Drug Administration**: www.fda.gov Clinical Trials: What Patients Need to Know
One day in 2011, I noticed that my right pinky toe was numb. For the next two years, the numbness spread to half of my right foot and it became painful. I asked my doctor about it, but he didn’t seem to be concerned. I was referred to a neurologist for neuropathy, which is a condition of the nervous system. However, the neurologist didn’t think I had neuropathy. He thought I had a B vitamin deficiency and recommended B-12 supplements. I saw the neurologist six times and he never thought my condition was more serious than a vitamin deficiency. I gave up going to him. In the summer of 2015, I noticed a lump on the inside of my foot. I returned to my primary care physician in December 2015, and I was referred to a podiatrist. At first, the podiatrist thought the lump was caused by Tarsal Tunnel Syndrome. He ordered an MRI and X-rays of my foot. The podiatrist reviewed the results and said I had a lipoma, which is a noncancerous fatty tumor. He recommended I go back to the neurologist.

The neurologist then ordered blood work and asked me to return in a month. In the meantime, I had increasing pain and numbness in my foot. I was frustrated with the neurologist and felt like no one believed that I had a serious condition. I called my podiatrist back and expressed my frustration. He said I could try pain management with the options of steroid injections or surgery to remove the lipoma. I tried pain medications and the injections, but they only made the pain worse. In April 2016, I met with a surgeon to remove my lipoma. I had the surgery on April 11, 2016. Four days later, the results of the pathology on the lipoma came back. I was told the lipoma was cancer. I had a mix of emotions from disbelief to anger that this wasn’t found sooner. I was frustrated that no one had believed me and that I’d been living with this for years.

On my first visit with the oncologist, he wanted to confirm if the surgery had removed all of the cancer in my foot, so I had a PET scan. We discovered the cancer was throughout my whole foot but had not spread beyond my foot to lymph nodes or other organs. He recommended amputating the foot because my official diagnosis was grade 3 epithelioid sarcoma, which is a very aggressive cancer that is known to spread and recur frequently.

Although I didn’t seek a second opinion, my oncologist told me he had consulted with another doctor who was the only sarcoma specialist in the area. They reviewed my results and agreed that amputation was the best course of treatment for me because this type of cancer does not respond to chemotherapy or radiation therapy.

It all happened so fast. By April 22, I had the surgery to remove my right foot. After the surgery, I asked my doctor if I could have the foot back, mostly as a joke, but the more I thought about it, the more I decided I wanted it. The foot was sent to pathology for a month. By the end of May, they gave me my foot and part of my leg bone.

I couldn’t have gone through this without the support of my family and friends. After the amputation, I thought my life was over. But with the help and support around me, I realized there is hope. I can do anything I want now; it just takes a little work and planning. However, I still wonder if I made the right decision.

Once I decided not to let this situation keep me from living my life, I took a new path. I took pictures of my foot and put them on my Instagram account so that I could make my cousin and friends laugh. I really did not expect my friends to start sharing the photos with their friends and their friends’ friends. Before I knew it, my Instagram account had grown to more than 17,900 followers. My amputated foot was being shown around the Internet. To my surprise, the local news station called and asked to write a story about me. I think my story can help others see that they can go through something and still keep a sense of humor and still live their lives. I recently adopted a new dog that is part Great Pyrenees and part Anatolian. I want to train him as a therapy dog and take him to children’s hospitals to show others you can survive after cancer. They can see my amputated foot and relate to me.

Don’t let cancer get you down. Find ways to keep smiling, laughing and living your life.
Pediatric sarcoma is a cancer that forms in the bone or soft tissues of the body. It is called pediatric sarcoma because it is primarily found in children, but it can also occur in adults.

Most pediatric sarcomas are one of three types. Following are descriptions of each of these types, along with staging and typical treatment information.

Rhabdomyosarcoma

Rhabdomyosarcoma forms in immature cells that normally become striated muscle. This type of muscle is skeletal voluntary muscle, which makes up the muscles that people can control, such as those of the arms and legs. Rhabdomyosarcoma has often spread beyond the original site by the time a diagnosis is made. This type of pediatric sarcoma is slightly more common in boys than in girls and is most common in children under the age of five.

There are three subtypes of rhabdomyosarcoma. Embryonal is the most common and occurs most often in the head and neck area or in the genital or urinary organs. Alveolar occurs most often 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.

Staging for rhabdomyosarcoma, which helps doctors plan treatment, involves the following.

- **The staging system** considers the size of the tumor, where it is in the body and if it has spread to other parts of the body. Each tumor is classified as "favorable" or "unfavorable" based on what the cells look like under a microscope (known as histology). In general, the more cancer cells look like normal cells, the more "favorable" they are and the greater the chance that treatment will be successful.

- **The grouping system** is based on whether the cancer has spread and whether all the cancer was removed by surgery.

- **The risk group** is assigned after the staging grouping systems are determined and is a description of the chance that rhabdomyosarcoma will recur (come back). The risk groups are low-risk, intermediate-risk and high-risk childhood rhabdomyosarcoma.

Treatment for rhabdomyosarcoma generally consists of surgery and combination chemotherapy (two or more chemotherapy drugs used together). Every child treated for this sarcoma should receive chemotherapy to decrease the chance cancer will recur. The type of drug, dose and the number of treatments given depend on the risk level.

**Ewing Sarcoma**

Ewing sarcoma forms in the bone or soft tissues when healthy cells in the bone change and grow uncontrollably, forming a mass called a tumor. It affects the bones or nearby soft tissue, most often developing in the leg, pelvis, rib, arm or spine. It also can occur in soft tissues. Ewing sarcoma can grow and spread to other parts of the body. It most often develops in children and young adults between the ages of 10 and 20, is more common in girls than boys and is rare among individuals of African descent.

Although there is no official staging system for Ewing sarcoma, doctors consider the following criteria to describe and plan treatment.

- **Localized Ewing sarcoma.** The tumor is found only in the bone where it began or has spread only to nearby tissues.

- **Metastatic Ewing sarcoma.** The tumor has spread from the bone where it began to another part of the body, such as the lungs, other bones or bone marrow. Rarely, the disease spreads to the lymph nodes, brain or spinal cord. Whether the tumor has spread is the most important factor used to determine treatment options and prognosis.

- **Recurrent Ewing sarcoma.** If the cancer returns, it is called recurrent Ewing sarcoma. Another round of tests, often similar to those done at the time of the original diagnosis, will be done to learn about the extent of the recurrence.

For Ewing sarcoma, multidrug chemotherapy is the primary treatment in combination with surgery and radiation therapy.

**Osteosarcoma**

Osteosarcoma can develop in any bone in the body. It destroys tissue and weakens the bone. The disease begins when immature bone cells become cancer cells instead of developing into mature bone cells. The most common place for osteosarcoma to start is in the bones around the knee joint, either at the femur, which is the lower end of the thigh bone, or the tibia, which is the upper end of the shin bone. Another common place for osteosarcoma to start is the humerus, the upper arm bone near the shoulder. Rarely, osteosarcoma occurs as a tumor in the soft tissue of the body, outside the bone. It most often affects teens and young adults in their twenties.

Doctors use these terms to describe the stages of osteosarcoma and plan treatment.

- **Localized.** The tumor is only in the bone where it began and in the tissue around it. It has not spread to other parts of the body.

- **Metastatic.** The tumor has spread from the bone where it began to another part of the body. Most often, osteosarcoma spreads to the lungs or other bones.

- **Recurrent.** Recurrent osteosarcoma is a tumor that has come back during or after treatment. It can come back in the same place where it started or in another part of the body. Osteosarcoma recurs most often in the lungs and other bones. If there is a recurrence, the cancer may need to be staged again. This is called re-staging.

Surgery is the primary treatment for osteosarcoma.

**IMPORTANT TREATMENT CONSIDERATIONS**

It is typically recommended that treatment begin right away because of how aggressive pediatric sarcoma can be. As you make these timely treatment decisions, also think about the following issues.

- **A second opinion** from a pediatric oncologist (preferably one who is experienced in treating sarcoma) will either confirm the original diagnosis and treatment recommendations or offer new information to consider.

- **Clinical trials** may offer your child access to promising new treatments that aren’t available outside of the trial. It may comfort you to know that your child will receive high-quality care and be closely monitored throughout the trial. And, by simply participating, your child will help others who will need cancer treatment in the future. Ask your doctor if a clinical trial is an option for your child (see *Clinical Trials*, page 10).
• **Treatment location** must be considered because most children with cancer receive treatment or participate in clinical trials at places that specialize in treating cancer in children, such as a children’s hospital, university medical center or cancer center. If you choose one of these facilities, you may have to travel for treatment. Staying in a hotel for an extended time can be very costly. Some hospitals and cancer centers offer free or reduced-cost accommodations for children in treatment and their families, or they may be able to refer you to nearby lodging. You may choose a treatment center for adults near your home. There are pros and cons to both. Talk with your pediatric oncologist and advocacy organizations to learn about your options (see **Support & Financial Resources**, page 16).

### HELPING YOUR CHILD COPE DURING TREATMENT

**Continuing to parent as you did before your child was diagnosed with sarcoma may seem like an extraordinary task, but keep in mind that to your child, you are still the same mom or dad — cancer or not.** Although you may feel overwhelmed at times, it helps to stay in a normal routine as much as possible. When the sarcoma or its treatments make you veer from “normal” life, switch gears, keeping in mind that flexibility, patience and honest communication are very important.

Most children, regardless of age, have challenges with nutrition during treatment, including a loss of appetite. That is understandable. When you don’t feel well, especially if you’re nauseated, food doesn’t sound good. Good nutrition is not only important for a growing body, eating right can help your child feel healthier and possibly even tolerate treatment better.

There are many ways you can encourage your child to eat. First, however, you must realize that your traditional meals and meal-times may go by the wayside for the time being, and that’s okay. Your child should eat whenever he or she is hungry. Offer small meals and snacks throughout the day, rather than three large meals. Peanut butter and crackers, cheese sticks, pudding, and cereal with milk are good options. The body uses a lot of calories when it is healing, so include high-calorie and high-protein foods, such as hamburgers, fries, pizza and ice cream, if your child wants them. Although those may not seem like healthy choices, fat is a rich source of energy and can be helpful when your child has trouble taking in enough calories.

For young children, getting creative with your food and dinnerware can help. Use cookie cutters to cut shapes from sandwiches, gelatin, meats and cheeses. Make faces out of fruits and vegetables. Use colorful cups and straws to encourage drinking fluids. Sometimes drinking with meals may make your child too full to eat, so encourage fluids between meals.

Mixing up the menu may appeal to older kids. Serve pizza for breakfast or pancakes for dinner. A change of scenery can be fun, too. Have picnics by spreading a blanket on the living room floor or eating in the backyard. Encourage physical activity with the doctor’s approval because it may increase your child’s appetite.

A cancer diagnosis is a lot to handle and will affect your family emotionally. Think of creative ways to boost your child’s spirits, such as shopping, books, movies or games. Explore new hobbies that can be done during hospital stays or at home when visitors aren’t recommended, such as music, art, reading or writing. If you notice your child is frequently sad or appears to be depressed, call the doctor.

A teen’s friends are often a lifeline, and your child may find it easier to confide in a friend instead of you or another family member. Find ways to encourage continued friendships, including staying connected with old friends and making new ones during treatment. Phone calls, texts, video chats and social media platforms make staying in touch easy, especially when an in-person visit may not be possible.

The physical side effects of treatment may be upsetting, too, especially if your child 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. Another physical change has to do with body image. Some treatments, such as steroids, can cause weight gain. Other treatments may make it difficult to eat, resulting in weight loss. Help your child pick out cute, comfortable clothes to accommodate any weight change. Feeling good about his or her appearance can make a tremendous difference in attitude.

Let your child know that some children (and even some adults) don’t always know how to act when a close friend becomes ill. People may stare, mistake your child’s gender or ask questions that are too personal. Even when there is no intent to hurt your child’s feelings, it may. Make a plan for how your child can respond to (or ignore) those moments. Humor is often a great way to keep the mood light.

Lastly, lead by example. Show your child that you’re positive about the road ahead. Most important, trust your instincts. After all, you know your child best. And, remember, you’re not alone. Your child’s medical team is available to assist or recommend others who can.

### ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org
- American Society of Clinical Oncology: www.cancer.net
- Ewing Sarcoma-Childhood and Adolescence
- Osteosarcoma-Childhood and Adolescence
- Rhabdomyosarcoma-Childhood
- Sarcoma Alliance: www.sarcomaalliance.org
- Children With Sarcoma
When cancer treatments affect healthy tissues and organs, they can cause side effects. Not everyone experiences the same issues, even when they have the same type of sarcoma or the same type of treatment, and how you respond to them will be unique to you. Before you start treatment, ask your medical team about the side effects to expect so you can be prepared if they occur. Preventing and managing them is extremely important for the success of your treatment because the better you feel, the more likely you’ll be able to complete your treatment as planned.

ALOPECIA (HAIR LOSS)
Hair loss occurs most commonly among people receiving chemotherapy and/or radiation therapy. Some targeted therapy drugs may also cause hair loss. Typically, chemotherapy and targeted therapy drugs cause hair loss on the head and body, whereas radiation therapy causes it only in the area being treated. However, not all people treated for cancer will lose their hair even when they take the same drug or have the same treatment.

COGNITIVE DYSFUNCTION (“CHEMO BRAIN”)
People being treated for cancer may refer to “chemo brain” when they can’t think clearly or have trouble remembering details, such as names and dates. Cognitive dysfunction is often associated with chemotherapy, but it can occur in people receiving many types of treatments, such as radiation therapy, during or after treatment. Research has shown that patients who haven’t had chemotherapy can also develop cognitive dysfunction as a result of stress or hormone depletion (for those on anti-hormonal therapy drugs).

There are many ways to help manage cognitive dysfunction. Use a daily planner to help keep track of tasks, and make a list each day of things to do. As you complete each task, draw a line through it and go on to the next item. Solve crossword puzzles or number games to strengthen your mental ability. Don’t multitask. Instead, focus on one thing at a time. Let others know you are having difficulties, and ask for their help.

DIARRHEA
Diarrhea is most likely to occur in people who receive radiation therapy to the abdomen or take certain chemotherapy or targeted therapy drugs. Cancer treatment-related diarrhea is a short-term side effect, but it can be an inconvenience and affect your quality of life. Try to track when it typically occurs so you can plan accordingly. Changes to your diet can help prevent or lessen diarrhea. A diet of only clear liquids may help the lining of your intestines heal. Clear liquids include water, cranberry juice, ginger ale, clear broth, popsicles, decaffeinated tea and gelatin. As diarrhea begins to improve, you can slowly add solid foods back into your diet, starting with low-fiber foods, such as white rice and boiled potatoes.

In addition, over-the-counter medicines are available to control diarrhea, but be sure to talk to your doctor before taking any of them, as instructions may differ from those on the drug label. If your diarrhea is severe, your doctor may also prescribe other medications or temporarily stop treatment with chemotherapy or targeted therapy and restart it when your diarrhea is controlled.

FATIGUE
Regardless of the type of cancer you have or the type of treatment you receive, almost everyone treated for cancer experiences fatigue at some point. Fatigue can be caused or worsened by several factors:

- The extra energy your body needs to repair healthy tissues damaged during treatment
- Treatment side effects, such as pain, nausea and vomiting
- Medications to relieve side effects
- The interaction of two or more medications

If your fatigue is severe, your doctor may prescribe something to help improve your alertness and raise your energy during the day, while also decreasing fatigue. Managing fatigue is an essential part of your health care, so be sure to discuss with your doctor.

### Strategies for Managing Common Side Effects

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Related Treatment</th>
<th>Ways to Manage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alopecia (hair loss)</td>
<td>Chemotherapy, radiation therapy, targeted therapy</td>
<td>Use a cooling cap, wear a wig, scarf or hat; use a wide-toothed comb, sleep on a satin pillow case; ask your doctor for a prescription for a wig because it may make it eligible for insurance coverage</td>
</tr>
<tr>
<td>Anemia (low red blood cell count)</td>
<td>Chemotherapy</td>
<td>Get plenty of rest, participate in regular physical activity</td>
</tr>
<tr>
<td>Changes in appetite</td>
<td>Chemotherapy, radiation therapy, surgery</td>
<td>Eat when you have the most hunger, eat high-calorie and high-protein foods, eat small meals, keep high-calorie snacks on hand</td>
</tr>
<tr>
<td>Cognitive dysfunction (“chemo brain”)</td>
<td>Chemotherapy, radiation therapy</td>
<td>Take notes, keep lists, use a daily planner, don’t multitask</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>Chemotherapy, radiation therapy, targeted therapy</td>
<td>Take antidiarrheal medicine, drink plenty of fluids, eat several small meals, avoid greasy foods</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Chemotherapy, radiation therapy, surgery, targeted therapy</td>
<td>Balance activity and rest, take short naps, sleep regularly, participate in regular activity</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>Surgery</td>
<td>Wear a compression garment, elevate the swollen limb</td>
</tr>
<tr>
<td>Mouth sores</td>
<td>Chemotherapy</td>
<td>Brush teeth often with a toothbrush with soft bristles, eat soft foods, drink plenty of fluids</td>
</tr>
<tr>
<td>Nausea, vomiting</td>
<td>Chemotherapy, radiation therapy</td>
<td>Take antiemetics as prescribed, eat several small meals, drink plenty of fluids, avoid unpleasant odors</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>Chemotherapy</td>
<td>Avoid tight clothes or shoes, keep hands and feet warm, avoid standing for long periods of time</td>
</tr>
<tr>
<td>Neutropenia (low white blood cell count)</td>
<td>Chemotherapy, radiation therapy</td>
<td>Wash hands frequently, avoid crowds, wash fruits and vegetables carefully</td>
</tr>
<tr>
<td>Skin reactions</td>
<td>Chemotherapy, targeted therapy, radiation therapy</td>
<td>Use mild soap, use thick cream (with no alcohol, perfume or dye) to moisturize skin</td>
</tr>
</tbody>
</table>
NAUSEA AND VOMITING
Prevention is the key to managing nausea and vomiting, as these symptoms are easier to prevent than to control once they’ve started. If your treatment plan includes chemotherapy, radiation therapy or targeted therapy, nausea and vomiting are potential side effects. Antiemetics are drugs that can help prevent and control nausea and vomiting.

Vomiting can be prevented with the appropriate medications, but some people may still have nausea without vomiting. Medications to prevent vomiting should be taken as prescribed before treatment, and they should be continued as directed by your doctor because the risk of vomiting may continue for several days after treatment.

It’s important to let your doctor know if you’re still experiencing nausea and vomiting even after taking an antiemetic as prescribed. This type of nausea and vomiting is known as “breakthrough,” and you may need a different antiemetic drug or a higher dose to control these symptoms.

NEUTROPENIA
Neutropenia is most likely to occur in people receiving a combination of radiation therapy and chemotherapy, but it’s also common in those who receive either of these two treatments alone. Neutropenia is a low number of neutrophils, a kind of white blood cell that helps fight off infection. Therefore, neutropenia increases the risk of infection. Neutropenia cannot be prevented, so it’s important to take steps to reduce your risk for infection. Studies have shown that the most effective way to prevent infection is to wash your hands frequently.

Your doctor will keep a close watch on your white blood cell count throughout your treatment period. If your neutrophil count is extremely low, your doctor may delay your next treatment until the count has increased. In the meantime, he or she will likely have you follow “neutropenic precautions,” which are extra measures to prevent infection:
• Taking your temperature four times each day
• Not eating uncooked foods
• Staying away from fresh flowers, plants and gardening
• Avoiding enemas, rectal suppositories and rectal thermometers
• Delaying dental work

Certain growth factors may help people with an extremely low neutrophil count. These growth factors are special proteins that can stimulate the bone marrow to produce more white blood cells, and they’re usually given as an injection under the skin. For people who have a high risk for infection, preventive antibiotics or antifungal medications may be used as well. If an infection develops, antibiotics are usually given immediately because cancer-related infections are considered emergencies.

SKIN REACTIONS
Skin reactions are likely for people who receive chemotherapy, radiation therapy or targeted therapy. Reactions caused by treatments can range from mild to severe. If a rash develops and spreads over a larger area and causes itchiness or pain, your doctor may prescribe a mild corticosteroid cream or an antibiotic gel. Severe rashes are usually treated with an oral antibiotic and perhaps an oral corticosteroid.

The acne-like rashes caused by some treatments also can be treated with topical and oral antibiotics and corticosteroids. If your rash is severe, your doctor may reduce the dose of the drug or temporarily stop treatment, restarting it if the rash gets better within two weeks.

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org Treatments and Side Effects
- American Society of Clinical Oncology: www.cancer.net Side Effects
- CancerCare: www.cancercare.org Side Effects
- Cancer Pain Research Consortium: www.cancerpainresearchconsortium.org
- National Cancer Institute: www.cancer.gov Side Effects

One of the most common side effects of cancer and its treatment is pain. For many people, pain is related to the cancer itself. But cancer treatments, such as surgery, can sometimes cause pain by damaging healthy cells, which can result in side effects such as a burning sensation, mouth sores, diarrhea, nerve damage and more. Be sure to talk to your doctor openly about any pain you experience so it can be controlled. You should not avoid treatment because of pain.

There are numerous options for managing cancer pain, and it can be helpful to think of them as tools in a toolbox. Sometimes just one tool can fix the problem, but other times, you may need a combination. In addition, you’ll sometimes need to use tools in a particular sequence or switch back and forth between tools.

The following descriptions of pain relief techniques provide a general overview of what’s available. If your doctor doesn’t mention one or more of them for your care, don’t be afraid to ask whether they might be right for you.

- **Pharmacotherapy** is the treatment of cancer pain with medications, including non-opioid drugs, opioids (narcotics), adjuvant drugs (drugs not typically used for pain but that may be helpful for managing some types of pain) and topical analgesics.
- **Percutaneous pain techniques** are procedures that enable access to inner organs and tissues through needle punctures into the skin. These procedures include ablative techniques (radiofrequency ablation or cryotherapy), nerve blocks, kyphoplasty, vertebroplasty and sacroplasty.
- **Neurosurgical** approaches to pain relief lessen pain at its source by interrupting pain signals between the spine and brain.
- **Intrathecal drug delivery,** also called a “pain pump,” sends pain medication directly to your spinal cord through the action of a small pump that’s implanted in the body through an incision in the abdominal wall.
- **Supportive oncology** usually involves a team of doctors who use palliative surgery, radiation therapy and chemotherapy to help relieve cancer pain.
- **Physical therapy** helps relieve pain through customized therapy programs designed to enhance mobility, overcome disabilities and avoid painful activities when cancer or its treatments have affected how you move and function. Anti-inflammatory injections are also a part of this technique.
- **Complementary strategies** include yoga, acupuncture, reflexology, massage therapy, aromatherapy, art therapy, music therapy and animal therapy. These strategies do not single-handedly resolve cancer pain, but they can often contribute to managing pain.
- **Psychosocial strategies** involve activities such as deep relaxation and meditation. They are useful in calming psychological symptoms, such as anxiety and depression, which often accompany cancer pain and can get in the way of its treatment.

All of the ways to relieve pain are associated with certain risks and benefits, so always review them with your medical team before taking any approach.
FERTILITY & CANCER
Alliance for Fertility Preservation ................................................................. www.alliancefertilitypreservation.org
American Society for Reproductive Medicine ........................................... www.asreprod.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.com
CancerCare ................................................................................................ www.cancercare.org
Financial Assistance Coalition ................................................................. www.cancerfac.org
The CHAIN Fund ........................................................................................ www.thechainfund.com
HealthWell Foundation .......................................................................... www.healthwellfoundation.org
Hope Lodge ............................................................................................. www.cancer.org/treatment/supportprogramservices/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.com
RxHope ....................................................................................................... www.rxhope.com
Social Security Administration ............................................................... www.ssa.gov
Social Security Disability Resource Center .............................................. www.ssdicenter.com
State Health Insurance Assistance Programs ......................................... www.shiphatchcenter.org
Stupid Cancer ......................................................................................... www.stupidcancer.org

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

MENTAL HEALTH SERVICES
American Psychosocial Oncology Society Helpline ................................... 888-276-7443

NUTRITION
American Cancer Society ........................................................................... www.cancer.org
CancerCare ................................................................................................ www.cancercare.org
LIVESTRONG Foundation ....................................................................... www.livestrong.org
OncoLink .................................................................................................... www.oncolink.org
PearlPoint Cancer Support ...................................................................... www.pearlpoint.org
Physicians Committee for Responsible Medicine ................................... www.pcrm.org/health/cancer-resources

PAIN MANAGEMENT
American Chronic Pain Association .......................................................... www.theapqa.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 .................................................................................. www.uspainfoundation.org

PRESCRIPTION EXPENSES
Brenda Mehlng Cancer Fund (patients 18-40) ................................................ www.bmf.net, 611-310-7940
CancerCare Co-Payment Assistance Foundation ...................................... www.cancercarepay.org, 866-552-6729
Cancer Financial Assistance Coalition ...................................................... www.cancerfac.org
The CHAIN Fund Inc. ................................................................................ www.thechainfund.com, 203-691-5955
Foundation for Health Coverage Education .............................................. www.coverageforall.org
GoodDays ................................................................................................. www.gooddaysfromcclf.org, 972-608-7141
HealthWell Foundation ............................................................................ www.healthwellfoundation.org, 800-675-8416
National Organization for Rare Disorders ............................................... 203-744-0100
NeedyMeds ............................................................................................... www.needymeds.org, 800-503-8897
Partnership for Prescription Assistance .................................................. www.ppaRx.org, 888-477-2669
Patient Access Network Foundation ......................................................... www.pannetwork.org, 888-316-7253
Patient Advocate Foundation Co-Pay Relief ............................................ www.copay.org, 888-512-3961
Patient Services, Inc. ................................................................................ www.patientservicesinc.org, 800-366-7741
Rise Above It (youth, young adults) ........................................................... www.raisebenefit.org
RxAssist ..................................................................................................... www.rxassist.com
RxHope ...................................................................................................... www.rxhope.com, 877-267-0517
RxOutreach ............................................................................................... www.rxoutreach.com, 888-796-1234
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
Amen Assist 360 ...................................................................................... www.amenassist360.com, 888-427-7478
Bayer Healthcare Pharmaceuticals .......................................................... 866-575-5002
Boehringer Ingelheim Patient Assistance ................................................. www.boehringer-ingelheim.us/our-responsibility/patient-assistance-program,
Bristol-Myers Squibb................................................................................
Access Support ........................................................................................ www.bmsaccesssupport.com, 866-861-0888
Bristol-Myers Squibb Patient Assistance Foundation ................................ www.bms.com, 800-786-0903
Eisa Reimbursement Resources ............................................................... www.eisa-reimbursement.com
GSK For You ............................................................................................. www.gskforyou.com, 888-625-5249
Halaven Patient Assistance Program ....................................................... www.halaven.com, 888-613-4724
Janssen CarePath ....................................................................................... www.janssencarepath.com, 877-227-3728
Janssen Prescription Assistance .............................................................. www.janssenprescriptionassistance.com
Johnson & Johnson Patient Assistance Foundation, Inc. ......................... www.jjpadf.com, 800-652-6227
Lilly PatientOne ........................................................................................ www.lillypatientone.com, 888-472-8663
Merck Access Program ............................................................................ www.merckaccessprogram.com, 855-257-3932
Merck Helps .............................................................................................. www.merckhelps.com, 800-727-5400
Novartis Oncology Universal Co-Pay Program ....................................... www.copay.novartisoncology.com, 877-577-7756
Novartis Patient Assistance New Oncology .............................................. www.oncologyaccessnow.com, 888-282-7630
Patient Rx Solutions .................................................................................. www.patientrxsolutions.com, 800-676-5884
Pfizer Co-Pay Line ..................................................................................... www.pfizerco payline.com, 855-612-1951
Pfizer RxPathways ..................................................................................... www.pfizerrxpathways.com, 844-989-7284
Sandoz Patient Connection ....................................................................... www.sanoxpathelpatientconnection.com, 888-847-4877
Stivarga Reach Program .......................................................................... www.stivarga.us/getting-and-paying/, 888-639-2827
Takeda Patient Assistance ........................................................................ www.takeda.com/responsibility/patient_assistance_program.aspx, 800-830-9159
Teva Cares Foundation Patient Assistance Programs ............................ www.tevacares.org, 877-237-4881
Teva Oncology Core Reimbursement Assistance & Support ................. www.tevaco re.com, 888-587-3263
Together with Tesaro ................................................................................ www.togetherwithtesaro.com, 844-283-7276
Xgeva Prescription Injection Cost Assistance ......................................... www.xgeva.com/cost-assistance-and-patient-support, 888-657-8371
Yondelis Janssen CarePath Savings Program ......................................... www.carepathingsavingsprogram.com, 844-966-3354

SARCOTA
Amishward Sarcoma Cancer Foundation .................................................. www.sarcomacancer.org
Be the Match ........................................................................................... www.bethematch.org
Blood & Marrow Transplant Information Network ................................ www.bmt.org
LM-Sarcoma Direct Research Foundation ............................................. www.lmsdr.org
National Bone Marrow Transplant Link .................................................. www.nwtlink.com
National Leukemia Sarcoma Foundation ................................................. www.nlms.org
Sarcoma Alliance .................................................................................... www.enterasym.org
Sarcoma Foundation of America ............................................................. www.curesarcoma.org

STOPPING TOBACCO USE
American Cancer Society .......................................................................... www.cancer.org
Quit Plan ................................................................................................. www.quitplan.org
National Cancer Institute Smoking Quitline .......................................... 877-448-7889
Plan My Quit ........................................................................................... www.planmyquit.com
QuitSTART .............................................................................................. teen.smokefree.gov/quitappspark
Quitter’s Circle ........................................................................................ www.quittercircle.com
Smokefree.gov ....................................................................................... www.smokefree.gov
SmokefreeTXT ........................................................................................ www.smokefree.gov

YOUNG ADULTS
Critical Mass: The Young Adult Cancer Alliance ..................................... www.criticalmass.org
Hope for Young Adults With Cancer ....................................................... www.hope4yac.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.nationalcancer.org
The Samfund Support For Young Adult Cancer Survivors ..................... www.thesamfund.org
Stupid Cancer .......................................................................................... www.stupidcancer.org
Teens Living With Cancer ...................................................................... 877-313-9010
The Ulman Cancer Fund For Young Adults .............................................. www.ulmanfund.org
Young Adult Cancer Canada ................................................................. www.youngadultscancer.ca
Young Survival Coalition ....................................................................... www.youngsurvivor.org
Lilly salutes all those involved in the relentless fight against sarcoma.