



**REIN IN
SARCOMA**

Increase awareness. Increase survivors.

Sarcoma Patient Guidebook

8th Edition, 2021



**Take Charge
of Your
Sarcoma
Story**

Conner, Sarcoma Survivor

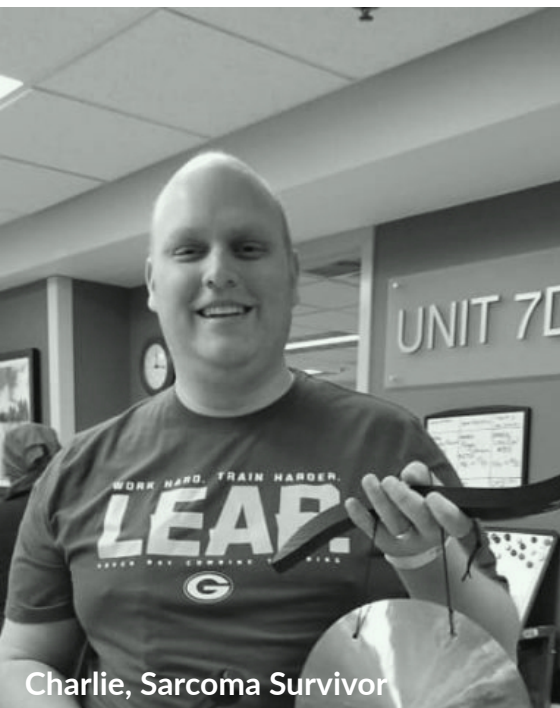


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Charlie, Sarcoma Survivor



Annette, Sarcoma Survivor



Tania, Sarcoma Survivor

Taking Charge of Your Sarcoma Story

www.reininsarcoma.org



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Dear Sarcoma Patient (and Caregivers):

We are glad you have this sarcoma patient education resource and we hope you find it meaningful for you. It has been carefully revised and updated by a team of volunteers, each of whom understand a sarcoma diagnosis. We want you to feel supported, cared for and have the best information to make decisions with your care team, for you.

You have learned sarcomas are rare forms of connective tissue cancers. You, or your family and friends may not have heard of sarcoma before you received your diagnosis. We know it is not always easy to find sarcoma information and support. This is why volunteers at **Rein in Sarcoma** and a network of community members come together; so that we all can receive accurate information and support. In community, we are stronger together.

This guidebook is reviewed bi-annually, revised and published with the most up-to-date information for you. This edition benefited from the work of third year medical students at the University of Minnesota collaborating with sarcoma patients, caregivers, and sarcoma specialists in Minnesota.

Founded in 2001 with a threefold mission: to **educate** the public and medical community about sarcomas, **support** sarcoma patients and their loved ones, and **fund research** directed toward developing new treatments and finding a cure for sarcoma cancers, **Rein in Sarcoma** is the vision of a wise and passionate woman, Karen Wyckoff. She wanted to ensure better outcomes for more patients and families.

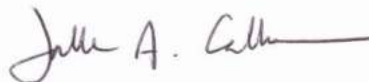
Rein in Sarcoma support services include a peer mentor program, monthly support group, gatherings throughout the year for sarcoma patients and their immediate loved ones, and the annual Rein in Sarcoma Family Picnic held in the Twin Cities on the last Monday of July in conjunction with our Party in the Park. We invite you to participate in events, groups and resources by signing up on our website: reininsarcoma.org.

At Rein in Sarcoma, you have a community to support and assist you. Please do not hesitate to contact us.

Yours in service,



Blake Hastings, President



Janelle Calhoun, Executive Director



Sarcoma Patient Guidebook

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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.



Rein in Sarcoma would like to thank the many organizations that provided information used in this Notebook. These include 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 Notebook 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 information in this Notebook or in any of the materials referenced herein.

While we have attempted to ensure that all internet sites referenced in this Notebook are valid and operational, we cannot guarantee that website 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.

This eighth edition of the Notebook has undergone a metamorphosis with the careful guidance of pediatrician Elsa Keeler, M.D., and student Yatharth Sharma. It has now become the Patient Guidebook with special consideration of those who have received a recent sarcoma diagnosis. Our hope is that readers will find it user friendly and easy to use.

Our great appreciation and thanks for renovating this edition go to Yatharth Sharma, Guy Gunther, Kristine Nachbor, David Supinski and Elsa Keeler, M.D. Our great thanks for additional skilled critique and editing support go to Mel Bassett, Leah Otto, Danielle Gerck and Katy Engelby.

In addition, our thanks go to the Red Flags Education Committee of Rein in Sarcoma and Katy Engelby for our cover design. For distribution, we recognize and thank the members of Patient and Family Support Committee and medical staff at partner medical systems: Mayo Clinic, University of Minnesota Fairview M Health, Children's Masonic Hospital, Duke University, The Froedtert & the Medical College of Wisconsin regional health network and University of Wisconsin Hospitals and Clinics.

This guidebook is a community effort to support sarcoma patients and families. Medical updates are made on the Rein in Sarcoma website at www.reininsarcoma.org. Please log on to the website for any updates or additional information since publication in the third quarter of 2021.

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. Requests for reproduction or additional copies of the Sarcoma Patient Guidebook should be sent to:

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Rein in Sarcoma hopes our Patient and Family Guidebook was helpful to you and your family. The Guidebook is made possible through volunteer efforts from our Red Flags Education Committee, Patient and Family Support Committee, PR and Marketing 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

We are stronger in community. Thank you!



SECTION II: AFTER YOUR SARCOMA CANCER DIAGNOSIS...NOW WHAT?

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

(1) SURROUND YOURSELF WITH A SUPPORT SYSTEM

You 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.

In addition:

- Rein in Sarcoma www.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 www.sarcomaalliance.org provides a peer-to-peer sarcoma support network, which consists of individuals that have been affected by sarcoma, including survivors, caregivers, and loved ones, who are in need of support and encouragement.
- Caring Bridge www.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 www.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.

(2) RESEARCH YOUR SARCOMA TYPE

Research everything you can about your sarcoma cancer diagnosis. It's important to understand what is happening to your body and what your medical options are. It will also help you to feel mentally prepared for what may lie ahead. Share your research findings with your doctors so they can add their expertise. This will help keep communication open and help you get the most current and best treatment. To help you get started, this notebook includes many trustworthy sites that can also be found on the Rein in Sarcoma website www.reininsarcoma.org.

The following websites provide reliable and up-to-date general and specific information about sarcoma cancers:

The American Society of Clinical Oncology (ASCO) - www.cancer.net

Soft Tissue Sarcoma: www.cancer.net/cancer-types/sarcoma-soft-tissue

Sarcoma of specific organs: www.cancer.net/cancer-types/sarcomas-specific-organs

Bone Sarcoma: www.cancer.net/cancer-types/bone-cancer

Find a Sarcoma Doctor: www.cancer.net/find-cancer-doctor

National Comprehensive Cancer Network (NCCN) - www.nccn.org

Up to date, comprehensive information for patients: www.nccn.org/patients

Information for Soft Tissue sarcoma:

www.nccn.org/patientresources/patient-resources/soft-tissue-sarcoma

National Cancer Institute – Cancer Information & Support Networks -

www.cancer.gov

Soft Tissue sarcoma - www.cancer.gov/cancertopics/types/soft-tissue-sarcoma.

Bone sarcoma - www.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 https://livehelp.cancer.gov/app/chat/chat_launch.

If you prefer to contact them in Spanish, please visit www.cancer.gov/espanol/global/contactenos.

Bone Tumor.org - www.bonetumor.org

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

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

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

(3) FINDING THE RIGHT EXPERTS FOR YOUR CARE

Choosing the best medical team to be at your side is an important step on your journey. Most likely, you will have a surgeon and/or an oncologist (cancer 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**. 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, orthopedic oncology, radiation therapy, pathology, and radiology.

For a state-by-state national listing including a map showing sarcoma centers visit: <https://sarcomaalliance.org/sarcoma-centers/>

Consider visiting a National Cancer Institute Cancer Center at www.cancer.gov or a surgeon from the Musculoskeletal Tumor Society www.msts.org/directory/search.aspx?directory=public

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.

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 Physician

A fellow physician is a doctor 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 Physician

A resident physician is a doctor who has received a medical degree and is training in a specific area, such as radiology or pediatrics. They 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 YOUR 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 cancer 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. It's also important to ask your medical care team for their notes of your visit as well. A written plan should be given to you at each visit.
- 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.

(5) UNDERSTANDING YOUR TREATMENT OPTIONS

Treatments for sarcoma cancers may be given and coordinated by not only your surgeon and/or oncologist, but also by other medical specialists on your cancer team. **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 tumor type
- The sarcoma tumor's "grade" and "stage"
- Possible treatment side effects
- Your overall medical and physical health

Take time to learn about your treatment options, and as always, ask lots of 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 instance, 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. Below we provide you with a brief summary of how tumors are given a "grade" and a "stage" as well as different treatment options:

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 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 specialists who are leading clinical trials or related research.

- **Grading:** The "grade" portion of your tumor describes how much of your cancer cells within your tumor look like normal healthy cells when under a microscope. This information is usually found on the pathology report.
 - 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.
- **Staging:** The "stage" portion of your tumor uses letter and number codes that describe all the places the cancer cells or tumors are located in your body. A common example of staging is the "TMN" 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 person with a stage 1 tumor has cancer cells that are located in one place, and the cancer cells are not found in any other tissues in the body at this point.

GENETIC TESTING:

- Genetic testing has become a common part of a cancer diagnosis and can help guide a treatment plan. Genetic testing looks for specific changes in a person's genetic makeup, or genes. These changes may be harmful, beneficial, or have no effect on the risk of developing cancer or how you respond to treatment. Genetic testing also looks for specific health risks that run in a family. These inherited genes are thought to contribute to about 5 to 10% of all cancers. Genetic testing may be covered by your health insurance or as part of a clinical trial.

For more information on genetic testing please visit: www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet#what-is-genetic-testing

TYPES OF TREATMENT:

- **SURGERY AND/OR BIOPSY**
 - Surgery is the option to remove your sarcoma tumor through an operation. Some patients will have had 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 will be done to remove the rest of the tumor and some healthy tissue around it.
 - By removing healthy tissue around your sarcoma tumor, it creates 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 tumors.
 - 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).

- CHEMOTHERAPY

- Chemotherapy, which is typically administered post-surgery, is medication given as a pill or intravenous (through an IV) that may stop cancer cells from growing, dividing, and making more cancer cells. It can also be given prior to surgery to help shrink a tumor for easier removal or after a 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 sarcoma cancers 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 on these drugs.

- 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 a 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 www.cancer.gov/about-cancer/treatment/types/radiation-therapy

- TARGETED THERAPY

- Targeted therapy is medicine taken by mouth or injection that works to “target” cancer cells at the level of molecules of the cancer cells. The objective of targeted therapy is to prevent the cancer cells from dividing and growing.

- Different tumors have different targets, so your doctor may order genetic testing on your tumor to see if these targets are present. Not all cancers and tumors have the specific targets for targeted therapy.
- There are many different types of targeted therapies. Your medical team and oncologist will discuss whether this is an option for you or not.
- Targeted therapies have been effective treatments that are changing the prognosis for many people with sarcoma cancers who previously had little hope of long-term survival.
- As research studies continue to identify more targets and develop more targeted therapies, this treatment option is constantly evolving.
- Immunotherapy is one type of targeted therapy designed to boost the body's natural immune defenses to fight cancer.
 - Generally, immunotherapy is comprised of antibodies that bind to cancer cells and trigger your immune system to kill the cancer cells.
 - Like all targeted therapies, some immunotherapies are readily available, and other types are given as part of research in a clinical trial. Your oncologist can guide you in these options.

For additional information, visit the National Cancer Institute at www.cancer.gov/about-cancer/treatment/types/targeted-therapies/targeted-therapies-fact-sheet#what-are-targeted-cancer-therapies

• CLINICAL RESEARCH TRIALS

Cancer researchers are always testing new treatments. A part of this research involves treating patients who are willing to receive a cancer treatment by participating in what are called clinical trials. The purpose of a clinical trial is to prove 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 parts called phases:

- 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

www.clinicaltrials.gov

National Institute on Aging

www.nia.nih.gov/health/clinical-trials-benefits-risks-and-safety



SECTION I: INFORMATION FOR THE NEWLY DIAGNOSED

WHAT IS SARCOMA?

Sarcoma is a type of cancer found in connective tissues. It usually is found as a tumor, that is, a lump, bump, or mass. Sarcoma cancers are 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**, and while all sarcoma tumors share certain characteristics, they are further sub-classified based on the type of cells found in the tumor. There are well over 100 different types of sarcoma tumors, most of which are very rare.

How rare are sarcoma cancers? Of the over 1.7 million people who are diagnosed with any cancer in the United States each year,

- About 1% of them will be diagnosed with sarcoma cancer.
- Some sarcomas are so rare that only a few people are diagnosed each year.
- In children under age 18, where cancer is rare to begin with, sarcomas are actually one of the top five most commonly diagnosed cancers.

Diagnosing a new sarcoma cancer can be hard for many reasons. The tumor can form almost anywhere in the body. The symptoms are ones that many people experience—a lump, a bump, or pain in a joint. They are easy to misdiagnose. Factors that determine treatment and recurrence include the type of tumor, where it is found, how far it has spread, and whether the cells have a known treatment. Even after all of these characteristics are known, it's important to note that each person diagnosed with these rare sarcoma tumors may react differently to their disease and treatment of these tumors. **Studies and statistics cannot accurately predict an individual patient's chances of survival. Sarcoma cancer survivors have more often than not defied all the odds, despite what seems to be an impossible challenge at the onset of their diagnosis.**

Our hope is that this guidebook will give you the information you need to better understand your own (or your loved one's) sarcoma cancer diagnosis and what comes next. Each and every page has been crafted with care, with input from medical experts as well as survivors of sarcoma cancer. If you would like further detailed information about sarcoma cancers, including any updates or corrections of this 2021 edition, you can find it on the Rein in Sarcoma website at www.reininsarcoma.org.

WHAT WE KNOW ABOUT THE CAUSES OF SARCOMA

Background

Since sarcoma cancers are so rare, there is still a lot to discover about what causes these tumors. Researchers often study a group of sarcoma cancers together, which can make it difficult to understand the many nuances between them. However, combining these cancers in research may be the only way to find potential causes, treatment and cure for something very rare.

Genetic causes

Genes are like blueprints for the building blocks of your body. Mutations, or changes, in genes cause too many or too few building blocks inside the body. Although there are many genes in the body that can prevent these mutations from happening, sometimes they fail and can lead to cancer tumors, including sarcoma tumors.

An example is the p53 gene (associated with Li-Fraumeni syndrome), which is linked with one of these genetic mutations. When this happens, it causes cells to grow and divide uncontrolled, thus leading to cancerous tumors, which can increase the likelihood of bone and soft tissue sarcoma tumors to form. In some cases, although not in all, parents can also pass these uncontrolled, spontaneous genetic mutations to their children.

Environmental causes

Certain exposures can increase a person's chances of developing sarcoma cancers. In particular, a certain viral infection, known as Human Herpes virus 8 (HHV-8), can lead to Kaposi's Sarcoma cancer. This tends to occur in those with Acquired Immunodeficiency Syndrome (AIDS). Additionally, having received ionizing radiation and chemotherapy for a previous cancer can increase the risk of sarcoma tumors later in life (although this is rare).

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 body organs and joints. They are found anywhere in the body, from head to toe, although more often in the extremities, such as arms or legs.

- It is estimated that close to 13,500 people will be diagnosed with a soft tissue sarcoma cancer in the US in 2021.
- In their early stages, soft tissue sarcoma tumors 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 can happen when a sarcoma tumor starts to press on nearby muscles and nerves.
- Imaging, such as MRI scans, can help diagnose if a lump or mass is suspected of being a sarcoma tumor.
- Soft tissue sarcoma tumors are diagnosed by removing either the entire tumor or a small piece of it. This is best performed by a skilled surgeon who is very familiar with sarcoma cancers, 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 cancer type that you (or your loved one) have been diagnosed with. It is always best to work closely with your own oncologist and sarcoma cancer 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.

Angiosarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Most patients have no symptoms (i.e., are 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 <u>anywhere</u> in the body, but most often in the skin, head, or neck.	<p>Angiosarcoma is a connective tissue sarcoma tumor that grows from the cells that line blood vessels and lymph channels ("Angio"). They represent approximately 1-2% of all sarcoma cancers and is seen most commonly in individuals above the age of 70, but can also occur at any age.</p> <ul style="list-style-type: none">• Can be caused by "lymphedema", which is swelling due to the body unable to handle fluid that collects 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.

Resources:

<http://sarcomahelp.org/angiosarcoma.html>

www.mayoclinic.org/diseases-conditions/angiosarcoma/symptoms-causes/syc-20350244

www.cancer.gov/pediatric-adult-rare-tumor/rare-tumors/rare-vascular-tumors/angiosarcoma

Epithelioid sarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Typically, it will appear as a small, painless lump under the skin of a finger, hand, forearm, lower leg, or foot.• May be a sore or open wound that doesn't heal.	<p>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.</p> <ul style="list-style-type: none">• Most commonly seen among teenagers and young adults.

Resources:

www.mayoclinic.org/diseases-conditions/epithelioid-sarcoma/cdc-20392420

Kaposi's sarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• 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.	<p>Kaposi's sarcoma is a connective tissue tumor named after the Hungarian doctor who discovered it. These tumors grow from cells that line blood and lymph vessels.</p> <ul style="list-style-type: none">• 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.

Resources:

www.mayoclinic.org/diseases-conditions/kaposi-sarcoma/cdc-20387726

Leiomyosarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Tumors located deep in the body that may not present with any symptoms until they grow larger.• May appear as painless masses below the skin.	<p>Leiomyosarcoma is a connective tissue tumor that grows from the type of muscle found in the intestines, gastrointestinal tract, large blood vessels, and in the uterus of women.</p> <ul style="list-style-type: none">• Accounts for 5-10% of all soft tissue sarcoma tumors.• No proven relation to any environmental exposures or lifestyle choices.• Genetic conditions (Hereditary Retinoblastoma and Li Fraumeni Syndrome) may predispose patients to Leiomyosarcoma cancer.

Resources:

<http://sarcomahelp.org/leiomyosarcoma.html>

Liposarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• 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.	<p>Liposarcoma is a connective tissue tumor that grows from fat cells located in deep connective tissues.</p> <ul style="list-style-type: none">• One of the most common soft tissue tumors mostly found in adults, but can occur at any age.• Some risk factors include exposure to chemical carcinogens, previous ionizing radiation and chemotherapy treatments.

Resources:

www.mayoclinic.org/diseases-conditions/liposarcoma/symptoms-causes/syc-20352632

Rhabdomyosarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• May appear as a painless mass underneath the skin.• Are commonly found in the head and neck region, followed by the extremities, such as arms and legs.	<p>Rhabdomyosarcoma is a connective tissue tumor that grows from skeletal muscles, such as the muscles in your arms, legs, abdominal wall, and back.</p> <ul style="list-style-type: none">• Mostly occurs in children and young adults, but can occur at any age.• Is associated with Neurofibromatosis, Li-Fraumeni, Beckwith-Wiedemann, and Costello syndromes.

Synovial Sarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Slow growing, painless mass found in the arms or legs where the joints are formed.• Masses may be painful if involving nerves.	<p>Synovial sarcoma tumors develop from immature cells that line the inside of a joint (synovium).</p> <ul style="list-style-type: none">• Typically affects people ages 15-40, but can occur at any age.• No definite risk factors.• Has been associated with Chromosome 18 and Chromosome X Translocations.

Resources:

www.cancer.gov/pediatric-adult-rare-tumor/rare-tumors/rare-soft-tissue-tumors/synovial-sarcoma

www.mayoclinic.org/diseases-conditions/synovial-sarcoma/cdc-20387747
sarcomahelp.org/synovial-sarcoma.html

Gastrointestinal stromal tumor (GIST)

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Symptoms vary based on size and location of tumors.• Small tumors may be asymptomatic while larger tumors may cause vomiting, GI bleeding, abdominal pain, nausea and weight loss.	<p>A Gastrointestinal Stromal Tumor (GIST) is a sarcoma cancer that develops from cells that help coordinate your intestinal movements throughout the day.</p> <ul style="list-style-type: none">• Most commonly occurs in adults between the ages of 50 and 70, but can occur at any age.• Some association with rare genetic syndromes.

Resources:

www.mayoclinic.org/diseases-conditions/gastrointestinal-stromal-tumors/cdc-20387715

Malignant Peripheral Nerve Sheath Tumor (MPNST)

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Symptoms vary based on the size and location of tumors.• May experience pain, numbness, weakness, or a burning/tingling sensation in the extremities at the tumor site.	<p>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).</p> <ul style="list-style-type: none">• Most commonly affects young and middle-aged adults.• 50% of these tumors occurs in the setting of a genetic condition called Neurofibromatosis 1.

Resources:

www.mayoclinic.org/diseases-conditions/malignant-peripheral-nerve-sheath-tumors/symptoms-causes/syc-20362603

<http://sarcomahelp.org/mpnst.html>

Myxofibrosarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Slow-growing, painless lump on extremities, such as arms or legs, that extends deep into tissues.• Symptoms vary based on size and location of tumors.	<p>Myxofibrosarcoma is a connective tissue tumor that surrounds and separates muscles from each other and from the skin.</p> <ul style="list-style-type: none">• 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.

Resources:

www.mayoclinic.org/diseases-conditions/myxofibrosarcoma/cdc-20387740

Dermatofibrosarcoma Protuberans (DFSP)

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• 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.	<p>A Dermatofibrosarcoma Protuberans (DFSP) tumor arises from connective tissue in the middle layer of the skin, known as the dermis layer.</p> <ul style="list-style-type: none">• Typically affects people ages 20-50.• 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.

Resources:

www.mayoclinic.org/diseases-conditions/dermatofibrosarcoma-protuberans/cdc-20352949

<https://edlineplus.gov/genetics/condition/dermatofibrosarcoma-protuberans/#causes>

Undifferentiated Pleomorphic Sarcoma

Type	How Does it Appear?	General Description
Soft tissue tumors	<ul style="list-style-type: none">• Appears as a lump in the extremities, such as arms or legs, and can also occur behind abdominal organs.• Although it can be found in either soft tissues or bone, it is considered a soft tissue tumor.	<p>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”.</p> <ul style="list-style-type: none">• Formerly known as Malignant Fibrous Histiocytoma.• Typically affects older adults.• Previous ionizing radiation therapy is a risk factor.

Resources:

www.mayoclinic.org/diseases-conditions/undifferentiated-pleomorphic-sarcoma/symptoms-causes/syc-20389554

<http://sarcomahelp.org/mfh.html>

Bone Sarcomas

Bone Sarcoma tumors develop in the bone tissue itself or in the cartilage that provides cushion between bones in the joints.

- Approximately 3,600 new cases of bone sarcoma cancers are diagnosed in the United States each year, accounting for less than 0.2% of all cancers.
- Unexplained 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, often being mistaken for an injury instead of a bone tumor. These tumors can also weaken the bones, causing easy fractures.
- A variety of imaging, such as X-Rays, CT scan or an MRI scan, can decide if a lump or mass is 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 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 oncologist and cancer team will help get you 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.

Resources:

www.cancer.gov/types/bone/bone-fact-sheet

Osteosarcoma

Type	How Does it Appear?	General Description
	<ul style="list-style-type: none">• 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 weakening by the tumor.• Most common tumor sites are found in the femur and tibia, both by the knee, and the humerus, near the shoulder.	<p>Osteosarcoma tumors come from bone forming cells, called osteoblasts, in immature bone tissue.</p> <ul style="list-style-type: none">• Most common bone tumors.• Most commonly diagnosed in children and young adults, under the age of 25.• Can also occur in older adults over 40.

Resources:

www.mayoclinic.org/diseases-conditions/osteosarcoma/symptoms-causes/syc-20351052

www.cancer.gov/types/bone/bone-fact-sheet

Chondrosarcoma

Type	How Does it Appear?	General Description
Bone tumors	<ul style="list-style-type: none">• 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, often near the joints.	<p>Chondrosarcoma is a sarcoma that arises from cells that produce cartilage, which is connective tissue surrounding bones and other organs in the body.</p> <ul style="list-style-type: none">• 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.

Resources:

www.hopkinsmedicine.org/health/conditions-and-diseases/sarcoma/chondrosarcoma

Ewing's Sarcoma

Type	How Does it Appear?	General Description
Bone tumors	<ul style="list-style-type: none">• 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).	<p>Ewing's sarcoma is named after the American doctor who discovered this sarcoma tumor in the 1920's. It is a tumor that arises from immature bone cells, but can also occur outside the bone in cartilage, nerves, or soft tissue.</p> <ul style="list-style-type: none">• 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.• Is more common in males than females.• Most cases involve a fusing of genetic material between chromosomes 11 and 22, causing the Ewing's sarcoma gene (EWS) to be "turned on".

Resources:

www.mayoclinic.org/diseases-conditions/ewing-sarcoma/symptoms-causes/syc-20351071

Chordoma Sarcoma

Type	How Does it Appear?	General Description
Bone tumors	<ul style="list-style-type: none">• Can occur anywhere within the spine and the base of the skull/brain, causing pain and nerve symptoms, including tingling, numbness and weakness.	<p>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.</p> <ul style="list-style-type: none">• Occurs most often in adults between ages 40 and 60, more in men than women.• Can be caused by some hereditary conditions, such as familial Chordoma and Tuberous Sclerosis Complex.

Resources:

www.mayoclinic.org/diseases-conditions/chordoma/cdc-20355401



SECTION III: SUPPORT FOR SURVIVING SARCOMA

Being a cancer survivor starts at diagnosis and continues for the rest of your life. Whether you are just starting or have completed treatment, the resources listed here can help with:

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

(1) LONG TERM CARE PLANNING RESOURCES

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

Survivorship resources:

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.

<https://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. www.mncanceralliance.org

National Comprehensive Cancer Network

Guidelines are available for patients focused on healthy living, managing effects of cancer and screening for recurrence. www.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. www.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. www.canceradvocacy.org

(2) FINANCIAL AND HEALTH COVERAGE SUPPORT

Many people have health insurance through their employers, including short-term and long-term disability options. It is important to check your policy to understand these options. This section will examine a handful of resources, including how to pay for excess medical costs as well as options for support if you don’t have access to health insurance. More information is available on the Rein in Sarcoma website www.reininsarcoma.org/resources/.

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 their spouse’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 www.healthcare.gov.

MEDICARE

www.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

www.socialsecurity.gov

Some people who have cancer are eligible for Social Security disability insurance payments (SSDI). These are monetary benefits given monthly up to age 65. Social Security disability benefits are available to adults who:

- Meet insured status. This is defined as having worked 5 out of the last 10 years prior to the onset of the illness/disability, and
- 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 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 our 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. 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)

www.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.

Cancer Financial Resource

www.cancer.org/treatment/supportprogramsservices/app/resource-search

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

www.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

<https://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

www.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

www.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

www.facebook.com/szottfoundation1/

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

www.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

www.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

www.rmhc.org

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

www.cancerfamilies.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

www.cancer.org/treatment/supportprogramsservices/hopelodge/index

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

www.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: www.aircharitynetwork.org

Serving the Midwest:

www.angelflightcentral.org

To request assistance: 877-621-7177

Angel Airlines for Cancer Patients

www.angelairlinesforcancerpatients.org/

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

Corporate Angel Network

www.corpangelnetwork.org.

The Corporate Angel Network helps cancer patients by arranging free travel to treatment across the country using empty seats on corporate jets. Patient line: (914) 328-1313

National Patient Travel Center

www.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

www.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

www.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

<https://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.

FOR CHILDREN AND YOUNG ADULTS

Believe in Tomorrow National Children's Foundation

www.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

www.lighthousefamilyretreat.org.

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

Make-a-Wish Foundation

<https://wish.org>

Grants wishes to children, 18 and under, with life-threatening medical conditions.

Marty Lyons Foundation

<https://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

<https://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)

<https://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.

FOR ADULTS

The Dream Foundation

www.dreamfoundation.org

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

Reeling and Healing Midwest

<https://fishon.org>

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

Second Wind Dreams

www.secondwind.org

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

STRESS MANAGEMENT

It is important to your health and well-being to have ways to cope with stress, as positive coping is associated with longevity and better health. Below are some helpful links to help you cope with having cancer:

HeartMath Institute

www.heartmath.org

Mayo Clinic: Stress Management - www.mayoclinic.org/healthy-lifestyle/stress-management/basics/stress-basics/hlv-20049495

MIT Medical: Sleep, Mindfulness Meditation, Relaxation, and Stress Reduction - <https://medical.mit.edu/community/stress-reduction>

University of Minnesota Center for Spirituality and Healing - www.takingcharge.csh.umn.edu

RESOURCES FOR CAREGIVERS

The Caregiver Action Network (CAN)

www.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

www.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

www.jackscaregiverco.org.

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



SECTION IV: REIN IN SARCOMA

Our Mission

Rein in Sarcoma is dedicated to **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.

Rein in Sarcoma (RIS), founded in 2001, is a resource for families touched by sarcoma cancer and is the largest sarcoma foundation in the Midwest. Working in partnership with Sarcoma Cancer Centers in the Upper Midwest, we seek to fund innovative, collaborative and high-impact research, funding over \$2 million to date. Our education and patient support activities reach thousands of people both regionally and nationally. Rein in Sarcoma is a Minnesota (based) Non-Profit tax exempt 501(C)(3) organization.

Some of the ways RIS strives to make an impact include:

- I. **Education:** Raising sarcoma cancer awareness, leading to earlier and more accurate diagnosis is a key to our work. Increasing awareness will lead to a significant increase in sarcoma survivors.
 - a. **Red Flags Education Program:** educates the public and medical professionals on the symptoms of sarcoma, with the goal of promoting early detection and ultimately saving lives. Available to you:
 - i. The Red Flags of Sarcoma Cancer brochure:
To order for yourself or others, use the attached form or visit www.reininsarcoma.org/red-flags-brochure-order/
 - ii. Red Flags video-“Never Heard of It” and other education videos
View and share the video at www.youtube.com/user/reininsarcoma
 - b. **Jan Mauldin Sarcoma Scholars:** These are scholarships that are awarded each year to medical students wishing to both learn and make a difference through work with RIS. The sarcoma scholars have been a cornerstone of our educational efforts as they work to educate other health sciences students and the public during their scholarship year. They carry the information forward about sarcoma with them as they practice medicine, the next generation of doctors more aware of sarcoma’s “red flags”. The scholarship program began in the 2009-2010 thanks to generous support

by Jan and Tim Maudlin. Jan was diagnosed with Myxoid Liposarcoma in 2001. Jan always felt a connection to the story of Rein in Sarcoma's founder, Karen Wyckoff. During Jan's first day of radiation cancer treatment, her doctor came and shared that a patient of hers with sarcoma had just died and that she was so young. That patient was Karen. Jan learned from her doctor about how little public information was available about sarcoma. Karen had wanted to change that. Jan became committed to raising awareness about sarcoma.

II. Support: For sarcoma patients, survivors, caregivers, and those who have lost a loved one to sarcoma. Rein in Sarcoma brings together a community of patients, loved ones, volunteers, and medical professionals dedicated to supporting those touched by sarcoma.

a. Sarcoma Support Team (SST): Supports sarcoma patient/caregiver by listening to their story and discussing experiences through one-on-one telephone/email conversations.

Each year thousands of people will be impacted by sarcoma. The RIS SST offers support through one-on-one conversations with a trained peer mentor volunteer that can understand and relate to the patient/caregiver.

Patients/Caregivers will be matched with a volunteer who is a survivor or caregiver who is similar to themselves. The volunteer will draw on his/her experience to provide emotional support and lend an empathetic ear.

To request a connection visit: www.reininsarcoma.org/ or submit attached form.

b. Tote Bags of Hope: Totes with useful items while going through treatment are delivered to sarcoma patients at local cancer centers.

c. Gatherings: Gatherings are held throughout the year for patients, survivors, and loved ones to connect with others impacted by sarcoma. Subscribe to receive up-to-date information:
www.reininsarcoma.org/subscribe/

d. Talk and Together Time: A monthly gathering of sarcoma survivors facilitated by a trained supporter to share our stories, fears and hope. The group discusses personal experience with traditional treatments, trials, nutrition and integrated treatments that may be of interest to others in the group.

Talk and Together time meets monthly, the second Tuesday of the month at 10 am. Intended as a support group for patients, we invite caregivers to attend with the patient they support. For more information visit: www.reininsarcoma.org/

e. Online Support: www.facebook.com/groups/reininsarcomacircleofsupport

This is a closed, members only Facebook group for sarcoma patients, survivors and caregivers within the upper Midwest region. This page connects those affected by sarcoma to offer support, ask questions, and share experiences. The focus of the group is to provide support, share knowledge, raise awareness and advocacy.

f. Social Media: Actively maintain social media platforms to provide support and education.

- i. Twitter: <https://twitter.com/reininsarcoma>
- ii. Facebook: www.facebook.com/reininsarcomafoundation
- iii. Instagram: www.instagram.com/reininsarcoma/

III. Raising money for sarcoma directed research: RIS has funded over \$2 million in sarcoma cancer research at the University of Minnesota, Mayo Clinic, and Children's Minnesota. This has resulted in additional grants of over \$13 million in public and private funding. To see all of the RIS funded research projects visit: www.reininsarcoma.org/research/

a. Sarcoma Research Symposium: Rein in Sarcoma funded research reports presented in a peer to peer format with medical researchers and medical students attending. This event educates students, builds relationships between sarcoma experts and sparks innovation to improve therapies and patient outcomes.

Sarcoma Patient & Survivor Stories

To read more stories visit: www.reininsarcoma.org/stories/

Conner

Conner was 26 years old in 2019 when he went from busy life to cancer diagnosis within days. He was about to serve as a panelist during a healthcare technology conference when he suddenly felt sick and coughed up blood. He headed to the ER and was quickly admitted to intensive care unit (ICU) with internal bleeding from a mass in his throat. He was very ill.

On his second day in ICU, he had surgery to biopsy the mass. It was a complicated surgery that had to be done with Conner awake. Conner's team listened to him at a tough moment during the procedure, which helped avoid additional surgery to put a breathing tube in his neck (tracheostomy). Two weeks later, Conner got the results: Rhabdomyosarcoma.

In the short time he was at the hospital, the resident doctor caring for him became a key player in Conner's care and recovery. He took the initiative to connect Conner with experts in sarcoma treatment, and Conner met with an oncologist at a sarcoma center soon after diagnosis.

He went through tough chemotherapy for ten months. This shrunk the tumor, and the next step was to remove what was left with surgery. Because of the risks involved, his sarcoma specialist helped him get a second opinion with the oncologist and cancer surgeon at another sarcoma center. The oncologists worked together to create seamless care across medical centers, which Conner says is not common. His oncologist always answered his questions, put him at ease, and led the plan for Conner's care.

While Conner was going through treatment for his sarcoma, he realized that if he got through it, he'd like to give back. He remembered being given a RIS New Patient Guidebook not long after he was diagnosed with rhabdomyosarcoma. Conner began volunteering with Rein in Sarcoma. He joined the board of directors in the spring of 2020.

Mel

On January 7, 1993, while working for a cellular company, I was dropping off some new cell phones to several local orthopedic doctors. One of them noticed that I had some swelling in my right knee that I had not yet noticed myself. After my sales call was finished, he sent me downstairs to get an x-ray, and in that instant, my life was changed forever.

The x-ray showed a large bone tumor in my upper right distal femur. The very next day, I found myself having surgery to biopsy the tumor. My surgeon came into my room, looking very somber, and told me the tumor was advanced osteosarcoma, already stage III. As a result, I would be moving to the "chemo ward" to start chemotherapy the next day!

A few months later, in April, after three rounds of chemo, I had surgery to remove a partial section of my right femur, which was replaced with a cadaver thigh bone (allograft). My scar was 60 staples long running from a few inches below my knee to nearly the top of my thigh. After several weeks of recovery, I continued on chemo for five days every month for over a year. Yes, it was grueling, awful, and very scary. But, with each chemo treatment behind me, I became more and more grateful for another day, another month, and that I was still here. In the end, when it was all behind me, I found myself to be a much more positive, upbeat thinking person. I am very grateful for every day. I can thank osteosarcoma for that.

I am now happily married, with a wonderful step-daughter and two beautiful daughters of my own, who are considered to be miracle babies as I was told that both pregnancies wouldn't go to full term due to the heavy amounts of chemo that I had had. In fact, the oldest of my two daughters was conceived before I had even gotten my first period since finishing chemo!

For new patients, I say hang in there! It can be, no doubt, one of the scariest and worst experiences you will ever go through. But you must be fully committed to completing all you need to do to stay healthy and alive. No one else can make that decision for you. "Just do it" was my motto throughout the entire time that I was going through chemo. That slogan really helped me to stay mentally strong and resilient throughout my journey, as did my wonderful family and friends, who stuck by me through it all.



In 2017, Rein in Sarcoma completed a review process with the Charities Review Council of Minnesota and was awarded the “Meets Standards” seal. The Charity Review Council analyzes nonprofit organizations in four critical areas: Public Disclosure, Governance, Financial Activity, and Fundraising. The review confirmed that Rein in Sarcoma’s operations, structure, and policies meet widely accepted standards for accountability and transparency.



Rein in Sarcoma Support Network Registration Form

Please complete this form to register with Rein in Sarcoma Support Network and to request support materials/services. The Rein in Sarcoma Support Network is an email list designed to provide resources and support for sarcoma patients, survivors and loved ones in the upper Midwest. You will receive updates about support events and gatherings of patients and survivors, which are held several times a year in Metro Twin Cities locations.

You may also register online at www.reininsarcoma.org/form-ris-support-network/

Resources are free and sent within the United States.

Please Print:

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Email: _____

☐ I am: Sarcoma Patient/Survivor

☐ Sarcoma Loved one of a Sarcoma Patient/Survivor

Patient Name: _____ Relationship to patient: _____

Type of Sarcoma: _____ Date of diagnosis: _____

I am interested in (Check all that apply)

- ☐ Sarcoma Support Team (peer mentor)
- ☐ Patient/Survivor Social Gatherings
- ☐ RIS Social Time (monthly patient talk & time together)

- ☐ Red Flags Brochure
- ☐ Patient Guidebook

Return to: Rein in Sarcoma
7401 Central Avenue NE STE
A Fridley, MN 55432



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 write down information to keep in one place.

- **Important contact information**
- **Physician/Nurse Encounter:** 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

Symptom Log

[illegible]



VI. ADDITIONAL RESOURCES

GENERAL CANCER INFORMATION

American Cancer Society

www.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.org

www.cancercare.org

National organization dedicated to providing free professional support services including counseling, support groups, educational workshops, and financial assistance.

CAC2

<https://cac2.org>

Advances childhood cancer causes by unifying the childhood cancer community through collaboration.

Macmillan Cancer Support

www.macmillan.org.uk

Europe's leading cancer information charity, with up-to-date cancer information and practical advice and support.

Minnesota Cancer Alliance

www.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)

www.canceradvocacy.org

Advocates for quality cancer care and provides tools to empower people to advocate for themselves.

Oncolink

www.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

<https://sarcomacoalition.org/>

This is a coalition of sarcoma advocacy groups that are marked in this list with an *

***Angiosarcoma Awareness, Inc.**

www.cureasc.org

Dedicated to researching better therapies and a cure for angiosarcoma.

Brian Morden Foundation

www.brianmordenfoundation.org

Ewing Sarcoma and childhood cancer research foundation that provides funding for higher education scholarships.

Carson Sarcoma Foundation

www.carsonsarcomafoundation.org

Funds sarcoma cancer research.

Chondrosarcoma Foundation

<https://csfshayna.org/>

Dedicated to education and advocacy for care, treatment and detection of chondrosarcoma.

Chordoma Foundation

www.chordomafoundation.org

Dedicated to chordoma

Cure Alveolar Soft Part Sarcoma International

<https://cureasps.org/>

Funds research and supports patients with ASPS.

***Desmoid Tumor Research Foundation**

<https://dtrf.org/>

Funds research to develop therapies and find a cure for desmoid tumors.

***EHE Foundation**

<https://fightehe.org/>

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

Finish Sarcoma

<https://finishsarcoma.org/>

Raises awareness, patient support, and supports sarcoma research.

***Focus on Rhabdo**

<https://focusonrhabdo.org/>

Online community of researchers, clinicians, & families dedicated to rhabdomyosarcoma.

Foster Foundation

www.fosterfoundation.com

Supports osteosarcoma research.

***Friends of TJ Foundation**

<https://friendsoftj.org/>

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

GIST Cancer Awareness Foundation

<http://www.gistawareness.org>

Volunteer-led online community providing information about GIST (gastrointestinal stromal tumors).

***GIST International**

www.gistsupport.org

Volunteer-led organization that provides GIST (gastrointestinal stromal tumors) education and support.

Jared's Juggernaut to Cure Sarcomas

<https://jaredsjuggernaut.org>

Educates the public about sarcoma and raise funds for research.

Josh Powell Foundation

www.joshpowellfoundation.org

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

Kristin Ann Carr Foundation

<http://sarcoma.com>

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

***Leiomyosarcoma Direct Research Foundation (LMSDR)**

www.lmsdr.org

Dedicated to empowering patients with leiomyosarcoma and funding research.

***Life Raft Group**

<https://liferaftgroup.org>

Mission is to enhance survival and quality of life for people living with gastrointestinal stromal tumors (GIST).

Make It Better Agents (MIB)

www.mibagents.org/

Foundation dedicated to pediatric osteosarcoma awareness and research.

***National Leiomyosarcoma Foundation (NLMSF)**

<https://nlmsf.org/>

Builds awareness in communities, and funds research for leiomyosarcoma.

***Paula Takacs Foundation**

<https://paulatakacsfoundation.org/>

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

***QuadW Foundation**

www.quadw.org/

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

Rutledge Foundation

<https://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)**

<https://sarctrials.org>

Nonprofit organization that is dedicated to the development and support of research for

***Sarcoma Alliance**

<https://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)**

www.curesarcoma.org

Advocate for sarcoma patients by funding research and increasing awareness.

Sarcoma Oma

<http://www.sarcoma-oma.org>

Provides transportation services for sarcoma patients nationwide.

***Summer's Way Foundation**

www.summersway.org

Advances childhood cancer and rhabdomyosarcoma research. Connects families dealing with rhabdomyosarcoma and childhood cancer through webinars and support groups.

***Slifka Foundation**

<http://www.slifkafoundation.org>

Funds a wide range of sarcoma research.

Synovial Sarcoma Research Foundation

[https://www.facebook.com/](https://www.facebook.com/SynovialSarcomaResearchFoundation/)

[SynovialSarcomaResearchFoundation/](https://www.facebook.com/SynovialSarcomaResearchFoundation/)

Funds synovial sarcoma research.

Wendy Walk Foundation

www.wendywalk.org

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

DRUG INFORMATION

National Cancer Institute (NCI)

www.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

www.rxlist.com

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

COMPLEMENTARY AND ALTERNATIVE MEDICINE

Memorial Sloan Kettering Integrative Medicine

www.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)

<https://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

<https://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-

www.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 AND FAMILY SUPPORT

Ben's Friends Patient Support Communities

www.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

www.cancerhopenetwork.org

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

Cancer Warrior Alliance

<http://www.cwa.life>

Mission to deliver cancer support resources to cancer community.

CaringBridge

www.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

www.chemoangels.com

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

Dear Jack Foundation

www.dearjackfoundation.org

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

Facebook

www.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

www.facebook.com/groups/reininsarcomacircleofsupport

Synovial sarcoma group

www.facebook.com/groups/synovialsarcomasupport

General sarcoma group

www.facebook.com/groups/sarcomasupportinitiative

Gilda's Club

www.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

www.grythealth.com

Mobile app platform for people affected by cancer to connect with other with similar experiences.

Imerman Angels

<https://imermanangels.org>

Connects cancer fighters, survivors, and caregivers with “mentor angels”

Jack's Caregiver Coalition

www.jackscaregiverco.org

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

Catus Cancer Society

<https://cactuscancer.org/>

Online support programs for young adults and caregivers.

Momcology

<https://momcology.org>

National platform of peer support for childhood cancer families and caregivers,

M Powerment

<https://cancerdudes.org>

Created to provide education and resources specifically tailored for males.

Negative Space

www.thenegativespace.life

Dedicated to shining light on caregivers

MISCELLANEOUS RESOURCES

Along Comes Hope

www.alongcomeshope.com

Provides advocacy, support, and financial assistance for travel associated with treatment, creative emotional support programs.

Beads of Courage

<https://beadsofcourage.org>

Coordinates with healthcare workers at hospitals to help children with serious illness cope with their treatment through art.

The Jessie Rees Foundation

<https://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

<http://www.kyleesdancingangels.org>

Provide the financial support to help sarcoma patients get to their "happy place."

The Kylie Rowand Foundation

www.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

www.goteamimpact.org

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

Triage Cancer

<https://triagecancer.org>

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

Wally's Smile

www.wallyssmile.org

Provides comfort and a smile by delivering free care packages to adults, children, and dogs fighting cancer.