REIN IN
SARCOMA
Increase awareness. Increase survivors.

Sarcoma Patient Guidebook

9th Edition: 2024

Take Charge of Your
Sarcoma Story

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Introduction

At every step, we are here to help.

This Sarcoma Patient Guidebook is written for you, someone who is learning about sarcoma and sarcoma treatments. We encourage you to share this with your family and friends who may find this helpful and want to read it too. We want you to feel supported, cared for and have the best information to make decisions with your care team.

This Guidebook will help you and your loved ones:
- Learn about sarcoma.
- Think about questions to ask your doctor.
- Prepare for treatment.
- Access resources through Rein in Sarcoma and other organizations.

Everyone's situation is unique, so it is important to talk with your treatment team.

To learn more about sarcoma from doctors and healthcare professionals, and hear from survivors and caregivers who've been through it, watch short videos at: youtube.com/@ReinInSarcoma/videos

Programs & Resources Available (reininsarcoma.org)

- ***Sarcoma Support Team:***
    - Connect with a trained volunteer who has been impacted by sarcoma. Our volunteers are survivors and caregivers and available to talk by phone or email, sharing their experience and tips. Connect just once or twice, or regularly as suits your needs.
- ***Support Group:***
    - Monthly gathering of sarcoma survivors and their caregivers. Individuals share their stories, provide updates on their treatment, and discuss topics related to sarcoma.
- ***Rein in Sarcoma's Circle of Support Private Facebook Group:***
    - facebook.com/groups/reininsarcomacircleofsupport
    - Designed to connect sarcoma patients, survivors, and caregivers to provide support, share knowledge and experience, and raise awareness and advocacy.
- ***Micro-Grants:***
    - One-time, financial support provided to patients to help with the out-of-pocket costs of treatment.
- ***Tote Bag of Hope:***
    - Tote bag filled with comfort items for sarcoma patients.
- ***Survivor Gatherings:***
    - Our gatherings are held periodically during the year in-person in Minnesota, with some virtually. They are a wonderful opportunity to meet and learn from others who are facing sarcoma. It is also a rare opportunity to get and give support. Our gatherings are low cost or free of cost for sarcoma patients, survivors, and their immediate families; as well as for persons who have lost a family member to sarcoma.
- ***Video Series:***
    - Sarcoma-centered, plain-language videos featuring survivor stories, caregiver interviews, sarcoma overview, treatment overview and supportive care.

Connect With Us

Call: 1-844-727-2662 or 763-205-1467
Get Support: reininsarcoma.org/patient-and-family-support
Request Support: admin@reininsarcoma.org

Follow us on social to learn more about Rein in Sarcoma: @reininsarcoma or @reininsarcomafoundation

Scan for Support Resources

Scan for Sarcoma Video Series

REIN IN
SARCOMA
Increase awareness. Increase survivors.

Rein in Sarcoma is a 501(c)(3) that serves as a resource for patients and families touched by sarcomas, an uncommon and often misdiagnosed group of bone and soft tissue cancers that strike children and adults alike.

We are a nationally known sarcoma foundation and provide support to patients and loved ones all across the world. Founded in Minnesota in 2001, we have funded over $2 million in innovative, collaborative and high-impact research and education initiatives at top medical research institutions such as Mayo Clinic, the University of Minnesota, and Children's Hospitals and Clinics of Minnesota.

The Rein in Sarcoma logo represents both a classic carousel horse and a sunflower. Together they symbolize hope and the search for cures for sarcoma cancers.

SECTION I
Information For The Newly Diagnosed

What is sarcoma?

Sarcoma is a type of cancer found in connective tissues. It is usually found as a lump, bump, or mass called a tumor. Sarcoma cancers may be found in fat, blood vessels, nerves, bones, muscles, deep skin tissues, tendons, and cartilage. They are divided into **two main groups,** bone tumors and soft tissue tumors. These two main groups can be broken down into more specific sub-types based on the type of cells found in the tumor. There are over 100 different types of sarcoma tumors, and most are very rare.

How rare are sarcoma cancers?

Of the 1.7 million people diagnosed with cancer in the United States each year:

- Only 1% of them (17,000) will be diagnosed with sarcoma.
- Some sarcomas are so rare that only a few people are diagnosed with that type each year.
- In children (<18 years old), where cancer is already a rare diagnosis, sarcomas are in the top 5 most diagnosed cancers.

How are sarcoma cancers diagnosed?

Sometimes the diagnosis of cancer comes quickly, if a person has obvious symptoms and receives prompt evaluation. However, diagnosing a new sarcoma sometimes can be challenging. Some reasons include:

- The symptoms might be vague. The symptoms are ones that many people experience, such as a lump, a bump, or pain in a joint.

- Sarcoma tumors can form almost anywhere in the body and may be present for a long time before they are recognized.
- Sarcomas can be misdiagnosed. Since non-cancerous diagnoses are far more common, sarcoma tumors can be easily mistaken for trauma, a “pulled muscle” or a benign fatty tumor called lipoma.

What We Know About The Causes Of Sarcoma

After a diagnosis of sarcoma, a common question that people ask is, “What caused this?” Since sarcomas are so rare, there is still a lot to discover about these tumors and what causes them. Researchers can study some sarcomas individually, or they may study different types of sarcomas in groups. Combining these rare cancers in research may be the only way to find potential causes, treatment and cures for the ultra-rare sarcoma types.

Cancer is basically a genetic disease.

Genes are like blueprints for the cells in your body. Changes in these genes are called mutations. There are many different types of mutations that can occur. Some genetic variants may be present at birth, others may occur throughout a person’s lifetime. These mutations can be harmful, beneficial, or have no effect on the risk of developing cancer. Sometimes, however, mutations in these genetic blueprints can cause cells to grow out of control and become cancerous.

Most of the time gene mutations happen spontaneously. Sometimes they can be inherited from a parent and/or present at birth. Genes associated with cancer predisposition are thought to contribute to about 5 to 10% of all cancers, and a small number are associated with sarcomas. Some of these risks can be detected by genetic testing of blood or saliva samples.

What causes mutations and other changes to happen?

Your body works hard to keep mutations from happening in cells and to repair harmful changes when they occur. Sometimes, despite these intricate systems, cells may acquire harmful changes, causing cells to grow in an uncontrolled way, leading to cancers such as sarcoma. In some cases, understanding the specific changes present within a particular tumor can lead to potential treatment options.

Certain exposures in the environment can increase the chances of developing sarcoma cancer. For example:

- A viral infection, known as Human Herpes virus 8 (HHV-8), can lead to Kaposi Sarcoma.
- Exposure to **ionizing radiation** or **chemotherapy** from a previous cancer can increase the risk of sarcoma later in life.

Tumor Mutation Burden

Sarcoma cancers can have many gene mutations and changes to DNA, or they may have just a few changes. This is what is known as the **tumor mutational burden.** Assessment of tumor mutational burden can provide information regarding the potential for newer treatment options and eligibility for certain clinical studies.

For more in-depth information:

The National Cancer Institute
cancer.gov/about-cancer/causes-prevention/genetics

ASCO Cancer Information
cancer.net/navigating-cancer-care/cancer-basics/genetics/genes-and-cancer

Types of Sarcoma Cancers

The following are descriptions of some of the most common types of soft tissue and bone sarcomas.

Soft Tissue Sarcomas

Soft tissue sarcoma tumors can occur in muscles, fat, nerves, blood vessels, tendons, and other soft tissues that support, surround, or protect the body's organs and joints. Soft tissue sarcomas can be found anywhere in the body, from head to toe, but they are more often found in the extremities, such as in the arms or legs.

- Approximately three-quarters of people diagnosed with sarcoma will be diagnosed with a type of soft tissue sarcoma. There are many types of soft tissue sarcoma. Some of those types are so rare that only a few cases will be diagnosed in the United States each year.
- In their early stages, soft tissue sarcomas rarely show any symptoms. Because soft tissue is very elastic, tumors can grow quite large before they are felt as a lump or bump.
- Pain may occur when a sarcoma starts to press on nearby muscles and nerves.
- Imaging, such as MRI scans, can help determine if a lump or mass has features consistent with a sarcoma.
- The only way to make a definitive diagnosis of soft tissue sarcoma is through a biopsy, which is when either the entire tumor or a small piece of it is surgically removed for testing. This is best performed by a skilled surgeon who is very familiar with sarcoma, and who will take great care in not allowing the spread of cancer cells during initial biopsies.

The most common types of soft tissue sarcoma cancers are described below. This is not intended to be a complete list and may not contain the specific sarcoma type that you (or your loved one) has been diagnosed with. It is always best to work closely with your own oncologist and sarcoma team who will help get you all the additional information that you will want to know.

Additional resources can also be found in Section II of this guidebook.

Alveolar Soft Part Sarcoma (ASPS)

Type	How Does it Appear?	General Description
Soft Tissue Tumors	In adults, ASPS is usually discovered as a painless lump in the leg or buttock. It can also emerge in the trunk or arms. In children, ASPS usually shows in the head and neck area, particularly around the tongue or eye socket.	Cancer that arises from a variety of soft tissue, such as muscle or fat. Tends to spread early because it builds a network of blood vessels that make it easy for cancer cells to travel around the body. In both children and adults, detecting ASPS early can be challenging. Most frequently found in young adults and teenagers.

National Cancer Institute: Alveolar Soft Part Sarcoma (ASPS)
cancer.gov/pediatric-adult-rare-tumor

Cure Alveolar Soft Part Sarcoma International
cureasps.org

Angiosarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Most patients have no symptoms (i.e., asymptomatic). They will appear as a raised, purple area of skin that resembles a bruise, growing over time. May be painful or bleed at the tumor site. Can occur anywhere in the body, but most often in the skin, head, or neck.	Angiosarcoma is a connective tissue sarcoma tumor that grows from the cells that line blood vessels and lymph channels. They represent approximately 1-2% of all sarcoma cancers and are seen most in individuals above the age of 70, but they can occur at any age. • Angiosarcoma can be caused by “lymphedema,” which is swelling due to extra fluid (lymph) collecting in tissues, often in the arms and legs. • Other causes of these tumors include radiation exposure and/or exposure to chemicals, such as vinyl chloride, arsenic, and thorium dioxide.

Angiosarcoma – Symptoms & Causes – Mayo Clinic
mayoclinic.org/diseases-conditions/angiosarcoma/symptoms-causes/syc-20350244

Angiosarcoma – NCI – National Cancer Institute
cancer.gov/pediatric-adult-rare-tumor/rare-tumors/rare-vascular-tumors/angiosarcoma

Angiosarcoma Awareness Inc.
cureasc.org

Dermatofibrosarcoma Protuberans (DFSP)

Type	How Does it Appear?	General Description
Soft Tissue Tumors	It often starts as a small, firm patch of skin that can be various tones of purple or red. Grows slowly over months to years and can become a raised nodule under the skin.	A Dermatofibrosarcoma Protuberans (DFSP) tumor arises from connective tissue in the middle layer of the skin, known as the dermis layer. • It typically affects people aged 20-50 years old. • Women and African Americans are more at risk. • Scars formed from burns or surgery can be risk factors. • There are many subtypes of these tumors that are based on the type of cells found in the dermis layer. These subtypes include Bednar tumors, Myxoid Dermatofibrosarcoma Protuberans tumors, and Giant Cell Fibroblastoma.

Mayo Clinic – Dermatofibrosarcoma Protuberans (DFSP)
mayoclinic.org/diseases-conditions/dermatofibrosarcoma-protuberans/cdc-20352949

Desmoid Tumor (AKA Aggressive Fibromatosis)

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Can be seen in the abdomen or in the arms or legs. Can disappear spontaneously, remain stable, or grow in size.	A non-cancerous tumor of the connective tissue, which are tissues that connect, support, and/or separate our organs. These tumors can locally grow very large and can damage nearby organs, but they do not spread to other parts of the body (metastasize).

Mayo Clinic – Desmoid Tumor
mayoclinic.org/diseases-conditions/desmoid-tumors

Desmoid Tumor Research Foundation
dtrf.org

Desmoplastic Round Cell Tumor

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Appears in the abdomen and pelvic area of the body. No symptoms initially but leads to one or a combination of the following symptoms: nausea and vomiting, diarrhea, constipation, abdominal swelling, abdominal pain and difficulty urinating.	A type of soft tissue sarcoma that begins on the tissue that lines the inside of the abdomen and pelvis called the peritoneum. Most often occurs in white males between the ages of 10 and 30.

National Cancer Institute – Desmoplastic Round Cell Tumor (DSCRT)
cancer.gov/pediatric-adult-rare-tumor

Mayo Clinic – Desmoplastic Small Round Cell Tumors
mayoclinic.org/diseases-conditions/dsrct/symptoms-causes/syc-20355405

Epithelioid Sarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Typically, it will appear as a small, painless, slow growing lump under the skin of a finger, hand, forearm, lower leg, or foot. May be a sore or open wound that doesn't heal.	Epithelioid sarcoma is a connective tissue tumor that grows from epithelial cells, which are cells that line the surfaces inside and outside of the body, including the skin, urinary tract, intestines, and other organs. • Most seen among teenagers and young adults. • More common in men than women (2:1).

Mayo Clinic: Epithelioid Sarcoma
mayoclinic.org/diseases-conditions/epithelioid-sarcoma/cdc-20392420

Fibrosarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Cancer that begins in the fibrous connective tissue located at the extremities of the arm or legs. May lead to limping or difficulty in using legs, feet, arms, and hands.	The tumor cells at the primary site frequently spread to nearby soft tissue. Can occur in children and adults. Infantile fibrosarcoma is the most frequent soft tissue sarcoma in children less than one year old. It presents as a growing mass at birth or soon after. This form has a slower growth rate and is usually less aggressive than fibrosarcoma seen in older children.

Boston Children's Hospital – Fibrosarcoma
childrenshospital.org/conditions/fibrosarcoma

Gastrointestinal Stromal Tumor (GIST)

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Symptoms vary based on the size and location of tumors. Small tumors may be asymptomatic while larger tumors may cause vomiting, GI bleeding, abdominal pain, nausea and weight loss.	A Gastrointestinal Stromal Tumor (GIST) is a sarcoma cancer that develops from the cells that help your intestines move food in your body. • Most commonly occurs in adults between the ages of 50 and 70 but can occur at any age. • Some association with rare genetic syndromes.

Mayo Clinic – Gastrointestinal Stromal Tumor (GIST)
mayoclinic.org/diseases-conditions/gastrointestinal-stromal-tumors/cdc-20387715

GIST Cancer Awareness Foundation
gistawareness.org

GIST International
gistsupport.org

Life Raft Group
liferaftgroup.org

Kaposi’s Sarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Appears as painless, purple-ish spots on the legs, feet, or face. Can also appear in genital areas, the mouth, lymph nodes, and, in severe cases, the digestive tract or lungs.	Kaposi’s sarcoma is a connective tissue tumor named after the Hungarian doctor who discovered it, Dr. Moritz Kaposi. These tumors grow from cells that line blood and lymph vessels. • It is caused by an infection with a virus called Human Herpes Virus 8 (HHV-8). • Immune system damage or suppression (especially in patients with organ transplant or HIV/AIDS) allows the cells infected with HHV-8 virus to multiply and form tumors.

Mayo Clinic – Kaposi Sarcoma
mayoclinic.org/diseases-conditions/kaposis-sarcoma/cdc-20387726

Leiomyosarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Tumors located deep in the body that may not present with any symptoms until they grow larger or are causing pressure in the space they are growing. May appear as painless masses below the skin. Uterine leiomyosarcoma may present with pain, pressure, and abnormal uterine bleeding, similar to benign fibroids.	Leiomyosarcoma is a connective tissue tumor that grows from smooth muscle, a type of muscle found in the uterus of women, and in the lining of intestines, gastrointestinal tract, and large blood vessels. • No proven relation to any environmental exposures or lifestyle choices. • Genetic conditions (Hereditary Retinoblastoma and Li Fraumeni Syndrome) may predispose patients to Leiomyosarcoma cancer.

National Cancer Institute – Leiomyosarcoma
cancer.gov/pediatric-adult-rare-tumor/rare-tumors/rare-soft-tissue-tumors/leiomyosarcoma

Leiomyosarcoma Direct Research Foundation (LMSDR)
lmsdr.org

National Leiomyosarcoma Foundation (NLMSF)
nlmsf.org

Liposarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Can occur anywhere in the body, but are mostly found in the limbs, muscles and abdomen. They are painless and slow growing – so many patients may be symptom free (asymptomatic). May appear as a growing lump under the skin of the arms or legs.	Liposarcoma is a connective tissue tumor that grows from fat cells located in deep connective tissues. • One of the most common soft tissue tumors, mostly found in adults, can occur at any age. • Some risk factors include exposure to chemicals, carcinogens and previous ionizing radiation and chemotherapy treatments.

Mayo Clinic – Liposarcoma
mayoclinic.org/diseases-conditions/liposarcoma

Malignant Peripheral Nerve Sheath Tumor (MPNST)

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Symptoms vary based on the size and location of tumors. May experience pain, numbness, weakness, or a burning/tingling sensation in the legs or arms at the tumor site.	A malignant nerve sheath tumor (MPNST) is a sarcoma cancer that develops from the cells that surround and protect the nerves of the peripheral nervous system (outside of the brain and spinal cord). • Most commonly affects young and middle-aged adults. • Approximately one-half of MPNST tumors occur in people with a genetic condition called Neurofibromatosis 1.

Mayo Clinic – Malignant Peripheral Nerve Sheath Tumors
mayoclinic.org/diseases-conditions/malignant-peripheral-nerve-sheath-tumors/symptoms-causes/syc-20362603

Sarcoma Help
sarcomahelp.org/mpnst.html

Myxofibrosarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Slow-growing, painless lump on extremities, such as arms or legs, that extends deep into tissues. Symptoms may be different based on the tumor's size and location.	Myxofibrosarcoma is a connective tissue tumor that affects the structures that surround and separate muscles from each other and from the skin. • It mostly occurs in people between the ages of 50 and 70. • Slightly more common in men than women. • Difficult to distinguish from other soft tissue sarcoma tumors, which can result in delayed diagnosis.

Mayo Clinic – Myxofibrosarcoma
mayoclinic.org/diseases-conditions/myxofibrosarcoma/cdc-20387740

Rhabdomyosarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	May appear as a painless mass underneath the skin. They are commonly found in the head and neck region, followed by the extremities, such as arms and legs.	Rhabdomyosarcoma is a connective tissue tumor that grows from skeletal muscles, such as the muscles in your arms, legs, abdominal wall, and back. • It mostly occurs in children and young adults but can occur at any age. • It is associated with Neurofibromatosis, Li-Fraumeni, Beckwith-Wiedemann, and Costello syndromes.

Nemours KidsHealth – Rhabdomyosarcoma
kidshealth.org/en/parents/rms.html?ref=search

Focus on Rhabdo
focusonrhabdo.org

Summer's Way Foundation
summersway.org

Mayo Clinic – Rhabdomyosarcoma
mayoclinic.org/diseases-conditions/rhabdomyosarcoma/symptoms-causes/syc-20390962

Synovial Sarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Slow growing, painless *mass* found in the arms or legs where the joints are formed. *Masses* may be painful if involving nerves.	Synovial sarcoma tumors develop from immature cells that line the inside of a joint (synovium). • It typically affects people ages 15-40 but can occur at any age. • No definite risk factors. • It has been associated with Chromosome 18 and Chromosome X Translocations.

National Cancer Institute – Synovial Sarcoma
cancer.gov/pediatric-adult-rare-tumor/rare-tumors/rare-soft-tissue-tumors/synovial-sarcoma

Mayo Clinic Synovial Sarcoma
mayoclinic.org/diseases-conditions/synovial-sarcoma/cdc-20387747

Synovial Sarcoma Research Foundation
synsar.org

Undifferentiated Pleomorphic Sarcoma

Type	How Does it Appear?	General Description
Soft Tissue Tumors	Appears as a lump in the extremities, such as arms or legs. It can also occur behind abdominal organs. Although it can be found in either soft tissues or bones, it is considered a soft tissue tumor.	An Undifferentiated Pleomorphic Sarcoma tumor has cells of different sizes and shapes. The tissue type it originates from is not able to be identified, which is known as "undifferentiated." • Formerly known as Malignant Fibrous Histiocytoma. • It typically affects older adults. • Previous ionizing radiation therapy is a risk factor.

Mayo Clinic – Undifferentiated Pleomorphic Sarcoma
mayoclinic.org/diseases-conditions/undifferentiated-pleomorphic-sarcoma/symptoms-causes/syc-20389554

Bone Sarcoma

Bone Sarcoma tumors develop in the bone tissue itself or in the cartilage, which is the cushion between bones that forms joints.

- Approximately one-quarter of sarcomas diagnosed in the United States each year will be bone sarcoma.
- Unexplained bone pain that does not go away, and/or a lump that may appear under the skin, are the most common symptoms of this type of cancer.
- As a tumor gets bigger, it can cause a joint, such as the knee or elbow, to swell. This swelling is often mistaken as an injury instead of a bone tumor. These tumors can also weaken the bones, causing easy fractures.
- A variety of imaging (X-Rays, CT scan or MRI) can decide if a lump or mass is suspicious for a bone tumor.
- An orthopedic bone surgeon, who is very familiar with sarcoma cancers, should be consulted for a diagnosis, and surgical and treatment plans.
- Bone sarcomas are definitively diagnosed by either removing the entire tumor or a small piece of it through a surgical biopsy.

The most common types of bone sarcomas are described below. Working closely with your orthopedic oncologist and cancer team will help you get all the information you need. This is not intended to be a complete list.

Additional resources for researching your type of bone sarcoma can be found in Section II.

National Cancer Institute – Primary Bone Cancer
cancer.gov/types/bone/bone-fact-sheet

SARC – Bone Sarcoma
sarctrials.org/education/bone-sarcoma

Chordoma Sarcoma

Type	How Does it Appear?	General Description
Bone Tumors	Can occur anywhere within the spine and the base of the skull/brain, causing pain and nerve symptoms, including tingling, numbness and weakness.	Chordoma sarcoma arises from cells that become the discs of the spine in the embryo. These cells typically go away after birth, but rarely some remain and become cancerous. • Occurs most often in adults between ages 40 and 60, more in men than women. • It can be caused by some hereditary conditions, such as familial Chordoma and Tuberous Sclerosis Complex.

Mayo Clinic – Chordoma
mayoclinic.org/diseases-conditions/chordoma/cdc-20355401

Chordoma Foundation
chordomafoundation.org

Chondrosarcoma

Type	How Does it Appear?	General Description
Bone Tumors	May feel a hard lump under the skin, causing pain, swelling, or limited movement. Usually starts in the long bones of the arms, legs, or pelvis. Because it is a sarcoma of the cartilage, tumors are often found near the joints.	Chondrosarcoma is a sarcoma that arises from cells that produce cartilage, which is connective tissue surrounding bones and other organs in the body. • It typically affects adults between the ages of 20 and 60. • These tumors are commonly found in men more than women. • This type of sarcoma is associated with other conditions, such as Ollier's Disease, Maffucci Syndrome, and Multiple Hereditary Exostoses.

SARC – Chondrosarcoma
sarctrials.org/education/bone-sarcoma

Chondrosarcoma Foundation
csfshayna.org

Ewing’s Sarcoma

Type	How Does it Appear?	General Description
Bone Tumors	May feel a lump under the skin causing pain, swelling, or limited movement. Typically develops in the pelvis, ribs and long bones (femur, tibia, humerus).	Ewing’s sarcoma is named after the American doctor, Dr. James Ewing, who discovered this sarcoma tumor in the 1920s. It is a tumor that arises from immature bone cells, but can also occur outside the bone in cartilage, nerves, or soft tissue. • It is the second most common type of bone cancer, behind Osteosarcoma. • Most often occurs in children and young adults between the ages of 10 and 20 but can also rarely occur in older adults. • It is more common in males than females. • Most cases involve a fusion of genetic material between chromosomes 11 and 22, causing the Ewing’s sarcoma gene (EWS) to be “turned on.”

Mayo Clinic – Ewing Sarcoma
mayoclinic.org/diseases-conditions/ewing-sarcoma/symptoms-causes/syc-20351071

Brian Morden Foundation
brianmordenfoundation.org

Osteosarcoma

Type	How Does it Appear?	General Description
Bone Tumors	Can experience unexplained pain in an affected area, such as in the knee, which can cause a limp or similar disability. Easy fractures can occur, due to the bone getting weakened by the tumor. Tumors most commonly occur near the knee (specifically, in the femur or tibia bones) or near the shoulder (specifically, in the humerus bone).	Osteosarcoma tumors come from bone forming cells, called osteoblasts, in immature bone tissue. • Most common bone tumors. • Most commonly diagnosed in children and young adults, under the age of 25. • Can also occur in older adults.

Mayo Clinic: Osteosarcoma
mayoclinic.org/diseases-conditions/osteosarcoma/symptoms-causes/syc-20351052

National Cancer Institute – Primary Bone Cancer
cancer.gov/types/bone/bone-fact-sheet

Foster Foundation
fosterfoundation.com

Make It Better Agents (MIB)
mibagents.org

Notes:

SECTION II
What’s Next After The Sarcoma Diagnosis

Understanding a sarcoma diagnosis and its treatment options can be both scary and challenging. To help you (or a loved one) through this journey, we have gathered the following information as a guide to use from the beginning of your diagnosis.

1. Understanding Your Sarcoma Type

Most people receive a diagnosis of sarcoma after a tissue biopsy. A biopsy is a surgical procedure where part of the tumor tissue is removed very carefully to identify what the tumor is. Many tests can be done to aid in the diagnosis and help with treatment decisions. These include pathology grading, staging, and genetic testing.

Grading and Staging

Grading and staging are the medical descriptions of your tumor cells and where they are found in your body. This provides your medical team with a universally accepted way to understand the risk of spread and recurrence. The information is also used by your medical team when deciding a treatment plan. It can also be helpful to cancer researchers who are leading clinical trials or related research.

Grading: The “grade” portion of your tumor is about appearance and describes how much of your cancer cells within your tumor look like normal healthy cells when under a microscope. This information is usually found in pathology reports.

Sarcoma tumors have four grades. In general, the lower the grade, the better the prognosis will be. For example, a *grade 1 tumor* is in an early stage of growth, may grow very slowly, and be unlikely to spread throughout your body. A *grade 3 tumor* has cells that are dividing and growing fast and may look very abnormal under the microscope. There are also cells described as *undifferentiated* or *dedifferentiated* which are cells growing and dividing very fast and look very, very abnormal.

Staging: The "stage" portion of your tumor is about location and describes all the places the cancer cells or tumors are located in your body. There are several different ways to describe the cancer stage. For some patients, the cancer will be described as "local" (in one place) or "metastatic" (meaning that it has spread in the body). A universally common staging system that is more detailed is the **Tumor, Node, Metastasis (TNM)** system, which tells information about:

- Tumor (T): How large is the primary tumor? Where is it located?
- Node (N): Has the tumor spread to lymph nodes? If so, where, and how many?
- Metastasis (M): Has the tumor spread to other parts of your body?

For example, a grade one/stage one cancer tumor is slow growing (grade one) and located completely in one place in your body (stage one).

It can be helpful for you to know and understand your cancer's grade and stage, as it will guide treatment plan and help you and your team understand risk of spread and recurrence.

Genetic Testing On Your Tumor

Each person's cancer has unique genes, proteins, and other markers that cause the cancer to grow. Looking for these changes is called genomic or genetic testing. It is also commonly called *tumor DNA testing, biomarker testing, or genomic testing*. This testing can be done after biopsy or surgery to remove your tumor. There are many, many different changes to genes, proteins, and other markers that can be tested for.

Genomic testing of tumors is becoming more and more important as scientists learn more about the genetics of cancer and develop new treatments. By knowing what makes your particular cancer grow, your oncologist can determine which treatments may be effective, especially the newer **targeted therapies** (see below). Genomic testing may also be necessary for you to qualify for **clinical trials** (see below). The area of genomic testing is rapidly expanding and will hopefully lead to more effective treatments for sarcoma cancers.

A term you may hear about is ***liquid biopsy***. Liquid biopsy is the means by which a person's blood is examined to find circulating tumor cells, bits of the genetic material of tumor cells, or other markers for their particular cancer. There are a number of challenges with the use of liquid biopsy in rare sarcomas. This is an area of active research.

For more in-depth information on genetic/genomic testing please visit:

The National Cancer Institute

cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet#what-is-genetic-testing

The American Society of Clinical Oncology (ASCO)

cancer.net

- Soft Tissue Sarcoma: cancer.net/cancer-types/sarcoma-soft-tissue
- Sarcoma of Specific Organs: cancer.net/cancer-types/sarcomas-specific-organs
- Bone Sarcoma: cancer.net/cancer-types/bone-cancer
- Find a Sarcoma Doctor: cancer.net/find-cancer-doctor

National Cancer Institute – Cancer Information & Support Networks

cancer.gov

- Soft Tissue Sarcoma: cancer.gov/cancertopics/types/soft-tissue-sarcoma
- Bone Sarcoma: cancer.gov/cancertopics/types/bone
- Personal Assistance (NCI): 1-800-4-CANCER (or 1-800-422-6237).
- The NCI's website also offers live online assistance with its ***LiveHelp*** service at livehelp.cancer.gov/app/chat/chat_launch
- If you prefer to contact them in Spanish, please visit - cancer.gov/espanol/global/contactenos

Sarcoma Alliance

sarcomaalliance.org

Research everything you can about your sarcoma diagnosis and possible treatments specific to the type of sarcoma you have. It may help you know what questions to ask and help you to feel mentally prepared for what may lie ahead. Share what you have read with your cancer team so they can add their collective expertise. This will help keep communication open and help you get the most current and best treatment.

The following websites provide reliable and up-to-date general and specific information about many sarcoma cancers and their treatment.

There are also resources specific to certain sarcoma types that you will find in Section I.

Bone Tumor.org
bonetumor.org

Sarcoma Patients EuroNet Association (SPAEN)
sarcoma-patients.eu

National Library of Medicine
ncbi.nlm.nih.gov/pubmed

PubMed is a service that includes millions of articles about the latest cancer research.
nlm.nih.gov/bsd/pubmed_tutorial/m1001.html

2. Finding the Right Experts For Your Care

Choosing the best medical team to be at your side is an important step in your journey. Most likely, you will have a surgeon and/or an oncologist (cancer treatment specialist) as part of your team. Ask them how much they know about your type of sarcoma. Honesty, trust, and open communication will lead to the best care possible for you. You have the right to choose your own doctors, hospitals, and treatment.

Consider a Sarcoma Center

The best information for patients with a sarcoma cancer diagnosis has been shown to come from designated **Sarcoma Centers** or **Sarcoma Centers of Excellence** (listed in Section VI). These centers are also designated by the **Sarcoma Alliance through Research and Collaboration**, or **SARC**, as having sarcoma clinical trials and other sarcoma research. They also have sarcoma expertise in a variety of specialties, including surgical/orthopedic oncology, medical oncology, pediatric oncology, radiation therapy, pathology, and radiology.

For Pediatric Patients

Approximately one-fifth of all soft tissue and bone sarcoma cancers are diagnosed in children and teens. The sarcomas that develop in younger people are often specific subtypes, such as osteosarcoma and rhabdomyosarcoma. Because of the unique health needs of children and the fact that they are still growing, care is often best in cancer centers that focus on young patients. Pediatric oncologists are experts in the care of children, adolescents and young adults with cancer. They are likely to be very familiar with sarcoma cancers because of the frequency of cancers found in children that are sarcoma cancers.

The Children's Oncology Group (COG) is a cooperative group of approximately 200 hospitals that treat children with cancer. Information about the COG can be found here:

childrensoncologygroup.org

and a list of member pediatric hospitals with cancer specialists can be found here: childrensoncologygroup.org/locations

For a state-by-state national listing including a map showing sarcoma centers visit:

Sarcoma Alliance Through Research and Collaboration
sarctrials.org/sarc-centers

Consider visiting:

National Cancer Institute Cancer Center
cancer.gov

or a surgeon from the

Musculoskeletal Tumor Society
msts.org/index.php

3. Know The Members Of Your Medical Team

You may encounter many different types of doctors, nurses, and other providers throughout treatment and follow-up. All are important members of your medical team and have very specific roles. The type of specialist on your team depends on your type of sarcoma and what sort of treatment is recommended specifically for you. Many people have multiple specialists involved with their care. Others only have one or two specialists.

Surgical/Orthopedic Oncology: These are surgeons with special training in cancer. They may help diagnose cancer with a biopsy and/or removal of tumors.

Medical Oncology: An oncologist will often oversee general care and coordinate treatment with other doctors. They will also manage medical treatments, such as chemotherapy, hormone therapy, targeted therapy, and immunotherapy.

Pediatric Oncology: Specialized oncologists who work with infants, children, teens, and some young adults.

Radiation Oncology: Specialists in performing radiation treatments.

Pathology: Pathologists provide diagnostic information. One way they do this is by looking at cells under a microscope. Pathologists create a diagnostic report naming the specific tumor that a patient has so that an oncologist can plan a treatment. Pathologists may also be involved in sending additional testing on tumor tissue.

Radiology: Radiologists mostly specialize in diagnosing illness through medical imaging, such as X-rays, computed tomography (CT), and magnetic resonance imaging (MRI). They evaluate imaging studies and provide reports of potential cancer diagnoses and/or recurrence of cancers.

Physical Medicine and Rehabilitation (PM&R): Cancer rehabilitation physiatrists are doctors that oversee the physical, cognitive, emotional, and social complications of your cancer diagnosis and treatment.

Palliative Care: The goal of palliative care is to improve the quality of life of patients with serious illnesses like cancer. People with cancer can receive palliative care from the point of diagnosis, throughout treatment, and beyond. Some examples of how palliative care can help are controlling side effects, supporting the needs of caregivers, and assisting with other life challenges related to work, insurance, and finances. Palliative care doctors work closely with your cancer care team.

Psychiatry: Psychiatrists are mental health doctors that can help with conditions like anxiety and depression, mental health therapy, sexual health counseling, therapy for families, and stress management.

Genetic Counselors: Genetic counseling gives you information about how genetic conditions might affect you or your family. The genetic counselor or other healthcare professional will collect your personal and family health history.

Additional Terms To Help You Understand Your Care Team:

Attending or Staff Physician

An attending physician is a doctor who has completed their training through a residency and/or fellowship program and now practices medicine in a clinic or hospital in their specialty or sub-specialty, such as in orthopedics or oncology. An attending physician may supervise fellow doctors, resident doctors and medical students.

Fellow

A fellow is a physician that has previously been a resident physician and who is now training in a sub-specialty fellowship program, such as oncology. Fellow physicians continue to treat patients under the supervision of an attending physician.

Resident

A resident is a physician who has received a medical degree and is training in a specific area, such as radiology or pediatrics. Residents are supervised by more senior physicians.

Medical Student

A medical student is studying to become a medical doctor. Medical students spend time learning all areas of specialties, both in the classroom as well as in clinics and hospitals, and may be involved in your care for part of your cancer journey. They are supervised by physicians.

Nurse Practitioner (NP)

A nurse practitioner is an advanced practice registered nurse (RN) who has completed additional training and certification. They can diagnose illness, develop and manage treatment plans, prescribe medications, and often serve as part of the cancer team.

Physician Assistant (PA)

Physician assistants are medical professionals who diagnose illness, develop and manage treatment plans, prescribe medications, and often serve as part of the cancer team.

Registered Nurse (RN)

A registered nurse is a nurse who provides assessment and medical care as part of the cancer team. RNs are often care coordinators for cancer teams in the clinics and hospitals, triaging health concerns, and are often administering chemotherapy.

Licensed Practical Nurse (LPN)

A licensed practical nurse provides direct patient care in a clinic or hospital setting under the supervision of an NP, PA, RN or a physician.

Health Care Assistant (HCA) or Nursing Assistant (NA)

Health care assistants and/or nursing assistants primarily assist patients at their clinic or hospital visits, performing basic nursing tasks. They work under the supervision of an RN and/or an LPN.

4. Be Prepared For Medical Appointments

You are the most important person on your medical care team. The more involved and informed you are throughout your journey, the better your overall medical care will be. Don't be afraid to ask anything of your medical team at any time. Ask all the questions you need to be comfortable with your treatment options and potential side effects of treatment. Look to your whole medical care team for answers. Sometimes the best answers come from the nurse care coordinator who can spend extra time with you at the beginning or at the end of your visit.

Below are some important tips to keep in mind prior to your medical appointments:

- It can be difficult to remember each question that you want to ask of your doctors when your emotions are running high, especially after receiving the news of your sarcoma diagnosis. It can be helpful to write your questions down before your medical appointment.
- You may also want to keep a binder or a journal of medical and treatment appointments, along with a list of your medications and doses. This is helpful in keeping you informed and organized. Make sure to bring this information to your medical appointments.
- During your appointments, it's important to take notes to keep as a reference point later on. Better yet, have your loved one take notes while you listen.
- Your medical information is contained in an electronic medical record (EMR) that can be available to you either on paper or electronically through an on-line patient portal. You must request access to your own personal on-line patient portal. You can access this portal through your computer or an App on your phone or hand-held device.
- Important information such as visit notes and after-visit plans, radiology reports, lab test results, surgery biopsy and other pathology results, treatment plans, medications and health concerns are all part of your record, and you can have access to all this information.
- Different medical record systems may be used by clinics, hospitals and cancer centers, and your permission is needed for information to be shared between them.

Questions you may ask your doctor:

- What is my official diagnosis? Stage and grade?
- What about genetic testing on my tumor? What mutations does my tumor have?
- How do I find clinical trials available to me?
- How can I keep myself as healthy as possible during treatment? What about complementary treatments?
- How does treatment work? What are the short and long-term effects of treatment?
- How long will treatment last? What will my life look like while I am in treatment?
- What are the top sarcoma centers/doctors you'd recommend for second opinion?
- What palliative care options are available?

5. Surround Yourself With A Support System

You (or a loved one) are not alone in your cancer journey. Reach out to people—your family, your extended family, your friends, your co-workers—anyone who wants to help you during this challenging time. Having a trusted support person accompany you to your medical appointments *(if possible)* can be of great help to you on many levels. To make sure valuable information is not missed, this person can assist you in taking notes, remembering which questions you want to ask, and recapping the information provided by the doctor after your visit.

Additional Support Resources:

- *Rein in Sarcoma* - reininsarcoma.org
    - Provides resources and support for sarcoma patients, survivors, and loved ones. It is centered in the Upper Midwest, but available by phone or on-line nationwide. Monthly peer support meetings, personalized support from another sarcoma survivor, and gatherings for patients and loved ones in the Minnesota area are a few examples of what Rein in Sarcoma can offer.
- *The Sarcoma Alliance* - sarcomaalliance.org
    - Provides on-line and in-person support groups, which consist of individuals that have been affected by sarcoma, including survivors, caregivers, and loved ones, who are in need of support and encouragement. In addition, they

provide grants to reimburse expenses for seeking second opinions from sarcoma experts.

- ***Caring Bridge*** - caringbridge.org
    - Enables you to create your own personalized website page to connect with family and friends, to keep people informed, to receive messages of hope, and to share your situation in a protected and respectful space.
- ***Meal Train*** – mealtrain.com
    - Allows you to set up a calendar and invite people to lend a hand, perhaps with chores, meals or errands.

Additional support networks are listed in the resources section of this guidebook.

6. Understanding Your Treatment Options

It's important to understand that your course of treatment is specific to you and your particular sarcoma diagnosis. There is not just a "one shoe fits all" approach. Your sarcoma treatment options will depend on several factors, including:

- Your sarcoma type.
- The sarcoma's grade and stage.
- Possible treatment side effects.
- Your overall medical and physical health.

Take time to learn about your treatment options and ask questions. If the information seems confusing or unclear, talk with your doctor about the goals of each treatment and what to expect. Certain treatments can have long-term effects. For example, chemotherapy and radiation can affect fertility in both men and women. Talk with your doctor about your concerns. Ultimately, you and your medical team should work together in shared decision making throughout your treatment.

National Comprehensive Cancer Network (NCCN) — nccn.org

The NCCN has continuously updated, comprehensive information about cancer diagnosis and treatment. The NCCN has two portals, one for providers (above) that has in-depth information and requires free registration, and patient directed guidelines that are available without registering.

Information for Patients:
nccn.org/patients

Information on Soft Tissue Sarcoma:
nccn.org/patientresources/patient-resources/guidelines-for-patients/guidelines-for-patients-details?patientGuidelineId=37

Information on Bone Sarcoma:
nccn.org/patientresources/patient-resources/guidelines-for-patients/guidelines-for-patients-details?patientGuidelineId=51

Types Of Treatment For Sarcoma Cancers

Surgery:

- Some patients will undergo removal of all or most of their sarcoma as a first step in treatment. Others will have a biopsy first, where a portion of the tumor is removed so that the cells can be looked at under a microscope. If a biopsy was performed, further surgery may be done later to remove the rest of the tumor and some healthy tissue around it.
- Removing healthy tissue around your sarcoma tumor may create a “margin” to help ensure that there are no tumor cells left in that area.
- Surgery is typically performed by a surgical oncologist or an orthopedic surgeon who specializes in sarcoma.
- Surgery might be the only treatment necessary in some small, low-grade sarcomas, but can also be combined with chemotherapy, radiation therapy, or targeted therapy (see below) in certain tumor types.

Chemotherapy:

- Chemotherapy is medication generally given orally or intravenously that may stop cancer cells from growing and dividing. Chemotherapy may be given prior to surgery to help shrink a tumor for easier removal or after surgery to destroy any cancer cells left behind.
- Chemotherapy may be given alone or in combination with surgery, radiation therapy, or both.
- Chemotherapy treatment “cycles” refers to a specific number of treatments given over a set period of time.
- Chemotherapy is coordinated by an oncologist.

- Many sarcomas are not responsive to chemotherapy.
- As there are both short and long-term side effects from having chemotherapy, it is important to discuss this information with your oncologist prior to starting these treatments.

Radiation Therapy:

- Radiation therapy is the use of high-energy X-rays or other ionizing particles to destroy cancer cells.
- Radiation therapy is guided by a radiation oncologist.
- A radiation therapy plan usually consists of a specific number of radiation treatments given over a set period of time.
- Radiation therapy may be done before surgery to help shrink a tumor for easier removal or after surgery to destroy any cancer cells left behind. It can also be used to treat the pain or side effects of tumors that may not be operable or treatable with chemotherapy.
- There are different types of radiation therapy so it's important to discuss with your radiation oncologist the best type of treatment for you. It's also important to discuss the specifics of your radiation treatment, including side effects, expectations, etc.
- For additional information, visit the National Cancer Institute at cancer.gov/about-cancer/treatment/types/radiation-therapy

Targeted Therapy:

- Targeted therapy drugs treat cancer by acting on parts of cancer cells that help them grow and divide that may be different from normal, non-cancerous cells.
- Targeted therapies may treat cancer by interfering with specific proteins or genetic changes that help tumors grow and spread.
- There are several different types of targeted therapies, and use varies by sarcoma type and stage, so it is best to talk to your oncologist about which treatments may be right for you. They may look for certain changes in genes (mutations) in your cancer that help the cancer cells to grow and divide to determine if targeted therapy will be effective against your specific sarcoma.
- Some targeted therapies are pills that you can swallow, while other medications are given intravenously (through an IV).
- Targeted therapies can work in many different ways. For instance:
    - They can help the immune system destroy cancer cells.
    - They can stop cancer cells from growing and dividing.

  - They can stop the cancer cells from forming blood vessels.
  - They can deliver cell-killing substances to cancer cells.
  - They can prevent cancer cells from getting hormones they need to grow.
- Targeted therapy can have side effects even though they are designed to specifically target cancer cells. Sometimes, healthy non-cancerous cells can be inadvertently targeted as well.
- As research studies continue to identify more targets and develop more targeted therapies, this treatment option is constantly evolving. ***There may be clinical trials testing new targeted therapy for your sarcoma.***
- Example of targeted therapy:
  - Monoclonal Antibodies: Monoclonal antibodies are proteins designed to attach themselves to specific targets on cancer cells. There are different types of monoclonal antibodies that perform different tasks. One way these can be used in cancer treatment is by attaching a cancer-killing medication to the antibody, so when the antibody binds to the specific target on the cancer cell, it kills the cancer cell.
- For additional information, visit The National Cancer Institute at cancer.gov/about-cancer/treatment/types/targeted-therapies

Immunotherapy:

- In addition to fighting off infections, the immune system also looks for and destroys cancer cells. This happens in all people with healthy immune systems.
- Sometimes, cancer cells have changes in their genes and proteins that make them less visible to the immune system.
- Immunotherapy is a cancer treatment that helps your immune system to better find and destroy cancer cells.
- There are several different types of immunotherapies, which vary by sarcoma type, grade and stage, so it is best to talk to your oncologist about which type may be right for you.
- Immunotherapies are taken in different ways, including through an IV or taken orally in a pill or capsule form. How often and where you go for immunotherapy depends on your type of sarcoma and the specific medication you might be taking.
- There can be side effects related to immunotherapy. Turning up the immune system can sometimes cause the immune system to damage healthy cells in addition to cancer cells. Talk to your oncologist about immunotherapy side effects.

- As research studies continue to develop more immunotherapies, this treatment option is constantly evolving. There may be clinical trials testing new immunotherapies for your sarcoma cancer.
- Example of Immunotherapy:
    - **Checkpoint Inhibitors**: An important part of immune system function is being able to prevent itself from harming normal cells in the body. The immune system does this by having proteins in cells that act as on-and-off switches known as *checkpoints* for the immune response. Sometimes cancer cells use these *checkpoints* to hide from the immune system. Immunotherapy drugs that can turn up the immune system response through these checkpoints to help destroy cancer are known as ***checkpoint inhibitors***.
- Some cancer treatments can work in more than one way. For example, some immunotherapy medications are used as both targeted therapies and immunotherapies.
- For additional information, visit The National Cancer Institute at cancer.gov/about-cancer/treatment/types/immunotherapy

Clinical Research/Clinical Trials:

Cancer researchers are always testing new treatments. A part of this research involves treating patients who are willing to receive cancer treatment by participating in what are called clinical trials. The purpose of a clinical trial is to determine whether a new treatment is safe and effective. This is especially important in cancers like sarcoma, which can have few proven chemotherapy treatments available. It may be possible for you to enroll in a clinical trial sometime during your treatment. Clinical trials are divided into several subtypes:

- **Phase 1 Trial:**
    - A new drug is tested in a small number of patients for the first time to make sure it's safe enough to offer as a treatment option, while also looking for its possible side effects.
- **Phase 2 Trial:**
    - Looks at the safety of the new drug and whether or not it works to treat the cancer it was intended to treat.
- **Phase 3 Trial:**
    - The new drug is given to a large number of patients to confirm that it works, while monitoring its side effects and gathering more information about its overall use.

- Phase 4 Trial:
    - After the new drug is approved for public use, it is studied further to monitor for overall effectiveness and possible side effects.

There are benefits and risks to participating in a clinical trial. Your medical team can help you decide if it's the right decision for you.

Further information about clinical trials can be found in the following websites:

The National Institute of Health
clinicaltrials.gov

National Institute on Aging
nia.nih.gov/health/clinical-trials-benefits-risks-and-safety

Notes:

about my cancer type and care team

SECTION III
Support for Surviving Sarcoma

What is a survivor? **Being a cancer survivor starts when you are diagnosed with cancer and continues for the rest of your life.** Whether you are just starting or have completed your treatment, the information listed below can help you with:

- Your emotional, mental, and physical health and well-being.
- The long-term effects of going through treatment.
- Specific information for children, adolescents and young adult survivors.
- Social and financial effects of having been diagnosed with cancer.
- Consistent monitoring for any long-term risks of possible recurrence and/or secondary cancers.

1. Support For Your Emotional & Mental Health As A Survivor

Whether you are someone with sarcoma cancer, a caregiver, or a loved one of someone with sarcoma cancer, we want you to know that it is common to struggle with mental health well-being when dealing with a sarcoma cancer diagnosis. Common feelings may include stress, anxiety, and depression. These can be specific to fears of recurrence, self-esteem changes related to body changes (such as hair loss), or grief around loss your life as you know it. If you have an existing mental health condition, you might find it harder to cope during this time.

We want you to know when and where to find help. You can ask for mental health support at any time, and you don't have to wait until you feel really sad about your new life situation to ask for help.

There are different types of support available to you and your caregiver or loved ones. The type that you need will depend on different things, such as how you are feeling and what kind of support that you feel that you need in each moment throughout your treatment journey. This is also true after your treatment finishes.

To start the process of getting support, you might consider:

Talking with your cancer team about your mental health well-being:

Your cancer team cares about your mental health well-being and can recommend a psychologist, psychiatrist, social work counselor, or another mental health professional to support you. Oftentimes they are a part of the cancer care team. If you would prefer to find a mental health provider on your own, you can contact your insurance company for a list of covered providers in your area.

Below is a tool to get you started:

Psychology Today
psychologytoday.com/us/therapists

Talking to someone you know and trust:

You may be experiencing grief at the loss of your life as it used to be before your sarcoma cancer diagnosis. A close friend, relative, or spiritual leader can lend a listening ear and support in difficult moments. Your circle of support may also change over time. Cancer support groups can provide a safe space for sharing the tough moments in your journey.

Here is one resource for cancer support that is free, welcoming, and provides a variety of social and emotional supports:

Gilda's Club Twin Cities
gildasclubtwincities.org

To find a group specific to your location:
cancersupportcommunity.org

Creating a self-care plan:

Whether you are getting help another way or not, creating a self-care plan can help you keep track of your personal and well-being needs and overall quality of life. Regular self-care practices can decrease stress and anxiety. Self-care can mean different things to different people.

Below are some ideas for creating your own self-care plan:

- Starting a journal or a calendar.
- Eating nourishing foods.
- Exercising-even small amounts of movement can improve your well-being.

  - Setting aside quiet time for yourself, especially on treatment days.
  - Prioritizing sleep.
  - Getting a massage.
  - Protecting your time and giving yourself permission to say no when you are not up for company, etc.
  - Spending time doing activities that bring you joy, such as being in your garden, crafting, singing, playing video games, watching sports, etc.

Utilizing online stress management resources:

There are many online organizations intended to help manage the stress of having cancer and going through life changes as a result.

Below are a few examples that can get you started:

HeartMath Institute

heartmath.org

Mayo Clinic – Stress Management

mayoclinic.org/healthy-lifestyle/stress-management/basics/stress-basics/hlv-20049495

MIT Medical – Sleep, Mindfulness Meditation, Relaxation, and Stress Reduction

medical.mit.edu/community/stress-reduction

University of Minnesota Center for Spirituality and Healing

takingcharge.csh.umn.edu

Mental Health Crisis Resources

If you find yourself or your loved ones in need of immediate mental health care, the hotlines below can connect you with on-the-spot mental health support in your area.

National:

- Call 911 for immediate or life-threatening mental or physical health needs.

- Call 988 Suicide and Crisis Lifeline. You can also start an online chat at 988lifeline.org/chat to access the Suicide and Crisis Lifeline. The Lifeline offers free help for those who are having a mental health crisis or are contemplating suicide.

Minnesota:

- Adult mental health crisis phone numbers by tribe and county
- Children's mental health crisis response phone numbers by county
- Example: Hennepin County 612-596-1223
- Cope: Mobile Crisis Response All Ages
    - 24/7, 365 days per year. "The Cope mobile crisis team can come to where you are. Cope responds to anyone in Hennepin County who needs an urgent response. Cope has bilingual and bi-cultural staff available for face-to-face, phone, and video visits and uses interpreters when needed."

2. Support For Physical Health As A Survivor

The changes to your body with a sarcoma cancer diagnosis may or may not be significant. Often surgery to remove a sarcoma tumor involves loss of healthy muscle, bone, or other tissues along with the cancer tumor. This may lead to pain and difficulty with movement. Some symptoms arise after the cancer has been removed or treated.

Chemotherapy and other treatments can have side effects that are sometimes very challenging and can last after treatment has ended.

Your ongoing health will depend on; your cancer treatment, your age, other diseases or diagnoses that you may also have, and how advanced your sarcoma cancer is.

You may experience the following:

- Nerve injury, known as ***neuropathy***, related to certain chemotherapy treatments.
- ***Heart concerns***, including damage to the heart muscle from exposure to radiation or chemotherapy. This can occur early in treatment or sometimes surface years later.

  For more information about cardiac complications during and after sarcoma cancer treatment:

  The Sarcoma Coalition Listen and Learn Series:

  youtube.com/watch?v=-LtpAd1owek

- ***Any major organ can have short or long-term effects of sarcoma cancer treatment,*** including your kidneys, lungs, thyroid, or other organs. Long-term weakening of the bones, known as ***osteopenia and/or osteoporosis***, can also occur.
- ***Cognitive effects*** and changes in memory, difficulty focusing, and brain "fogginess" or body fatigue can be common effects of sarcoma cancer treatments. These symptoms typically go away after treatment is over, but they can continue long-term.
- ***Future fertility for children, youth, and adults of child-bearing age***, the ability to conceive a biological child (produce viable sperm in males or egg in females) is known as fertility. Fertility can be affected by your age and the type and amount of sarcoma cancer treatment that you receive. Both radiation and chemotherapy treatments may affect your ability to be fertile afterwards. It is important that you ask your doctor about options for preserving fertility for you or your loved one ***before you start sarcoma cancer treatment.*** A fertility specialist can help you plan for the possibility of conceiving a biological child in the future.

  More information can be found at:

  National Comprehensive Cancer Network:
  nccn.org/patients/guidelines/content/PDF/aya-patient.pdf

- ***Risk of other cancers.*** It is important to keep up with screening for other cancers as recommended by your primary doctor and/or your cancer care team. Screening mammograms and cervical cancer tests for women, colon cancer tests, and/or other cancer screenings as recommended should all continue during and/or after your sarcoma cancer treatment is finished.
  - In some instances, you may be at increased risk of additional cancers because of having had sarcoma cancer and/or sarcoma cancer treatment. This may happen due to *genetic syndromes* that occur in families or *chemotherapy* and *radiation* therapy that can, in rare instances, trigger cells to mutate and form new cancerous tumors, **as mentioned in Section I**.

Your primary doctor and/or your cancer care team are important members of your overall health team that are there to help you address any health concerns as they arise. Keep up with regular check-ups, immunizations, and routine health screenings both during and especially after treatment ends. **And remember, taking care of your physical body supports your mental and emotional self.**

3. Support Specific For Children, Adolescents & Young Adult (AYA) Survivors

Because most children, adolescents and young adults with sarcoma cancer will be long-term survivors, the **Children's Oncology Group** has developed the ***Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers***. This resource includes technical guidelines specific for your medical team, as well as plain language health links for survivors and their families, so all can be aware of side effects of treatments and the need for follow-up.

The guidelines also are intended to be used by young adult cancer survivors as well as adults of any age who were treated when they were children, adolescents, or young adults. The health links are listed by organ system, and intended to help survivors stay healthy physically, mentally, and emotionally. The guidelines themselves are arranged by treatment type (such as chemotherapy medication, or location of radiation or surgery), and include technical references that support the care and monitoring recommendations.

For more information, see:

The Children's Oncology Group
survivorshipguidelines.org

Who are young adult survivors? Adolescents and young adults (AYA) are defined as cancer patients who were diagnosed *between the ages of 15 and 39*. AYA survivors may have additional physical, financial, or psychosocial concerns because of their age, including fertility issues, educational or employment disruptions, arranging childcare, or other challenges unique to older teens or people in their 20s or 30s. Finding support or peers who understand their issues can be difficult. The National Comprehensive Cancer Network (NCCN) has made a guideline just for this age group. Among other topics, it includes information on treatment, fertility preservation, mental and emotional support, and survivor follow-up care.

The National Comprehensive Cancer Network
nccn.org/patients/guidelines/content/PDF/aya-patient.pdf

4. Cancer Survivorship Programs

After the intensity of your cancer diagnosis and initial cancer treatment plans, it is not uncommon to feel anxious about what the future may hold. Many major cancer centers now have **Cancer Survivorship Programs** that offer a wealth of information ranging from diagnosis to treatment and life afterwards. You can find these resources by contacting your cancer care team or by searching for ***cancer survivorship programs*** online.

Some cancer survivorship programs are included below:

Annual Cancer Survivorship Conference – Minneapolis

This annual free spring conference, sponsored by the University of Minnesota Survivorship Program, is held on a Saturday in the spring at the University of Minnesota Alumni Center.
survivorship.umn.edu/cancer-survivorship-conference

Cancer Survivor Care Plan – Minnesota Cancer Alliance

Minnesota Cancer Alliance provides a Cancer Survivor Care Plan in a free booklet: ***"What's Next? Life After Cancer Treatment,"*** a road map of sorts for your sarcoma journey.
mncanceralliance.org

National Comprehensive Cancer Network

Guidelines are available for patients focused on healthy living, managing effects of cancer and screening for recurrence. nccn.org/patients/guidelines/cancers.aspx

Cancer Survival Toolbox®

The Cancer Survival Toolbox is a free, self-learning audio program that helps people develop important skills to better meet and understand the challenges of their illness. The program contains a set of basic skills to help navigate a diagnosis and special topics on key issues faced by people with cancer. canceradvocacy.org/toolbox

National Coalition for Cancer Survivorship (NCCS)

NCCS advocates for quality cancer care for everyone touched by cancer and provides tools that empower people to advocate for themselves.
canceradvocacy.org

5. Financial & Health Insurance Support

The financial stresses associated with the health effects of your sarcoma cancer and its treatments can be hard. Many people who are working have health insurance through their employers, including short-term and long-term disability options. It is important to check your policy or your human resource department to understand these options. This section will examine a handful of these resources, including how to pay for excess medical costs as well as options for support if you don't have access to health insurance.

Health Insurance Coverage

Affordable Care Act

The Affordable Care Act, or ACA, is a law passed in 2010 that supports access to health insurance for all Americans in every state. This is especially helpful for people who do not have access to health insurance through their own or a family member's employment. The ACA provides more options for health insurance, allows for adults under age 26 to stay on their parent's policy, assures coverage for people with pre-existing conditions, and covers cancer screenings and other preventative care. The number and types of options for healthcare coverage will differ in each state. People in most states use the website below to apply for and enroll in health coverage. All information and links for each state can be found at healthcare.gov.

Medicare

medicare.gov

People who are 65 and older are eligible for Medicare, a federally funded health insurance program. Medicare also covers certain people who are younger than 65 with disabilities. Medicare has Part A, which helps cover hospital and skilled nursing care, and Part B, which helps cover doctor's visits and out-patient care. Part B is optional for people who have health insurance through their employer. Even after you sign-up for Medicare, it is important to check that your health care will be covered at your clinic or hospital. This is called being "in-network." Medicare Advantage (Part C) is an "all-in-one" alternative plan that includes extra benefits.

If you qualify for Social Security disability benefits (see below), you will automatically be eligible for Medicare after 24 months of receiving Social Security disability payments.

Medicare also has Part D, which covers prescriptions and is optional. You should also check that your prescription plan covers all your cancer medications.

Social Security Disability Payments

socialsecurity.gov

Some people who have cancer may be eligible for Social Security disability insurance payments (SSDI). These are monetary benefits (that are not income-based) that are given monthly up to the age of 65. Social Security disability benefits are available to adults who:

- Meet insured status, which is defined as having worked 5 out of the last 10 years prior to the onset of the illness/disability.
- Meet medical requirements, including the inability to work for a period of 12 months or longer.

How do I apply for SSDI?

You can apply directly online using the Social Security website disability section, which has further information as to documents that you will need to include that will be helpful during the application process. You can also complete a claim with the assistance of a local and/or national Social Security representative, who will help to schedule your "tele-claim" appointment to start your application. Because this process can take time, you want to consider Social Security disability benefits soon after your diagnosis.

Once your application is submitted, a disability determination is generally made within 60-90 days. You can track your status online, once you have registered for your own Social Security account. You will receive written notification as to whether you are approved for SSDI payments. Once your application has been approved, an ongoing benefit amount will be paid monthly for as long as your disability (or your inability to work) continues, up to age 65, when your Social Security retirement benefits begin instead. The monthly payment amount will be based on your prior earnings. If you apply for SSDI and are not approved, you may re-apply after a period of time.

Young adults (age 18-24) may also be eligible for SSDI benefits. Their work history is computed differently when evaluating insured status. Minor disabled children can also receive disability benefits under a parent's record, who is currently receiving Social Security retirement or disability benefits themselves.

Supplemental Security Income (SSI)

ssa.gov/ssi

For adults with limited work history and minor children with disabilities, the Supplemental Security Income program exists. This is a needs-based program that has specific income/resource requirements that must be met, in addition to the medical approval. The Social Security website has additional information regarding this program and its requirements.

Other Financial Assistance

The following organizations primarily provide direct financial support to families of cancer patients, including some that are national organizations. Your cancer care team will have additional resources specific to your geographic location and/or state.

– Cancer Financial Resource
cancer.org/support-programs-and-services/resource-search.html
This page of the American Cancer Society's website helps patients find resources to help manage their lives during treatment and recovery and to get emotional support if needed.

– Cleaning for a Reason
cleaningforareason.org
Cleaning for a Reason partners with cleaning services to offer professional house cleaning to people undergoing treatment for any type of cancer.

– Hand in Hand: Suzanne R. Leider Memorial Assistance Fund
sarcomaalliance.org/resources/financial-assistance
Hand in Hand offers financial assistance for second opinion consultations by reimbursing expenses related to travel, phone bills, costs of the evaluation, and related expenses.

– HealthWell Foundation
healthwellfoundation.org
The HealthWell Foundation provides financial assistance to cover coinsurance, copayments, health care premiums, and deductibles for certain medications and therapies.

– The Pinky Swear Foundation
pinkyswear.org
The Pinky Swear Foundation was formed to provide relief and respite for all families with cancer who are being treated in the state of Minnesota.

– The Szott Foundation

szottfoundation.org
The Szott Foundation is a Minnesota-based nonprofit organization that provides financial support when a parent stays home from work to care for a child with cancer.

– Spare Key

sparekey.org
Spare Key is a Minnesota-based nonprofit organization that provides housing grant assistance to families with critically ill or seriously injured members.

– Angel Foundation of Minnesota

mnangel.org
The Twin Cities-based Angel Foundation provides emergency financial assistance, education, and support to local adults with cancer and their families.

Housing

Some patients with cancer need to be away from home for extended periods of time while undergoing their treatments. Below are some housing options that may be more financially accessible.

– Ronald McDonald House

rmhc.org/ronald-mcdonald-house
A Ronald McDonald House is that "home-away-from-home" for families so they can stay close by their hospitalized child at little or no cost.

– A Shelter for Cancer Families

sarcomacancer.org
A Shelter for Cancer Families provides appropriate housing for out-of-towners seeking cancer care in the Houston, Texas area (near the MD Anderson Cancer Center).

– Hope Lodge

cancer.org/search.html?q=hope+lodge

Hope Lodge, a program of the American Cancer Society (ACS), offers cancer patients and their caregivers a free place to stay when their best hope for effective treatment is in another city.

Minnesota Locations

Minneapolis: The Richard M. Schulze Family American Cancer Society Hope Lodge
Rochester: Sandra J. Schulze American Cancer Society Hope Lodge

Legal Assistance

Cancer Legal Care

cancerlegalcare.org
Cancer Legal Care can help with estate planning, tax issues, foreclosure proceedings, and more.

Travel Assistance

There are several options for free or low-cost transportation services to cancer centers. Be sure to inquire if individual cancer centers have arrangements for low-cost or flexible air travel on major airlines.

Air Charity Network

National: aircharitynetwork.org
Midwest: angelflightcentral.org
To request assistance: 877-621-7177

Angel Airlines for Cancer Patients

angelairlinesforcancerpatients.org
Angel Airlines for Cancer Patients (AACP) facilitates no-cost commercial airline tickets for cancer patients and their families.

Corporate Angel Network

corpangelnetwork.org
The Corporate Angel Network helps cancer patients by arranging free travel to treatment across the country using empty seats on corporate jets.

National Patient Travel Center

patienttravel.org
The National Patient Travel Center provides information about all forms of charitable, long-distance, medically related transportation.

Recreation

Finding supportive and safe environments for recreation and respite can be hard when people are facing cancer. The following organizations support people with cancer and their loved ones.

– Camp Kesem

campkesem.org
Camp Kesem is a nationwide community, driven by passionate college student leaders, that supports children through and beyond their parent's cancer. Student volunteers at the University of Minnesota organize the Minnesota summer camp. Camp is free for children whose parents have cancer and is held every summer with two one-week sessions.

– Camp Mak-A-Dream

campdream.org
Camp Mak-A-Dream is a medically supervised, cost-free camp for children, teens, and young adults with cancer, and for siblings whose lives have been affected by cancer. Secluded and peaceful, Camp Mak-A-Dream is located in Gold Creek, Montana, 65 miles east of Missoula.

– Faith's Lodge

faithslodge.org
Faith's Lodge is a nonprofit organization located in northwestern Wisconsin that provides patients and their families an opportunity to retreat to the Northwoods for fun and relaxation.

Wish Fulfillment Organizations

The organizations below provide chronically or seriously ill children and their families the opportunity to have dreams come true. Wishes usually fall into one of three categories: trips, celebrity meetings, or special items.

Resources For Children & Young Adults

Believe in Tomorrow National Children's Foundation

believeintomorrow.org.

Believe in Tomorrow provides a variety of programs and services to children with life-threatening illnesses, including hands-on adventures and retreat housing in various locations throughout the United States, free of charge.

Lighthouse Family Retreat

lighthousefamilyretreat.org.

Provides a seaside family retreat for children with cancer and their families.

Make-A-Wish Foundation

wish.org

Grants wishes to children, between the ages of 2.5 to 18, with life-threatening medical conditions.

Marty Lyons Foundation

martylyonsfoundation.org

Provides wishes to children ages 3–17 who have been diagnosed with terminal or chronic life-threatening illnesses.

Ulman Cancer Fund for Young Adults

ulmanfund.org

A leading voice in the young adult cancer movement, this group works at a grassroots level to support, educate, connect, and empower young adult cancer survivors.

United Special Sportsman Alliance (USSA)

childswish.com

Nonprofit Christian organization that coordinates with other agencies to grant terminally ill and disabled children and youth the outdoor adventure of their dreams.

Resources For Adults

– *The Dream Foundation*

dreamfoundation.org

The Dream Foundation grants wishes to terminally ill adults over the age of 18 and their families.

– *Reeling and Healing Midwest*

reelingandhealing.org

This nonprofit organization hosts several fly-fishing retreats for women with cancer.

– *Second Wind Dreams*

secondwind.org

Second Wind Dreams grants wishes to older adults living in eldercare facilities or hospice care.

Resources For Caregivers

– *The Caregiver Action Network (CAN)*

caregiveraction.org

CAN (the National Family Caregivers Association) is a nonprofit organization providing education, peer support, and resources to family caregivers across the country free of charge.

– *CaringInfo*

caringinfo.org

CaringInfo is dedicated to promoting a better understanding of all aspects of end-of-life care including advance care planning, caregiving, grief, hospice, pain and palliative care.

– *Jack's Caregiver Coalition*

jackscaregiverco.org

Jack's Caregiver Coalition exists to serve the male caregiver and help build support systems. Phone (612) 547-6929.

Notes:

SECTION IV
Rein in Sarcoma Is Here To Help

We are here to help you get reliable, easy-to-understand information. Call or email us for confidential support. We will listen and help you find answers as best we can. All of our programs and resources are free.

Our team can help you:

- Learn about sarcoma.
- Understand the treatment process.
- Identify sarcoma centers of excellence.
- Connect you with other sarcoma survivors and caregivers through our Sarcoma Support Team.

Our services include:

- Tote bags of hope (comfort items for patients going through treatment).
- Financial assistance to patients.
- Support groups and webinars.
- Caregiver support.
- Tips for talking with your healthcare team.
- Newsletters, educational materials and videos.
- Private Facebook Group: facebook.com/groups/reininsarcomacircleofsupport

Contact Us

Call: 1-844-727-2662 or 763-205-1467
Email: admin@reininsarcoma.org
Visit: reininsarcoma.org/patient-and-family-support

Follow Our Social Media

- X (formerly known as Twitter): twitter.com/reininsarcoma
- Facebook: facebook.com/reininsarcomafoundation
- Instagram: instagram.com/reininsarcoma

Scan For Support Resources

Scan For Sarcoma Video Series

SECTION V

Tools to Organize Information

Some people prefer to write down information and keep it in a notebook. Others prefer having everything in a digital format for easy access. The following are templates that might be helpful if you'd like to record information to keep in one place.

Questions to Consider When Facing "New" Treatment (listed below):

- Important Contact Information
- Physician/Nurse Encounter Log to take notes at visits
- Pharmacy Log to keep record of medications you take at home
- Food and Drink Log: To help keep track of your nutrition, especially during treatment
- To-Do List for your support network
- Symptoms Log to help track what you are feeling between visits and during treatment

Questions You May Consider Asking Your Doctor When Deciding On A New Treatment

There will hopefully be more and more treatment options for people with sarcoma cancers in the coming years. No matter where you find the information, you can never ask too many questions before deciding on a new treatment, especially if this treatment is new and either in clinical trials or just approved. You will almost certainly be tempted to WANT the new treatment to be the answer, but if you are going to be the expert, you need to be a little skeptical. Here are twenty questions to help you to judge the quality of the information you have found:

1. Why do you think this treatment would work for my type of sarcoma?
2. How many people with this sarcoma have you treated?
3. Did the other people have a similar subtype, stage, and location?
4. What were the results for those people?
5. Has this treatment been tested in clinical trials?
6. Are there results for this sarcoma or related cancers and if so, what are they?
7. Do the results of the clinical trials show this treatment is relatively safe?
8. Do the results of the trials show that the treatment is effective?
9. Are the results published in technical journals – NOT just the popular press?
10. How many people were in these studies?
11. Were the patients treated with any other treatments?
12. Can the doctor or clinic send me copies of the results?
13. How does the treatment work? (Make sure the explanation makes sense. You may have to do some homework here).
14. What is the goal of the treatment and how is its efficacy measured (for example, is survival measured in weeks, months, or years)?
15. How do they measure success for treatments where, say, the goal of treatment might be to strengthen the immune system?
16. What are the risks of the treatment?
17. What are the side effects, short- and long-term?
18. Can they provide any information showing the percentage of patients who develop these side effects?
19. If the drugs are complementary medicines used during treatment, how will they interact with traditional treatment drugs? Are there studies that show there will not be adverse interactions?
20. Anything else you can think of. You will make the best choices if you have educated yourself thoroughly about each choice.

SECTION VI
Additional Resources

The following are just some of the many resources available to you and your loved one.

General Cancer Information

American Cancer Society
cancer.org
Provides accurate, up-to-date information on cancer and is a good site for questions and support needs involving care, free lodging, transportation and more.

Cancer Care
cancercare.org
National organization dedicated to providing free professional support services including counseling, support groups and financial assistance.

CAC2
cac2.org
Advances childhood cancer causes by unifying the childhood cancer community through collaboration.

Macmillan Cancer Support
macmillan.org.uk
Europe’s leading cancer information charity, with up-to-date details.

Minnesota Cancer Alliance
mncanceralliance.org
Helps cancer patients and their caregivers connect to resources; such as support groups, transportation, financial assistance, palliative care, treatment options, clinical trials, and pain management.

National Coalition for Cancer Survivorship (NCCS)
canceradvocacy.org
Advocates for quality cancer care and provide tools to empower people to advocate for themselves.

Oncolink
oncolink.org
Treatment and disease information for a newly diagnosed patient, support through the side effects of treatment, and into survivorship.

Sarcoma Cancer Advocacy Organizations

Sarcoma Coalition

sarcomacoalition.us

This is a coalition of sarcoma advocacy groups that are marked in this list with an "*", joined together to support the joint mission of working together on behalf of the sarcoma patient-family community.

Carson Sarcoma Foundation

carsonsarcomafoundation.org

Funds sarcoma cancer research.

**EHE Foundation*

fightehe.org

Seeks treatments and a cure for Epithelioid Hemangioendothelioma (EHE).

Finish Sarcoma

finishsarcoma.org

Raises awareness, patient support, and supports sarcoma research.

**Friends of TJ Foundation*

friendsoftj.org

Established to increase sarcoma research, improve treatment, and with the goal of finding a cure.

Jared's Juggernaut to Cure Sarcomas

jaredsjuggernaut.org

Educates the public about sarcoma and raises funds for research.

Josh Powell Foundation

joshpowellfoundation.org

Aims to empower newly diagnosed sarcoma patients by providing "Powell Packs" to patients on their first day of treatment.

Kristen Ann Carr Foundation

kristenanncarrfund.org

Provides grants for cancer research and seeks to improve all aspects of cancer patient life with an emphasis on adolescents and young adults.

**Paula Takacs Foundation*

paulatakacsfoundation.org

Raises funds that will directly benefit the fight to end sarcoma.

**QuadW Foundation*

quadw.org

Provides financial support for innovative ideas and opportunities in the area of higher education and sarcoma research.

Rutledge Foundation

rutledgecancerfoundation.org

Supports sarcoma research, and clinical trials for pediatric patients. Also supports adolescents and young adult cancer patients.

**Sarcoma Alliance for Research through Collaboration (SARC)*

sarctrials.org
Nonprofit organization that is dedicated to the development and support of research for the prevention, treatment, and cure of sarcoma.

**Sarcoma Alliance*

sarcomaalliance.org
Strives to improve the lives of people affected by sarcoma through accurate diagnosis, improved access to care, guidance, education, and support.

**Sarcoma Foundation of America (SFA)*

curesarcoma.org
Advocate for sarcoma patients by funding research and increasing awareness.

Sarcoma Oma

sarcoma-oma.org
Provides transportation services for sarcoma patients nationwide.

**Slifka Foundation*

slifkafoundation.org
Funds a wide range of sarcoma research.

Wendy Walk Foundation

wendywalk.org
Supports patients and their loved ones, funds international sarcoma research, and increases sarcoma awareness.

Drug Information

National Cancer Institute (NCI)

cancer.gov/about-cancer/treatment/drugs
Consumer-friendly summaries about certain drugs that are approved by the U.S. Food and Drug Administration (FDA) to treat cancer or conditions related to cancer.

RxList

rxlist.com
Online medical resource dedicated to offering detailed and current pharmaceutical information on brand and generic drugs.

Complimentary & Alternative Medicine

Memorial Sloan Kettering Integrative Medicine

mskcc.org/cancer-care/integrative-medicine/about-herbs-botanicals-other-products
Provides evidence-based information about herbs, botanicals, supplements, and more.

National Center for Complementary and Integrative Health (NCCIH)

nccih.nih.gov
Provides research on the diverse medical and health care systems, practices, and products that are not generally considered part
of conventional medicine.

Survival 2 Strength

survival2strength.com
Free Strength Training for Cancer Survivors in Minnesota. Survival 2 Strength is a program for strength, coordination and mobility.

University of Texas MD Anderson Integrative Medicine Center–

mdanderson.org/patients-family/diagnosis-treatment/care-centers-clinics/integrative-medicine-center.html
Offers therapies that reduce patients' stress and anxiety and improve their physical, mental, and emotional wellbeing.

Patient & Family Support

Ben's Friends Patient Support Communities

bensfriends.org
Online forum for individuals diagnosed with rare diseases or chronic illnesses. The site features open discussion, as well as recommendations for doctors and clinics.

Cancer Hope Network

cancerhopenetwork.org
Provides 1:1 emotional peer support to adult cancer patients and their loved ones.

Cancer Warrior Alliance

cwa.life
Mission to deliver cancer support resources to cancer community.

CaringBridge

caringbridge.org

You can write journal entries, post photographs, post a calendar for help with tasks and read supportive messages from guests.

Chemo Angels Support Network

chemoangels.com
Volunteer organization dedicated to enriching the lives of those undergoing IV chemo treatment.

Dear Jack Foundation

dearjackfoundation.org
Programming is directed towards adolescents and young adults diagnosed with cancer in order to improve life and create positive outcomes.

Facebook

facebook.com
Several support groups for individuals dealing with sarcoma. Search for groups under your specific sarcoma type or using the term "sarcoma."

Rein in Sarcoma Circle of Support

facebook.com/groups/reininsarcomacircleofsupport

Synovial Sarcoma Group

facebook.com/groups/synovialsarcomasupport

General Sarcoma Group

facebook.com/groups/sarcomasupportinitiative

Gilda's Club

GildasClubTwinCities.org
A nonprofit and the local affiliate of the Cancer Support Community, where everyone living with cancer can come for social, emotional, and psychological support.

GRYT

grythealth.com
Mobile app platform for people affected by cancer to connect with others with similar experiences.

Imerman Angels

imermanangels.org
Connects cancer fighters, survivors, and caregivers with "mentor angels."

Jack's Caregiver Coalition

jackscaregiverco.org
Support for anyone 18 and older that identifies as male and has provided care for a loved one facing a health crisis.

Lacuna Loft

lacunaloft.org
Online support programs for young adults and caregivers.

Momcology

momcology.org
National platform of peer support for childhood cancer families and caregivers.

M Powerment

cancerdudes.org
Created to provide education and resources specifically tailored for males.

Negative Space
thenegativespace.life
Dedicated to shining light on caregivers.

Sarcoma Alliance
sarcomaalliance.org/peer-to-peer

Peer-to-Peer Network is to facilitate positive relationships between individuals affected by sarcoma, so that they may find emotional support, encouragement, and information.

Additional Resources

Along Comes Hope
alongcomeshope.com
Provides advocacy, support, and financial assistance for travel associated with treatment, creative emotional support programs.

Beads of Courage
beadsofcourage.org
Coordinates with healthcare workers at hospitals to help children with serious illness cope with their treatment through art.

The Jessie Rees Foundation
negu.org
Free 64-ounce plastic jars filled with toys and activities for kids 18 and under who have cancer.

Kids Konnected
1-800-899-2866
Children facing cancer are offered quarterly newsletters, support groups, children's camps, online chat rooms, and other events.

Kylee's Dancing Angels
kyleesdancingangels.org
Provide the financial support to help sarcoma patients get to their "happy place."

The Kylie Rowand Foundation
kyliestrong.org
Dedicated to raising money and awareness for new, promising, less toxic treatments for childhood cancer. Sends personalized care packages to children fighting cancer and provides financial assistance to families.

Team IMPACT
goteamimpact.org
Connects children facing serious and chronic illnesses with local college athletic teams, forming lifelong bonds and life-changing outcomes.

Triage Cancer
triagecancer.org
Non-profit that provides education on practical and legal issues that impact individuals diagnosed with cancer.

Wally's Smile
wallyssmile.org
Provides comfort and a smile by delivering free care packages to adults, children, and dogs.

The resources listed are not a complete list of all available resources. If you are seeking resources not listed, please contact Rein In Sarcoma and we will do our best to connect you with the appropriate information.

Rein in Sarcoma would like to thank the many organizations that provided information used in this Guidebook; including the University of Minnesota Cancer Center, Mayo Clinic, the National Cancer Institute, and other sources noted. The material within is to be used for informational and educational purposes only. It is not intended as medical advice, nor is it intended to create a physician-patient or other clinical relationship. This Guidebook is not a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified healthcare provider regarding questions you may have about a medical condition. Do not forgo or delay seeking medical advice because of the information in this Guidebook or in any of the materials referenced herein.

While we have attempted to ensure that all internet sites referenced in this Guidebook are valid and operational at the time of publication, we cannot guarantee that information will remain up-to-date or accurate. Rein in Sarcoma does not endorse, or verify the validity of any of the websites, books, articles, or other information referred to within. Updates or additional information can be found at www.reininsarcoma.org.

Special thank you to the volunteers, medical professionals and staff that dedicated their time and shared their talents in updating this valuable resource.

The material provided herein is for the sole use of patients, families, and caregivers of patients currently dealing with sarcoma. It should not be used for any other purpose without the express written consent of Rein in Sarcoma.

REIN IN
SARCOMA
Increase awareness. Increase survivors.

About Rein in Sarcoma:

Rein in Sarcoma is a non-profit 501c3 Tax Exempt organization for patients and families touched by sarcomas, an uncommon and often misdiagnosed group of bone and soft tissue cancers that strike children and adults alike. We are a nationally-known sarcoma foundation and provide support to patients and loved ones all across the world. Founded in Minnesota in 2001, we have funded over $2 million in innovative, collaborative and high-impact research and education initiatives at top medical research institutions such as Mayo Clinic, the University of Minnesota, Cleveland Clinic and Children's Hospitals and Clinics of Minnesota.

Our Mission:

Our three-pronged mission: educating the public and medical community about sarcomas, supporting sarcoma patients and their loved ones, and funding research directed toward developing new treatments and finding a cure for sarcoma cancers.

We are stronger together. Thank you!

Rein in Sarcoma hopes our Sarcoma Patient Guidebook was helpful to you and your family. The Guidebook is made possible through volunteer efforts from our Red Flags Education Committee, and the Medical Advisory Board of Rein in Sarcoma. Help us extend our outreach to others who are newly diagnosed with sarcoma. Please consider a donation to Rein in Sarcoma:
www.reininsarcoma.org/donate

scan to donate

☎ (763) 205-1467
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reininsarcoma.org