Take charge of your sarcoma story.
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Adapted by the Rein in Sarcoma Foundation with permission from the Amschwand Sarcoma Cancer Foundation, Sarcoma Survivor Starter Notebook, Houston, Texas, 2005.
Dear Sarcoma Patient (and Caregivers):

The diagnosis of sarcoma is a lonely one. Sarcoma is a rare form of cancer, and you might not have even heard of it before you received your diagnosis. We know that it may be difficult for you to find the information and support you need to deal with this disease. The Rein in Sarcoma Foundation, with inspiration from the Amschwand Sarcoma Cancer Foundation, is pleased to provide you with this Sarcoma Patient Starter Notebook as a resource for you in your battle against sarcoma.

The Rein in Sarcoma Foundation is a nonprofit foundation with a three-fold mission: (1) to raise money for research into the cause, diagnosis, and treatment of sarcoma; (2) to educate doctors, other caregivers, and the public about these rare cancers; and most importantly, (3) to provide support for people whose lives are being affected by sarcoma.

We hope that this Notebook serves as a resource to support you as you deal with sarcoma. Developed by patients, caregivers, and professionals who have joined us in the fight, it is our sincere hope that this Notebook will provide you and your loved ones with a jump-start towards becoming a sarcoma survivor. Our other support services include Rein in Sarcoma Gatherings throughout the year for sarcoma patients and their immediate loved ones and the annual Rein in Sarcoma Family Picnic held in late July at Como Park in St. Paul in conjunction with our Party in the Park.

One of the hurdles you will face in your battle against sarcoma is a sense of isolation. However, while sarcomas are rare, many people in the Upper Midwest have been on the journey that you are beginning. A group of men and women who have been touched by sarcoma and who are associated with the Rein in Sarcoma Foundation are dedicated to helping others who have been similarly affected. They and the Rein in Sarcoma Foundation are here to support and assist you as you confront this disease. Please do not hesitate to contact us.

Yours in service,

Peter Wyckoff, President and Chairman of the Board of Directors
Rein in Sarcoma Foundation (www.reininsarcoma.org)
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# Sarcoma Patient Starter Notebook

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The Rein in Sarcoma logo represents both a classic carousel horse and a sunflower. Together these symbolize the search for cures for sarcoma cancers and increasing survivors.
Some of the information in this Notebook has been borrowed from a similar document produced by the Amschwand Sarcoma Cancer Foundation (ASCF). Other information has been obtained from the Sarcoma Alliance, the University of Minnesota Cancer Center, Mayo Clinic, 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.

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This sixth edition of the Notebook is our biggest revision to date. Special thanks for editing this edition go to our Medical Advisory Board: Christian Ogilvie, M.D.; L. Chinsoo Cho, M.D., M.S.; Emily Greengard, M.D.; Jutta Ellerman, M.D. of the University of Minnesota; Nancy McAllister, M.D. and Julie Chu, M.D. of Children’s Hospitals and Clinics of Minnesota; and Scott Okuno, M.D. and Steven Robinson M.B.B.S. of the Mayo Clinic. In addition, our thanks go to the Red Flags Committee of Rein in Sarcoma for their input on the content. We also thank Taylor Dale for our cover design and Elisabeth Will for copyediting. Continual updates are made on the Rein in Sarcoma website at: www.reininsarcoma.org. We greatly appreciate the RIS Julian Baultrippe, Brett Dale, Jan Maudlin, Beverly and Dean Osterman Funds and Thrivent Action Team Dollars for sponsoring this 2016 updated edition.

The material provided here is for the sole use of patients, families, and caregivers of patients currently struggling with sarcoma. It should not be used for any other purpose without the express written consent of the Rein in Sarcoma Foundation and the Amschwand Sarcoma Cancer Foundation. Requests for additional copies of the Sarcoma Patient Starter Notebook should be sent to: The Rein in Sarcoma Foundation, 3312 Richmond Avenue, Shoreview, MN 55126.

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SECTION I: GETTING STARTED

WHAT IS SARCOMA? INFORMATION FOR THE NEWLY DIAGNOSED

Malignant (cancerous) tumors of the connective tissues are called “sarcomas,” a term derived from the Greek word meaning “fleshy growth”. As cancers of the connective tissue, sarcomas develop in fat, blood vessels, nerves, bones, muscles, deep skin tissues, tendons, and cartilage. Sarcomas are divided into two main groups—bone tumors and soft tissue tumors. While all sarcomas share certain microscopic characteristics and produce similar symptoms, they are further sub-classified based on the type of cell found in the tumor.

Approximately 15,000 new cases of sarcoma are diagnosed in the United States every year. While sarcomas account for fewer than 2% of all adult cancers, they are one of the top five most commonly diagnosed cancers afflicting children. Sarcomas do not discriminate on the basis of age, gender, race, or socioeconomic status.

A sarcoma diagnosis can be difficult because a sarcoma can originate virtually anywhere in the body, and there is no standard set of presenting symptoms in patients. Sarcoma type, staging, metastasis (whether it has spread beyond its primary or initial site), and treatment all play a role in determining the ultimate outcome to the patient. Because sarcomas are rare and there are so many different forms of the disease, often there is insufficient data (or numbers of cases) to provide an accurate estimate of a patient’s prognosis or chance of survival. For this reason, a review of the statistics that can be found online or in medical journals may be disheartening. If you choose to review these statistics, you should do so cautiously. Each patient may react to the disease and to treatment differently, so no journal or statistic can predict an individual patient’s chance of survival. In fact, many sarcoma survivors have defied all odds, overcoming what at one point seemed to be an impossible challenge.
If you or a loved one has been diagnosed with sarcoma, please seek a specialist who sees a large number of sarcoma patients each month. Consider visiting a National Cancer Institute-designated Cancer Center or a surgeon from the Musculoskeletal Tumor Society (see Section V, page 3 for detailed listings).

We hope that the information contained in this Notebook will be helpful to you in better understanding your (or your loved one’s) sarcoma and in discussing it with members of your support group. Further detailed information, including any updates or corrections of this edition, can be found on the Rein in Sarcoma website at www.reininsarcoma.org.
Sarcomas are cancers of connective tissues like muscle, bone, and fat. There are many different types of sarcoma, which are generally either bone or soft tissue sarcomas. All sarcomas are rare, regardless of the type. For example, the incidence of all soft tissue sarcomas combined is 5 cases per 100,000 people per year\(^{1}\). Unlike most other types of cancer, an appreciable fraction of sarcomas occur in children 0-19 years of age\(^{2-4}\). It is not uncommon for patients in their 20s to be seen at pediatric hospitals or clinics. Most osteosarcomas, Ewing’s sarcomas, and rhabdomyosarcomas occur in children. Sarcomas like pleomorphic sarcomas, liposarcomas, and leiomyosarcomas occur mainly in adults. The occurrence of different types of sarcomas varies according to sex, race, and age.

Very little is known about what causes sarcomas, primarily because they are so rare. It is difficult to bring a sufficient number of cases into a study of useful size; often, diverse types of sarcoma, which may have different causes, must be lumped together. The rarity of sarcoma also means that most investigations use a retrospective study design, asking about exposures in the past, which is not always a reliable method of analysis.

As with most other types of cancer, inherited genetic predisposition is known to cause some sarcomas\(^{5}\). For instance, osteosarcomas and soft tissue sarcomas occur much more frequently among people with Li-Fraumeni syndrome, which involves inherited gene mutations. Sarcomas associated with such familial syndromes, however, are a small portion of the total. Recent efforts to sequence cancer predisposition genes suggest that about 20% of children with sarcoma\(^{6}\) and 50% of adults with sarcoma\(^{7}\) have some degree of harmful mutations even in the absence of a family history.

A few environmental causes are known for particular types of sarcoma. In particular, human herpesvirus 8 (HHV-8) is an established risk factor for Kaposi’s sarcoma, especially in the presence of a suppressed immune system, which commonly occurs with the Acquired Immunodeficiency Syndrome (AIDS)\(^{6}\). Exposure to high doses of ionizing radiation also causes sarcoma (and many other types of cancer), although this kind of significant exposure is so rare that few cancers are attributable to it \(^{7,8}\). Chemotherapy for childhood cancer, in addition to high-dose therapeutic radiation, can also increase the risk of sarcoma\(^{9,10}\). Apart from the factors mentioned above, there are no other established risk factors, although many have been investigated\(^{11}\).
TYPES OF SARCOMAS: AN INTRODUCTION

Sarcomas are relatively uncommon tumors, accounting for less than 2% of all malignancies. They are classified according to the histologic tissue from which they are derived, and more than 30 histologic subtypes have been identified. While both carcinomas and sarcomas are cancerous tumors, sarcomas arise from the body’s connective tissue—bone, muscle, blood vessel cells, cartilage, nerves, and supporting elements. Conversely, carcinomas arise from organs such as the stomach, kidney, lung, breast, etc. Approximately 80% of sarcomas originate from soft tissues, while 20% arise from bone.

**Bone cancer** frequently occurs after a cancer has spread or metastasized from the original site (for example, breast, prostate, lung), resulting in a bone metastasis. When the cancer first starts or originates in bone, it is called a primary bone cancer. Cancers that spread to bone (metastases) represent 98% of all bone cancers. Cancers that start in the bone (primary bone cancers) are rare. Only about 3,000 new cases of primary bone cancers are diagnosed in the United States each year, and primary bone cancers tend to be more common in children and adolescents than in adults. The term “tumor” and “cancer” are used interchangeably, and there is very little practical difference between the two terms. When the word “benign” is placed in front of other terms, as in “benign tumor” and “benign cancer,” it is indicative of less aggressive and often non-lethal disease.

**Soft tissue sarcomas** are cancers of the supporting tissues of the body. Soft tissue tumors can occur in muscle, fat, nerve, tendon, and other tissues that support, surround, and protect the organs of the body. While such tumors are common, many are benign; those that are malignant are called soft tissue sarcomas. Approximately 12,000 soft tissue sarcomas of the body are diagnosed annually.

**Pediatric bone and soft tissue malignant tumors** are common tumors in children. They are also called musculoskeletal sarcoma, which describes a cancer of mesenchymal tissues, such as bone, soft tissues, and connective tissue. This kind of cancer is highly malignant and harmful to children. Bone and soft tissue sarcomas, particularly osteosarcoma, Ewing's sarcoma, and rhabdomyosarcomas most often occur in children. Their symptoms and treatment may differ from the same sarcoma occurring in an adult.
**Soft Tissue Sarcoma**

Select Types of Soft Tissue Sarcoma (and the tissue in which it arises)
(This list does not contain all types)

<table>
<thead>
<tr>
<th>Soft Tissue Sarcoma</th>
<th>Tissue Origin</th>
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<tbody>
<tr>
<td>Alveolar Soft Part Sarcoma (ASPS) (unknown origin)</td>
<td>Leiomyosarcoma (smooth muscle, e.g. of blood vessels or uterus)</td>
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<tr>
<td>Dermatofibrosarcoma Protuberans (DFSP) (skin)</td>
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<tr>
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<td>Malignant Fibrous Histiocytoma (unknown origin)</td>
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<tr>
<td>Epithelioid Sarcoma (unknown origin)</td>
<td>Malignant Peripheral Nerve Sheath Tumor (MPNST) (peripheral nerves)</td>
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<td>Extrasosseous Tumor (including Ewing’s Sarcoma, Extraskeletal Myxoid Chondrosarcoma, and Osteosarcoma)</td>
<td>Mesenchymoma (mesenchymal tissue)</td>
</tr>
<tr>
<td>Fibrosarcoma (fibrous tissue)</td>
<td>Neurofibrosarcoma (peripheral nerves)</td>
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<tr>
<td>Gastrointestinal Stromal Tumor (GIST) (interstitial cell of Cajal in bowel wall)</td>
<td>Rhabdomyosarcoma (skeletal muscle)</td>
</tr>
<tr>
<td></td>
<td>Synovial Sarcoma (unknown origin)</td>
</tr>
<tr>
<td></td>
<td>Vascular Sarcoma (including Angiosarcoma, Hemangiopericytoma, and Kaposi Sarcoma)</td>
</tr>
</tbody>
</table>

**Soft Tissue Sarcomas**

*Soft tissue sarcomas* are cancers of the supporting tissues of the body. Soft tissue tumors can occur in muscles, fat, nerves, blood vessels, tendons, and other tissues that support, surround, or protect body organs and joints. While most of these tumors are benign (not cancerous) and not life-threatening, those that are malignant are called soft tissue sarcomas. Approximately 12,000 soft tissue sarcomas are newly diagnosed each year in the United States. About 40% of soft tissue sarcomas occur in the legs, usually at or above the knee,
while 15% develop in the hands or arms, 15% in the head or neck, and the remaining 30% in the shoulders, chest, abdomen, or hips.

It is not clear why some people develop sarcoma, but researchers have been able to identify some common characteristics in groups with high rates of soft tissue sarcoma. Some studies have shown that people exposed to herbicides with phenoxyacetic acid and wood preservative with chlorophenols have an increased risk of developing soft tissue sarcoma. People with certain inherited diseases such as neurofibromatosis also have a higher risk, as do those exposed to high doses of significant ionizing radiation. Researchers are studying genetic abnormalities and chromosome mutations as possible causes of soft tissue sarcomas.

In their early stages, soft tissue sarcomas rarely display any symptoms. Because soft tissue is very elastic, tumors can grow quite large before they are felt. The first symptom is usually a painless lump. As the tumor grows and begins to press against nearby nerves and muscles, soreness or pain will be felt. Soft tissue sarcomas can be diagnosed by a surgical or radiology-guided biopsy procedure in which tissue from the tumor is removed for analysis under a microscope. Soft tissue sarcomas are treated using surgery, radiation therapy, and/or chemotherapy. Depending on the size, location, extent, and severity of the tumor, a combination of all or some of these treatments may be used. Non-cytotoxic therapy is also used as a treatment for certain sarcomas. The most common types of soft tissue sarcoma are described below.

**Alveolar Soft Part Sarcoma (ASPS)**

Alveolar soft part sarcoma (ASPS) is a slow-growing and often painless tumor of unknown cell origin. It typically occurs in adolescents and young adults. In children, ASPS is commonly located in the head and neck area; in adults, the lower extremities.

ASPS grows slowly, but frequently metastasizes to other parts of the body, such as the lungs and brain. Although it is characterized as a soft tissue sarcoma, ASPS can spread and grow inside bones.

Treatment of the primary tumor includes surgery (wide resection of the lesion) and often radiation. For disease that travels to the lungs, surgery is sometimes possible to remove nodules. New therapies using oral tyrosine kinase inhibitors, such as sunitinib and cediranib, have been shown to be effective in some people.
Dermatofibrosarcoma Protuberans (DFSP)
Dermatofibrosarcoma protuberans (DFSP) develops in the deep layers of the skin and can spread to the surrounding fat, muscles, and bone. It can occur at any age, but is more likely to strike adults in the thirties.

DFSP usually forms as a small, firm patch of raised skin. It may appear purple or red and typically grows very slowly. Less commonly, it appears as a soft and depressed area of skin. DFSP is most often found on the torso, but can also occur on the arms, legs, head, and neck.

DFSP rarely metastasizes, but does have a tendency to recur. Treatment consists of Mohs micrographic surgery or excision, both usually performed in a dermatologist’s office. If DFSP metastasizes, tyrosine kinase inhibitors, such as imatinib, can be effective at controlling the disease. In certain instances, radiation therapy is prescribed.

Epithelioid Sarcoma
Epithelioid sarcoma typically occurs in the hands or feet of young adults. It appears in the form of small nodules, which sometimes merge together. This sarcoma tends to recur and may metastasize to regional lymph nodes and other locations, including the scalp.

Extraosseous Tumors
There are three types of extraosseous tumors, which are actually bone sarcomas found in the soft tissue: (1) mesenchymal chondrosarcoma; (2) extraskeletal osteosarcoma; and (3) Ewing's sarcoma (see pages 16-19). Chondrosarcoma and osteosarcoma may not be treated in exactly the same way as their bone varieties, but extraosseous Ewing's sarcoma is treated similarly and responds well to radiation therapy.

Fibrosarcoma
Fibrosarcoma is a tumor derived from fibrous connective tissue around scars, muscles, nerves, tendons, and bone linings. It is usually found in adults between thirty and fifty years old, but can occur at any age, even infancy. Fibrosarcoma generally affects the fibrous tissue in the legs, arms, or trunk and may metastasize to other parts of the body. As with other forms of soft tissue sarcoma, the mainstay of treatment is surgery.

Gastrointestinal Stromal Tumor (GIST)
Gastrointestinal stromal tumor (GIST) affects the digestive tract or nearby structures within the abdomen. GIST most commonly occurs in adults over fifty years old. Children are affected very rarely, and their disease is different than that in adults.
GISTs arise either from cells called interstitial cells of Cajal (ICCs) or from less differentiated stem cells or precursor cells that can develop into ICCs. The ICCs are known as the “pacemaker cells of the gut” because they send signals to trigger peristalsis, the digestive tract’s muscular contractions that move food along its course. Primary GISTs (in the original development site) may occur anywhere along the gastrointestinal tract from the esophagus to the anus. The most frequent site for GISTs is the stomach (about 55%), followed by the duodenum and small intestine (about 30%), esophagus (about 5%), rectum (about 5%), colon (about 2%), and rare other locations.

In GIST, the most common sites for metastasis are the liver and the abdominal membranes. Systemic treatment options include the use of tyrosine kinase inhibitors such as imatinib, sunitinib, and regorafenib, as well as others.

*Note: Information on GIST, above, was provided by GIST Support International.*

**Leiomyosarcoma**
Leiomyosarcoma originates in smooth muscle tissue, which is muscle over which the brain does not have conscious control, such as muscle in the walls of blood vessels, the uterus, or the gastrointestinal (GI) tract. It can originate anywhere in the body, but the uterus and gastrointestinal tract are the most common sites of origination, with over 60% of the GI tract tumors originating in the stomach. Uterine and GI leiomyosarcomas typically are accompanied by significant bleeding and pain. Metastases usually occur in the lungs or, in the case of GI tumors, in the liver. The average age of patients diagnosed with this type of sarcoma is 60 years.

Leiomyosarcomas of the retroperitoneum and the vena cava are found mostly in women. Pregnancy accelerates tumor growth. Treatment for uterine leiomyosarcoma is total abdominal hysterectomy. Sometimes this treatment is followed by radiation, chemotherapy, or hormone therapy.

**Liposarcoma**
Liposarcoma arises in fatty tissue and is the most commonly diagnosed soft tissue sarcoma. While liposarcoma can develop anywhere in the body, it most often originates in the lower extremities and the lining of the abdominal cavity. Liposarcoma tumors are typically large and bulky with smaller satellites beyond the confines of the main tumor. Liposarcoma generally affects adults between the ages of 40 and 60 years old.

There are four types of liposarcoma: (1) Well-differentiated liposarcoma, the most common subtype, which begins as a low-grade tumor and tends to grow and change slowly; (2)
Myxoid liposarcoma, an intermediate to high-grade tumor; (3) Pleomorphic liposarcoma, the rarest subtype, a high-grade tumor; and (4) De-differentiated liposarcoma, which occurs when a low-grade tumor changes, and the newer cells are high-grade. The risk of recurrence and metastasis with liposarcoma increases with higher-grade tumors.

Surgery and radiation therapy aim to prevent recurrence at the surgical site. Chemotherapy may be recommended in situations where patients are at high risk of recurrence or have more advanced disease.

**Lymphangiosarcoma (Stewart-Treves Syndrome)**

Lymphangiosarcoma occurs in long-standing cases of primary or secondary lymphedema, which is a condition involving localized fluid retention and tissue swelling caused by a compromised lymphatic system. It involves either the upper or lower lymphedematous extremities, but is more common in upper extremities.

Lymphangiosarcoma first appears as a bruise mark and progresses to an ulcer with crusting. It metastasizes quickly.

Lymphangiosarcoma was previously a complication of massive lymphedema of the arm following removal of axillary lymph nodes and lymphatic channels as part of the classical Halstedian radical mastectomy to treat breast cancer. The classical radical mastectomy has now been replaced by the more conservative modified radical mastectomy and, more recently, by segmental breast tissue excision and radiation therapy. Lymphedema and incidences of lymphangiosarcoma are now incredibly rare. When lymphangiosarcoma follows mastectomy, it is known as Stewart-Treves syndrome.

The most successful treatment for lymphangiosarcoma is amputation of the affected limb, if possible. Chemotherapy may be administered if there is metastatic disease.

**Malignant Fibrous Histiocytoma (MFH)/Undifferentiated Pleomorphic Sarcoma**

Malignant Fibrous Histiocytoma (MFH) is the most common soft tissue sarcoma occurring in older adults (age 50-70). It rarely affects children. It occurs more often in Caucasians than those of African or Asian descent and is twice as common in men as it is in women.

MFH occurs most often in the extremities and retroperitoneum (the anatomical space behind the abdominal cavity). Metastasis occurs in the lungs, bones, and liver.
MFH has remained an enigma—no true cell of origin has ever been identified. In 2002, the World Health Organization (WHO) declassified MFH as a formal diagnostic entity and renamed it as undifferentiated pleomorphic sarcoma. MFH, however, represents the diagnosis for many patients and is still commonly used by both patients and physicians.

MFH is considered a diagnosis of exclusion for sarcomas that cannot be more precisely categorized. Studies to exclude other sarcomas, such as rhabdomyosarcoma and liposarcoma, are usually completed.

MFH has four main subtypes: (1) Storiform-pleomorphic, the most common type, accounting for up to 70% of most cases; (2) Myxoid, the second most common, accounting for approximately 20% of cases; (3) Giant cell; and (4) Inflammatory.

Treatment consists of surgical excision and, in almost all cases, radiation.

**Malignant Peripheral Nerve Sheath Tumor (MPNST)**
The malignant peripheral nerve sheath tumor (MPNST) (also known as malignant schwannoma or neurofibrosarcoma) is the malignant counterpart to benign soft tissue tumors such as neurofibromas and schwannomas. It accounts for 5-10% of soft tissue sarcomas and occurs most commonly in deep soft tissue, usually in close proximity to a nerve trunk. The most common sites include the sciatic nerve, brachial plexus, and sarcal plexus.

The most common symptom is pain, which usually prompts a biopsy. Most tumors are more than 5 cm in diameter when diagnosed. About half the cases of MPNST are diagnosed in people with neurofibromatosis. It usually occurs in adults 20-50 years old, but patients with neurofibromatosis may develop tumors at an earlier age.

MPNST tumors typically spread to the surrounding soft tissue to form a nodular tumor. Metastasis can occur through the bloodstream. Tumors can be painful, and sometimes nerve function is affected. Treatment is generally wide resection of the nerve. Surgery is often followed by radiation therapy to reduce the chance of recurrence. In some instances, chemotherapy drugs are also used.

**Mesenchymoma**
Mesenchymoma is a rare soft tissue sarcoma showing two or more distinct types of malignant mesenchymal differentiation. Malignant mesenchymomas are considered high-grade sarcomas with a poor prognosis. However, low-grade malignant mesenchymomas
have been reported; they have a better prognosis. These tumors are frequently located in the trunk (for example, the chest wall and retroperitoneum) and lower extremities (usually the thigh). Mesenchymomas mainly occur in adults. These tumors are quite invasive, especially when they occur in the skeletal muscles. Treatment is wide excision, often combined with radiation and/or chemotherapy.

**Rhabdomyosarcoma (RMS) (Striated Muscle Tumor)**
Rhabdomyosarcoma is an aggressive form of cancer that develops from skeletal (striated) muscle cells that have failed to fully differentiate. The vast majority of cases occur in children under the age of 18. RMS can occur anywhere on the body, but is generally found in the head, neck, genitourinary tract, genitals, and extremities.

Rhabdomyosarcoma is generally divided into three histological subsets: (1) embryonal rhabdomyosarcoma (ERMS); (2) alveolar rhabdomyosarcoma; and (3) anaplastic rhabdomyosarcoma.

**Embryonal Rhabdomyosarcoma**
This is the most common variant, comprising almost 70% of childhood cases. It is most common in children under 4 years old. Tumors often occur in the head and neck, as well as the genitourinary tract. ERMS has two defined subtypes, botryoid and spindle cell ERMS, which are both associated with a favorable prognosis. Chemotherapy is commonly used to treat these tumors, and there is a high cure rate when combination therapy (i.e. surgery and chemotherapy) is used.

**Alveolar Rhabdomyosarcoma**
The second most common type of rhabdomyosarcoma, alveolar rhabdomyosarcoma (ARMS), occurs in the large muscles of the trunk, arms, and legs. It typically affects older children or teenagers. It is called “alveolar” because the malignant cells form small hollow spaces, or alveoli. ARMS is typically more aggressive than ERMS.

**Anaplastic Rhabdomyosarcoma**
Anaplastic rhabdomyosarcoma (also known as undifferentiated or pleomorphic rhabdomyosarcoma) occurs most often in adults and is usually found in the extremities. Anaplastic rhabdomyosarcoma is the most aggressive type of RMS and requires intensive treatment, usually surgery and chemotherapy.

**Synovial Sarcoma**
Synovial sarcoma is most commonly found in the arms or legs, often next to a joint. The most common site is adjacent to the knee, although it is also often found near the foot,
ankle, or hand. This sarcoma usually occurs in young adults. While synovial cells normally line the joints of the body, the name of this particular form of sarcoma is somewhat of a misnomer—synovial sarcoma does not necessarily arise in a joint, and the cancer cells in synovial sarcoma are likely to be very different from normal joint cells. The term “synovial” was chosen due to this cancer cell’s similarity, under a microscopic, to the normal synovial cells lining joints.

Unlike other soft tissue sarcomas, synovial sarcoma is often painful from the outset. Treatment usually consists of wide surgical excision and radiation. Chemotherapy is also used if the risk of recurrence is significant enough to justify its side effects.

**Vascular Sarcoma**
Vascular sarcomas are so named because they develop in the lining of blood vessels. There are several different forms of vascular sarcoma, including: (1) angiosarcoma; (2) hemangiopericytoma; and (3) Kaposi sarcoma.

**Angiosarcoma**
Angiosarcomas account for less than 2% of all sarcomas. This rare malignancy arises from endothelial cells of either lymphatic or vascular origin. When the cell of origin can be identified as lymphatic, the lesion is termed a lymphangiosarcoma; when vascular derivation can be determined, the correct term is hemangiosarcoma. Often, the cell of origin cannot be determined with certainty; hence, the more general term angiosarcoma is used.

Approximately half of these lesions occur in the head and neck, specifically the scalp and face. Angiosarcoma typically occurs in those between 50 and 70 years old, and males are more commonly affected than females. While most patients are asymptomatic at the time of diagnosis, some have pain or bleeding at the tumor site. Conditions associated with angiosarcoma include long-standing lymphedema and prior irradiation. Exposure to vinyl chloride is associated with angiosarcoma of the liver, but this association has not been reported with head and neck angiosarcoma.

**Hemangiopericytoma (HPC)**
Hemangiopericytoma is a very rare form of a vascular tumor that originates in the pericytes in the walls of capillaries. The most common locations reported are the brain, lower extremities, pelvic area, head, and neck. Rarely, hemangiopericytoma tumors can be located in the nasal cavity and paranasal sinuses. Most cases occur in adults, with a median age of 45-50 years. Males and females are equally affected.
Complete surgical excision is the treatment of choice for patients with hemangiopericytoma. Compared with other sarcomas of the head and neck, hemangiopericytoma is associated with a better prognosis. Local recurrence rates of 10-50% have been reported; fewer than 20% of patients have local recurrence after surgical excision.

Kaposi Sarcoma
Kaposi sarcoma typically occurs in the tissues under the skin or in the mucous membranes that line the mouth, nose, and anus. The cancer originates in multiple sites in the mid-dermis (second layer of skin) and extends to the epidermis (outer layer of skin). Some forms of Kaposi sarcoma look nodular or plaque-like on the skin. Radiation therapy is usually the treatment for Kaposi sarcoma; however, when tumors have spread to the organs, chemotherapy may also be used. Karposi sarcoma typically affects three different patient groups:

The first group of affected patients includes older men of Jewish, Italian, or Mediterranean heritage. This type of Kaposi sarcoma usually progresses slowly over 10-15 years. Patients commonly develop a bluish lesion on the front of the lower leg, which typically multiplies and spreads to other organs.

The second group of Kaposi sarcoma patients consists of people who have received organ transplants and have a weakened immune system as a result of the immunosuppressive treatment following the transplant.

The third patient group is composed of AIDS patients; whose weakened immune systems make them more susceptible to the disease. Kaposi sarcoma in AIDS patients usually spreads quickly and can be found in many parts of the body.
Bone Sarcoma Cancers

Select Types of Sarcoma of the Bone
(This list does not contain all types)

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<tr>
<th>Type</th>
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<td>Adamantinoma</td>
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<td>Angiosarcoma</td>
<td>Osteosarcoma</td>
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<td>Chondrosarcoma</td>
<td>Paget's Sarcoma/Pagetoid Osteosarcoma</td>
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<td>Chordoma</td>
<td>Parosteal Osteosarcoma</td>
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<td>Clear Cell Chondrosarcoma</td>
<td>Periosteal Chondrosarcoma</td>
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<td>Ewing’s Sarcoma of Bone</td>
<td>Periosteal Osteosarcoma</td>
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<tr>
<td>Fibrosarcoma</td>
<td>Primitive Neuroectodermal Tumor of Bone (PNET)</td>
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<td>/Solitary Fibrous Tumor</td>
<td>Small Cell Osteosarcoma</td>
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<td>High-Grade Surface Osteosarcoma</td>
<td>Telangiectatic Osteosarcoma</td>
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<tr>
<td>Malignant Fibrous Histiocytoma (Pleomorphic Undifferentiated Sarcoma)</td>
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Bone Sarcomas: Introduction

The second group of sarcoma is bone cancer. It is very rare, with approximately 3,000 new cases diagnosed in the United States each year. The incidence is slightly higher in males than females. No race has a higher incidence than another, although Ewing’s sarcoma is particularly rare among African and American blacks. Due to the rarity and severity of bone cancer, a bone cancer specialist such as an orthopaedic oncologist should be consulted in the treatment of this disease. Visit the Musculoskeletal Tumor Society at www.msts.org to find a sarcoma surgeon. For more information, see Section V, page 3 of this Notebook.

Bones consist of three types of tissue: (1) compact tissue, the hard outer portion of the bone; (2) cancellous tissue, the spongy tissue inside the bone containing the bone marrow;
and (3) subchondral tissue, the smooth bone tissue of the joints. Cartilage surrounds the subchondral tissue to form a cushion around the joints.

Bone tumors can be benign (non-cancerous) or malignant (cancerous). Benign bone tumors are rarely life threatening and do not spread within the body; however, they can grow and compress healthy bone tissue. Cancer that develops in the bone is called primary bone cancer. It is differentiated from secondary bone cancer, which spreads to the bone from another part of the body.

Scientists are uncertain about what causes bone cancer, but they have been able to identify certain factors that may put a person at risk. Children and young adults who have undergone radiation therapy or chemotherapy for other diseases are at an increased risk for bone cancer. Additionally, adults with Paget’s disease, which is a disease characterized by abnormal growth of new bone cells, have an increased risk of osteosarcoma. There are also some hereditary conditions that can increase the risk of bone cancer.

Symptoms of bone cancer can vary depending on the size and location of the tumor. Pain is the most common symptom. Tumors arising in or around the joints often cause swelling and tenderness. Tumors also can weaken the bones, causing fractures. Other symptoms can include weight loss, fatigue, and anemia.

The first step in diagnosing primary bone cancer is a complete medical history and a physical examination performed by a physician. The doctor may order a blood test to determine the level of an enzyme called alkaline phosphatase. Approximately 55% of patients with primary bone cancer will have elevated levels of alkaline phosphatase. However, it isn’t a completely reliable indicator for bone cancer, because growing bones in children will also cause the enzyme to be elevated.

X-rays are also used to locate a bone tumor. If an x-ray suggests that a bone tumor is present, a doctor may order further testing, such as a CT scan, Magnetic Resonance Imaging (MRI), or a bone scan. Finally, a biopsy must be performed to determine if cancer is present. A biopsy is a procedure used to remove sample tissue from the tumor. A surgeon, usually an orthopaedic oncologist, performs either a needle biopsy or an incisional biopsy. During a needle biopsy, the surgeon makes a small hole in the bone and removes sample tissue with a small instrument. For an incisional biopsy, the surgeon cuts into the tumor and removes sample tissue. Certain tumors are can be appropriately biopsied by a radiologist using imaging guidance with a CT scan or under ultrasound. A pathologist—a doctor specializing in
identifying disease—will then study the cells and tissues under a microscope to determine whether the tumor is cancerous.

The treatment of bone cancer depends on the size, location, type, and stage of the cancer. Surgery is often the primary treatment. While amputation of a limb is sometimes necessary, using chemotherapy either before or after surgery has allowed physicians to save the limb in many cases. Radiation is also used sometimes, in combination with the other treatments.

New and more effective treatments are being developed in clinical trials at many sarcoma centers and cancer centers. The most common types of bone sarcomas are described below.

**Chondrosarcoma**
This is a cancer of that usually grows within a bone or on its surface. It is most typically found in middle-aged adults. Chondrosarcoma generally grows slowly, and the most common sites are the pelvis, shoulder, and the upper part of the arms and legs.

The treatment for chondrosarcoma relies heavily on surgical removal, as there is usually no response to radiation and/or chemotherapy. One of the reasons for aggressive treatment is that 10% of low-grade tumors have been reported to develop a much more aggressive biologic behavior, a process called dedifferentiation.

**Ewing’s Sarcoma Family of Tumors (EWST)**

*Note: This section is used with permission from the author, Edward Y. Cheng, M.D., Mairs Family Professor, Department of Orthopaedic Surgery, University of Minnesota Cancer Center, and a charter RIS Board member. It was originally printed in the Journal of the American Academy of Orthopaedic Surgeons, October 2004. The full article, including figures, can be found in the Internet edition of this Notebook at [www.reininsarcoma.org](http://www.reininsarcoma.org).*

Ewing’s Sarcoma Family of Tumors (EWST) begins in the soft tissues (extraosseous Ewing’s sarcoma). Doctors do not know the exact cell of origin, but it is thought to be neuroectodermal. Recently, doctors have defined the disease to include a family of tumors, which includes Ewing’s sarcoma of bone or soft tissue, primitive neuroectodermal tumor (PNET), and Askin tumor of the chest wall. Sometimes these tumors are called small blue cell (round cell) tumors, because of their appearance under a microscope.

Compared with other cancers, all malignant bone tumors are rare. Among malignant bone tumors in children and young adults, Ewing’s sarcoma is the second most common. It occurs
in 1.7 per million to 2.7 per million children younger than 15 years old. There is no known cause.

A doctor will use imaging studies to diagnose a bone tumor. These include x-rays, MRI (magnetic resonance imaging), CT (computed tomography) scans, and bone scans. The doctor confirms the diagnosis by taking a piece of tissue to look at under a microscope (biopsy). This may be done in an operating room or radiology department. Under the microscope, “small blue round cells” are seen.

Then, special tests can help the doctor diagnose Ewing’s sarcoma. The hallmark is an abnormality in the cell’s chromosomes. Genetic material is mismatched. Chromosomes #11 and #22 are affected.

Additional tests (blood tests, lung CT scan, bone scan, and bone marrow biopsy) are needed to determine the extent of disease. This process is known as “staging.” Tests can show if the cancer has spread to other sites. This can include the lungs or bone marrow. The part of the body where the first tumor develops is called the “primary” site. Any parts of the body where it spreads are called “metastatic” sites.

**Risk Factors/Prevention**

There are no known risk factors for developing Ewing’s sarcoma. There is no known genetic link. There is no means of prevention. The tumor does not develop as a result of any dietary, social, or behavioral habit. Parents of affected children should know that there is nothing they could have done to prevent the tumor.

**Symptoms**

There is usually pain and/or swelling at the affected site. But the tumor may be present for many months before it becomes large enough to cause pain and swelling. Injuries are not a known cause, but injury may draw attention to a tumor. A bone weakened by disease may break after a minor injury. Ewing’s sarcoma usually affects the long bones. These include the thighbone (femur), shinbone (tibia), and upper arm (humerus) bone. The bones of the pelvis also may be affected.

**Treatment Options**

Doctors in many specialties help treat Ewing’s sarcoma. These include orthopaedic surgical oncologists, pediatric or adult medical oncologists, radiation oncologists, pathologists, and radiologists. Most patients are treated at major hospital institutions or cancer centers. The main treatments are:
• Chemotherapy to kill the primary tumor and any unknown microscopic spread.
• Surgery to remove the primary tumor, and occasionally metastatic lesions. If necessary, surgery can also rebuild the limb or body part.
• Radiation to lower the chance of the primary tumor coming back (recurring). It may be used instead of surgery at sites where surgery is too risky or complicated.

Ewing’s sarcoma is usually diagnosed as a primary bone tumor without evidence of spread elsewhere. Even if tests do not show spread, the treatment strategy assumes that a very small amount of spread (micrometastatic disease) has already happened.

Chemotherapy
Chemotherapy uses multiple medications. The most common agents are vincristine (Oncovin®), dactinomycin (actinomycin D®), cyclophosphamide (cytoxan®), and doxorubicin (adriamycin®). Recent evidence shows the addition of ifosfamide (Ifex®) and etoposide (VePesid®, VP-16) helps. The chemotherapy is given through an indwelling central venous catheter. This is placed just before treatment is started. Chemotherapy is done in cycles. It uses combinations of the various drugs. The time between cycles enables the body’s blood cell count to recover. This includes white blood cells and platelets. The drugs depress them. Patients will lose their hair. Various medications can lessen other side effects such as nausea, mouth sores, and fevers.

It generally takes close to one year to finish all the cycles of chemotherapy, with surgery and/or radiation. Many advances in chemotherapy have been made by studying patients in clinical trials. Your doctor can tell you more. A physician may request permission to enroll a patient in a specific clinical trial.

Surgery
Both surgery and radiation are effective treatments for the primary tumor. Many surgeons remove the tumor when doing so will not cause a major loss of function of the body part involved. Many doctors use radiation treatment only when a tumor cannot be removed completely or without the patient losing function.

The surgeon can reconstruct the bone, joint, or soft tissue site. He or she may use bone grafts, artificial joints, or a combination thereof. The goal is to restore the body part so the patient can do his or her normal everyday activities. Strenuous or athletic activities are likely to cause too much stress or wear on the reconstruction.
Some patients may need additional operations to keep the limb functioning for the rest of their lives. Reconstruction of a bone in a growing child is a special challenge. As the child grows, multiple procedures are needed to lengthen the reconstructed bone. Surgery and/or radiation can be done either before or during chemotherapy. Most centers will stop the chemotherapy sessions at some time during the first half of the treatments to complete the surgery/radiation. Chemotherapy is restarted once the wound site is adequately healed, usually about 2-3 weeks following the surgery.

Depending on the site involved, the patient may need to limit weight-bearing activity on the limb. Ongoing rehabilitation with physical therapy will be needed to optimize function.

In many cases, doctors can avoid amputation by surgically removing the primary tumor. Rebuilding the bone and joints is then necessary. It’s important to consider the risks and complications associated with the surgery. Infections, problems with a prosthesis, and wound healing are the most frequent concerns.

**Radiation**

When radiation treatment is used, daily treatments are given over the course of 4-7 weeks. While the discomfort of surgery may be avoided, there are risks associated with radiation, including:

- skin reaction
- decreased joint flexibility
- potential damage to nearby organs
- loss of bone growth in growing children
- potential secondary cancers caused by radiation
- possible chronic swelling of an extremity
- slow wound healing after surgery

Recently, more doctors are using surgery to remove the tumors, when possible. Most physicians work as a team to tailor their recommendations regarding surgery and/or radiation to a patient’s specific situation.

**Treatment Outcome and Success**

The outcome for patients with Ewing’s sarcoma has improved a great deal over time. This is thanks to improvements in chemotherapy, diagnostic imaging, and reconstructive techniques. In general, two-thirds of patients without any demonstrable spread will survive at least five years after diagnosis with standard treatment. When tumors come back, it usually happens within the first few years after treatment. The absence of known spread is
the most important factor in favor of a better likelihood of survival. Other factors include having an excellent response to chemotherapy, having primary tumors in the extremities instead of the pelvis, and complete removal of the tumor.

**Fibrosarcoma of Bone**  
This type of bone cancer is also most commonly found in adults, particularly during middle age. A typical site is the thighbone. Fibrosarcoma cancers arise in the fibroblast-type cells—any cells from which connective tissue is developed in the body. These cells form scars as well as perform other important connective functions. This sarcoma contains much connective tissue.

**Malignant Fibrous Histiocytoma/Undifferentiated Pleomorphic Sarcoma**  
This is a very rare type of bone cancer that occurs in adults. It is usually found in the arms and legs, especially around the knee joints.

**Osteosarcoma (Osteogenic Sarcoma)**  
*Note: This section is used with permission from the author, Edward Y. Cheng, M.D., Mairs Family Professor, Department of Orthopaedic Surgery, University of Minnesota Cancer Center, and a charter RIS Board member. It is based on an article entitled: “Osteosarcoma, An unusual cancer arising in the bone.” The full article, including figures, can be found in the Internet edition of this Notebook at www.reininsarcoma.org.*

Most cancers in the bone have spread or metastasized to the bone from another part of the body such as the lung, breast, or kidney. These areas of origin are considered the “primary” sites. Bone cancers may also be related to a cancerous tumor of blood cells, as in myeloma. On rare occasion, however, a cancer can begin in the bone itself from cancerous cells that make bone tissue. A malignant tumor that forms bone tissue from cancerous cells is called an osteosarcoma. Although cancers that begin in the bone (primary bone cancer) are much less common than those that metastasize to the bone, among the primary bone cancers, osteosarcoma is the most common type.

**Epidemiology and Anatomic Site**  
Osteosarcoma is a rare tumor. Only about 2,000 new cases are diagnosed in the U.S. per year, comprising less than 1% of all new cancer cases in the U.S. annually. The vast majority of these tumors develop in patients with bones that are growing rapidly—namely, adolescents or young adults. However, a small concentration of osteosarcomas also affects the elderly. This is in part due to another disease, Paget’s disease, that occurs in older people and may turn into an osteosarcoma. The higher prevalence of osteosarcoma in younger people makes sense, if one thinks of cancer as an error in cellular replication that results in uncontrolled growth. During the pubertal growth spurt, a higher number of bone
cells are multiplying, and it is more likely that an error in the cellular duplicating machinery will occur at that time.

Just as osteosarcomas tend to occur in the rapidly growing adolescent, tumors tend to occur in those bony sites growing most rapidly, namely the distal femur, proximal tibia, and proximal humerus. Tumors may also start growing in the spinal column or the pelvis. Obviously, depending on the extent of the tumor, these anatomic sites are much more difficult to operate on in an effort to completely eradicate the mass.

**The Different Types of Osteosarcoma**

There are many different types of osteosarcoma, and they are quite different in their natural histories and their potential for lethal growth (Table 1). By far, the most common osteosarcoma is the so-called *classical* or *conventional high grade central* type which accounts for 90% of all osteosarcomas. The “grade” is a term used to indicate the level of aggressive growth and potential for metastasis, usually based on the appearance of the tumor under microscopic analysis. Several other unusual high grade types are the *telangiectatic*, *small cell*, and *secondary* (associated with another pre-existing disease such as Paget’s disease or prior radiation exposure).

There are low grade types of osteosarcoma, too. These include the *surface* or *juxtacortical low grade* osteosarcoma (also known as *parosteal* osteosarcoma), and low grade central osteosarcoma. For the most part, osteosarcoma can be divided into two groups for the purposes of treatment and management: high grade and low grade. Most, but not all, tumors arising from the central or medullary portion of the bone are high grade; most, but not all, tumors arising from the surface of the bone are low grade.

**What is the Cause of Osteosarcoma, and Why Does One Have This Rare Cancer?**

In most instances, osteosarcoma is not caused by any previous behavioral, dietary, environmental, or genetic factors. It is a random event, and there is no predisposing factor or decision that a patient, parent, or other family member could have made that would have had any bearing on the tumor’s development. No patient or parent should believe that they

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<th>Table 1</th>
<th>World Health Organization Classification of Osteosarcoma [Schajowicz, 1993]</th>
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<tr>
<td><strong>Osteosarcoma</strong></td>
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<tr>
<td>A. Conventional central (medullary)</td>
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<tr>
<td>1. Chondroblastic</td>
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<td>2. Fibroblastic</td>
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<td>3. Osteoblastic</td>
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<td>B. Telangiectatic</td>
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<td>C. Small cell</td>
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<tr>
<td>D. Low grade central</td>
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<tr>
<td>E. Secondary</td>
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<tr>
<td>F. Surface</td>
<td></td>
</tr>
<tr>
<td>1. Parosteal</td>
<td></td>
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<tr>
<td>2. Periosteal</td>
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<td>G. High grade surface</td>
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are in any way responsible for the existence of the tumor. In some very rare cases, there is a genetic link to the disease (see below).

**Is it Genetic, and Should Immediate Family Members Be Concerned About Having the Tumor Too?**

There are two instances in which there is a known genetic link for osteosarcoma. An eye tumor known as retinoblastoma is associated with a mutation of a gene that also is associated with osteosarcoma. Additionally, the Li-Fraumeni syndrome is characterized by an osteosarcoma occurring in one family member in conjunction with a higher prevalence of breast cancer and other types of sarcomas in other family members. Again, a gene mutation is associated with this syndrome. For this reason, any family history of cancers should be mentioned to a treating physician.

**Signs or Symptoms Suggestive of the Tumor, and Establishing the Diagnosis**

There are no particular signs or symptoms that herald the onset of this cancer. Although patients usually will have pain and subsequent swelling of a body part, some patients do not have pain and notice only the swelling. An injury may direct attention to a particular body part, but usually the tumor precedes the injury. If the tumor has eroded enough bone to reduce its structural integrity, a fracture may occur with only a slight amount of force applied to the bone. A fracture may compromise treatment, so any patient experiencing pain with weight-bearing (lower extremities) or lifting (upper extremities) should notify their physician immediately, so that appropriate steps can be taken to minimize the risk for a fracture. The tumor’s presence is seen on x-rays most commonly, and x-rays are the best screening tool for this tumor. Additional complementary information is gained from magnetic resonance imaging (MRI), which defines the extent of the tumor and its relationship to surrounding anatomic structures much more clearly, creating a so-called anatomic “map.” Other tests that might be performed on newly diagnosed patients are bone scans, positron emission tomography (PET) scans, and various blood tests, which would look at how actively the body is making or remodeling bone tissue.

Once a tumor is suspected based on imaging tests, a tissue sampling (biopsy) is necessary before embarking upon a treatment plan. The appearance of the tumor cells under the microscope is characteristic in most cases, but other tests can help establish the diagnosis by ruling out other types of tumors. Some of these other tumors’ microscopic appearance may resemble osteosarcoma, so diagnosing this tumor is greatly facilitated by viewing the imaging studies. Having experts in pathology, radiology, and orthopaedic surgery work together as a team is the best way to make an accurate diagnosis.
Treatment of Osteosarcoma

In the U.S. and in many other developed countries, most patients are enrolled in various clinical trials or protocols established by national experts in osteosarcoma. Nearly all major cancer centers work together, participating in cooperative groups that gather experts together to design, modify, and implement protocols. This collaboration enables doctors and researchers to collect meaningful information about how to make sarcoma treatments more effective and improves their chance of success.

For classical, high grade, conventional osteosarcoma (and other high grade types), most major cancer centers will recommend initial treatment with systemic multi-agent chemotherapy for a period of several months. This would be followed by surgical excision with limb reconstruction or amputation, as appropriate. Chemotherapy would then resume as soon as the surgical incision has healed sufficiently—usually around 2 weeks post-operatively—and would continue for many more months. The chemotherapy is given in cycles with various combinations of drugs during each cycle. The most commonly used drugs effective against osteosarcoma are adriamycin, ifosfamide, cis-platin, methotrexate, and etoposide. The response to the chemotherapy is closely observed using various tests and scans. Frequently, patients wonder why the tumor isn’t removed immediately—why chemotherapy is given first, before surgical removal. Administering chemotherapy prior to surgery theoretically stops the growth of microscopic deposits of tumor cells elsewhere in the body that are undetectable, despite the most powerful scanners. In addition, if chemotherapy shrinks the tumor, the surgery is greatly facilitated.

For surface osteosarcoma (and other low grade types), chemotherapy is generally not advisable, and instead surgical excision is performed, with reconstruction of the remaining extremity after bone or joint loss. Various types of bone grafts, prosthetic implants, or a combination of the two are employed in the reconstruction process. In general, radiation is not considered an effective treatment against an osteosarcoma in the usual doses given to patients.

Does Removal of the Tumor Require an Amputation?

Decades ago, amputations were much more commonly needed as a means of eradicating the main tumor. Today, however, most extremities are preserved after removing the tumor and reconstructing the remaining limb. The tumor removal involves resecting the tumor with a layer of normal tissue surrounding it (wide local excision) so that the wound is not exposed or contaminated with tumor cells as it is gradually taken out. To the extent possible, the nerve and major blood vessels will be preserved, as long as that does not compromise adequate removal of the tumor. Reconstruction of the joint defect is done with specialized
artificial joint prostheses. Bone is reconstructed with either a structural bone graft or a prosthetic implant. Soft tissue and muscle function restoration, at times, requires tendon reattachment. Major arteries can successfully be reconstructed using either autogenous vein grafts or a tube made of Gore-Tex® material. The primary goal of limb salvage surgery is complete removal of the tumor and, secondarily, reconstruction to restore normal function to the greatest extent possible.

Patients with lower extremity tumors who have yet to go through their growth spurt present an unusually challenging situation. In these cases, the growing limb can either be reconstructed with an expanding type of prosthesis, or the opposite limb can be shortened slightly. Additionally, an unusual surgery can be performed that removes the tumor and knee, but uses the healthy lower ankle to function as a knee by rotating the remaining limb 180 degrees and transporting the ankle to the knee level (Van Ness rotationplasty).

Adults or youth considering amputation as an option may find the information provided in the RIS-funded videos on this subject helpful. Visit: http://www.reininsarcoma.org/what-is-sarcoma-2/bone-sarcomas/video-for-cancer-patients-facing-amputation/

How Effective are the Treatments for Osteosarcoma and What is the Prognosis?
At nearly all major cancer centers, patients have a 65-75% chance of being free of osteosarcoma cells five years after the diagnosis of an osteosarcoma that had not metastasized. The response to chemotherapy is one of the most important predictive factors of outcome. This response can be assessed by using x-rays and scans, but the percentage of tumor cells killed by the chemotherapy, analyzed microscopically, is a more important determinant.

The functional outcome of treatment depends heavily on where within the bone the tumor began, and which structures must be sacrificed in order to completely remove the tumor. Most types of reconstruction with limb salvage procedures will allow a gait independent of any aids, but strenuous athletic activity is discouraged. Any type of reconstruction will have limited durability and lifespan. Device failure through loosening, breakage, infection, or fracture of the bone around the implant may result in a series of operations being done during the course of a patient’s lifetime.

Summary
Osteosarcoma is a rare and challenging cancer to treat, considering the multiple different types of the cancer and the functional consequences of partially losing a major bone or joint. Fortunately, a multidisciplinary team approach—along with biological, surgical, and
technological advances—has resulted in the majority of patients surviving their cancer and the majority of limbs being preserved.

**Pleomorphic Undifferentiated Sarcoma, Formerly Malignant Fibrous Histiocytoma (MFH)**
This is a very rare type of bone cancer that occurs in adults. It is usually found in the arms and legs, especially around the knee joint.

**Primitive Neuroectodermal Tumor (“PNET”)** (see Ewing’s Sarcoma, page 16)

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The Sarcoma Alliance

Amschwand Sarcoma Cancer Foundation

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SECTION II: RECOMMENDATIONS FOR THE NEWLY DIAGNOSED SARCOMA PATIENT

Here are some key suggestions for those newly diagnosed with sarcoma cancer. Additional information can be found in the New Patient Checklist on the Rein in Sarcoma (RIS) website at [www.reininsarcoma.org](http://www.reininsarcoma.org) and in the Resources Section of this Notebook (Section V).

(1) **Research doctors, hospitals, and targeted cancer centers.** Seek an opinion from a sarcoma center or doctor who has considerable experience treating sarcoma cancers. Sarcoma can be very different from other cancers in how it responds to treatment; therefore, it is wise to seek the opinion of someone who is experienced in treating this specific form of cancer. Consider visiting a National Cancer Institute Cancer Center or a surgeon from the Musculoskeletal Tumor Society ([http://msts.org/directory/search.aspx?directory=public](http://msts.org/directory/search.aspx?directory=public)). See Section V, page 3 for detailed listings.

Do not assume that your doctor knows sarcoma. Many well-qualified oncologists have never treated a patient diagnosed with sarcoma. Ask your doctor how many sarcoma patients s/he has treated throughout his/her practice and within the last year. If you or a loved one has been diagnosed with sarcoma, please seek a specialist who sees a number of sarcoma patients each month.

(2) **If a sarcoma specialist is not available in your area** and travel is out of the question, ask your doctor to consult with a sarcoma specialist elsewhere. Often, treatment can be administered by your hometown oncologist with guidance from a sarcoma center.

(3) **Find a personal advocate** or someone whom you trust to carry out your wishes and provide emotional support for you throughout your treatment. This can be a friend, loved one, or co-worker. It is also strongly suggested that if possible, this person be willing to act as your
medical advocate or defender, in the event you are unable to make your own case. Share your feelings with this person. If you are ill or upset, it can be helpful to have someone with you during meetings with your doctor to remember exactly what was said. Having this person serve as your “secretary” by taking notes during meetings with your healthcare providers can help ensure that valuable information is not lost.

(4) **Research sarcoma cancers and the particular sarcoma** you have been diagnosed with. Start by visiting the **University of Minnesota Physicians** Sarcoma Information pages: [http://www.umphysicians.org/cancercare/cancer-information/bone-soft-tissue-cancers/index.htm](http://www.umphysicians.org/cancercare/cancer-information/bone-soft-tissue-cancers/index.htm). This site serves as an educational tool for both physicians and patients. It is designed to provide current information about sarcomas for patients and their families following a diagnosis or presumptive diagnosis of sarcoma. The University of Minnesota has been a national and international leader in basic science, clinical research, and advances in the treatment of bone and soft tissue tumors. The information compiled on this site is derived from the interdisciplinary tumor team at the University of Minnesota. The Sarcoma Information Center is funded and sponsored in part by the Rein in Sarcoma (RIS) Foundation.


In addition, the RIS website ([www.reinsarcoma.org](http://www.reinsarcoma.org)) contains extensive information about sarcomas, along with information about local and national sarcoma resources and allied organizations.

(5) **Join the Rein in Sarcoma Foundation Support Network.**

The Network is designed to provide resources and support for sarcoma patients, survivors, and loved ones in the Upper Midwest. You will also be sent updates on RIS support events. If you would like to talk with another sarcoma survivor in the area, please call Rein in Sarcoma at (844) SARCOMA (727-2662). Join through the RIS website ([www.reinsarcoma.org](http://www.reinsarcoma.org)) or use the form in the back of this Notebook.

(6) **Join and “Like” the Rein in Sarcoma Facebook Group and follow RIS on Twitter**

Join hundreds of others on Rein in Sarcoma’s Facebook page at: [https://www.facebook.com/reininsarcomafoundation](https://www.facebook.com/reininsarcomafoundation). This is a great way to meet others who may be on a sarcoma journey. You can also follow us and spread the word on Twitter: [https://twitter.com/ReininSarcoma1](https://twitter.com/ReininSarcoma1).
(7) **Get local support.** RIS hosts several events in the Twin Cities throughout the year to support sarcoma patients and their friends and families (see [www.reinsarcoma.org](http://www.reinsarcoma.org)). This includes RIS Gatherings for sarcoma patients, survivors, and loved ones, and a free annual *Sarcoma Family* picnic held in conjunction with the RIS “*Party in the Park*” event. The annual RIS event is normally held on a Monday evening late in July at Como Park in St. Paul.

Many sarcoma centers have sarcoma-specific support groups. Look into a sarcoma specific support group or explore more general cancer support groups in your community. Also, do not minimize the impact that an online support group may offer (especially for people in rural areas). There are also support groups for loved ones and parents of children with sarcoma.

(8) **CaringBridge**

Reach out to people—family, extended family, friends, and others—who may want to help. At the Caring Bridge website, you can create your own personalized page to connect with family and friends, keep people informed, receive messages of hope, and share your situation in a protected and respectful space. Through the site, you can also set up a Support Planner; this enables you to invite people to lend a hand, get help with chores and errands, coordinate care, and organize tasks. [http://www.caringbridge.org/](http://www.caringbridge.org/)

(9) **Peer to Peer Sarcoma Network**

The Sarcoma Alliance, based in San Francisco, has created the Peer to Peer Sarcoma Network to serve the entire country. The RIS Foundation is pleased to partner with the Sarcoma Alliance in promoting the Peer to Peer Network. Its mission is to facilitate positive relationships between individuals affected by sarcoma so that they can find emotional support, encouragement, and information. The Peer to Peer Network consists of individuals affected by sarcoma—survivors, caregivers and loved ones—who wish to correspond with others in the sarcoma community. The Sarcoma Alliance matches peers based on the specific needs of the individuals, and peers correspond on terms they each agree upon (415) 381-7236 ([www.sarcomaalliance.org](http://www.sarcomaalliance.org)).

(10) **ACOR (Association of Cancer Online Resources)**

Join the ACOR (Association of Cancer Online Resources) sarcoma LISTSERV and start a dialogue with other sarcoma patients, survivors, and family members. Share treatment options, diagnoses, helpful advice, and emotional support. Participation in this online email list is helpful...
and offered at no cost to you. If you are unable to join, ask a trusted friend to do so on your behalf (www.acor.org).

(11) Consider fertility options before treatment if possible. A sarcoma diagnosis often requires immediate action, and treatments can affect a patient's fertility. If fertility is important to you, bring it up with your doctor. Men's options include sperm banking. Proactive patients usually have time to arrange for this procedure before treatment begins. Women's options are more complex, but can still be discussed and considered. Some men and women regain fertility after treatment and go on to have healthy children.

(12) Research cancer-fighting diets and optional minerals and/or supplements. Be sure to discuss any options you are considering with your doctor or a dietician. Some supplements may adversely interact with treatment and/or medications.

(13) Read relevant books and videos: medical, science, support, inspirational, religious, spiritual, complementary (mind/body), informational, and dietary. For an extensive list, see the Resources section of the RIS website: http://www.reininsarcoma.org/resources-books.

*Use caution when seeking health information. Section V of this Notebook provides an abundance of good sources with Internet links. While the Internet and the library can be helpful sources of information, not all resources found will be accurate. Look for books, websites, and other resources endorsed or recommended by qualified professionals. If in question, ask your doctor, nurse, or social worker for an opinion.

**TIPS FOR INTERACTING WITH MEDICAL PROVIDERS**

(1) Prepare a written list of questions for your doctor or nurse prior to each meeting. It can be difficult to remember each question when emotions run high or after receiving news about your treatment’s progress. Write all of your medical appointments on a calendar. Keep a treatment schedule and a list of all the medications you are taking, along with the dosage, and keep this with your list of questions. Some patients start a binder with different sections for various information—calendar/schedule, medication list, test results, questions to ask, notes from appointments, etc. Bring it to all of your appointments. This will make it easier to refer back to information, if necessary, when talking with your doctor or nurse.

(2) Do not be intimidated or afraid to ask anything. Your doctor and the others on your healthcare team work for you. And you have a right to fully understand all of your treatment options and any potential side effects associated with your choices.
(3) **Ask for clarification on any tests or procedures that you do not understand.** “Are they necessary?” “How can this help me?” “What are the side effects?”

(4) **Get copies of your x-rays, scans, and test results.** Store them in a safe place so that you can refer back to them, if necessary, or bring them with you to seek a second opinion.

(5) **Do not assume that no news is good news.** Learn about your own health condition and treatment by asking your doctor and nurse and by using other reliable sources.

(6) **Share the RIS Foundation website** ([www.reininsarcoma.org](http://www.reininsarcoma.org)), its Red Flags of Sarcoma educational campaign ([http://www.reininsarcoma.org/redflags](http://www.reininsarcoma.org/redflags)), and other sites that you find to be helpful with your physician.

(7) **Stay involved in your treatment and be proactive.** Research shows that involved and engaged patients often feel better than those who take a more passive role.

8) **Remember that you have choices.** You have the right to choose your doctor, hospital, and course of treatment.

**MEMBERS OF YOUR MEDICAL TEAM**

You may encounter many different types of doctors, nurses, and other providers throughout the course of your treatments and surgeries. What do all those titles and/or letters after their names mean?

**Attending or Staff Physician** An attending physician is a physician who has completed residency and/or fellowship and practices medicine in a clinic or hospital, often focusing on the specialty learned during residency and/or fellowship. An attending physician also can supervise fellows, residents, and medical students. Legally, attending physicians have final responsibility for patient care, even when many of the minute-to-minute decisions are being made by subordinates (nurse practitioners, physician assistants, residents/fellow physicians, and medical students).

**Fellow Physician** Although their training is more advanced than that of residents, fellows usually continue to treat patients under the supervision of an attending physician—that is, one who has already completed a fellowship in the relevant subspecialty and is permitted to practice without direct supervision by other physicians. Fellows are undergoing additional training in their chosen specialty beyond their residency.
Resident Physician  Residency is a stage of postgraduate medical training and leads to eligibility for board certification in a primary care or referral specialty. It is filled by a resident physician who has received a medical degree (M.D. or D.O.) and focuses almost entirely on the care of hospitalized or clinic patients, mostly with direct supervision by more senior physicians.

Nurse Practitioner (NP)  A nurse practitioner is an advanced practice registered nurse who has completed additional training beyond that of a registered nurse. NPs can act as primary healthcare providers. The profession is state-regulated, and thus the scope of care varies from state to state.

Registered Nurse (RN)  An RN is a healthcare professional responsible for implementing the practice of nursing in concert with other healthcare professionals.

Licensed Practical Nurse (LPN)  An LPN can perform simple and complex medical procedures, but must operate under the supervision of a professional registered nurse (RN) or a physician.

Health Care Assistant (HCA) or Nursing Assistant (NA)  HCAs and NAs assist residents or patients with activities of daily living and provide bedside care, including basic nursing tasks. They work under the supervision of RNs and/or LPNs.

Medical Student  This is a person studying to become a medical doctor. Medical students often observe physicians as part of their medical training. Medical students are not licensed.

OTHER HEALTH CARE PROVIDERS YOU MAY ENCOUNTER

Physical Therapist (PT)  A PT is a healthcare professional who treats people with health-related conditions that limit their ability to move and perform activities in their daily lives. The minimum educational requirement is a master's degree, yet most educational programs now offer the doctor of physical therapy (DPT) degree. PTs are licensed by their state.

Occupational Therapist (OT)  An OT is a healthcare professional who helps people improve their ability to perform tasks in their daily living and working environments. They work with individuals who have conditions that are mentally, physically, developmentally, or emotionally disabling. They also help them to develop, recover, or maintain daily living and work skills. Currently, a bachelor’s degree in occupational therapy is the minimum requirement for entry into the field.

Audiologist  An audiologist is a healthcare professional who specializes in testing, monitoring, and diagnosing disorders of the auditory and vestibular systems of the ear. An audiologist diagnoses and treats hearing and balance problems. Audiologists have received an Au.D.
(Doctorate in Audiology), or a master's degree from an accredited university graduate or professional program in audiology. All states require licensure, and audiologists may also carry national board certification.

**Speech-Language Pathologist (SLP)** An SLP is a healthcare professional involved with the prevention, diagnosis, habilitation, and rehabilitation of communication, swallowing, or other upper aero digestive disorders. These professionals work to modify and enhance communication behaviors. The minimum educational requirement is a master's degree. SLPs are licensed by their state.
SECTION III: TAKING CONTROL

BEING PROACTIVE

Being a Proactive Patient (Means Asking Questions). A proactive patient is one who has dedicated himself/herself to surviving sarcoma. You may have many questions regarding sarcoma and your treatment. In order to get the most out of your appointments, this section suggests ways to prepare yourself for each health visit, establish a rapport with your healthcare team, and develop a system or identify a person to assist you in taking notes.

Be prepared. If possible before your appointment, do some research or have a loved one do it for you. The more you know, the more likely you will be able to ask targeted questions about your specific needs. This will also show your physician that you are committed to learning as much as you can about your disease and its treatment. In the Resources section (Section V) of this Notebook, you will find resources to aid in your learning process.

Establish a rapport. It is important from the onset to establish a positive relationship with your physician and healthcare team. Keep in mind that good teams communicate well. Your doctor will have questions for you, and likewise you will have questions for him/her, too. This is a part of having a healthy rapport.

It is important to note, however, that while your doctor inherently wants to answer your questions, s/he likely has time constraints and limitations. Focus your questions and start with the most important ones first. Remember that each member of your healthcare team may be a resource for different topics. While you have a right to have all of your questions answered, numerous or repetitive questions might irritate some doctors. Keep in mind that your doctor has many patients who need his/her time and attention. Also remember that each doctor has a different style. If one style does not work for you after a few encounters, you may consider changing to a doctor whose communication style is more in line with your own. Once you find a good fit, make yourself known as a person, not just as a patient, to your doctor. Show him/her a photograph of your children, parents, siblings, nieces, nephews, or pets. Introduce him or her to your caregivers.
Take notes. The log sheets at the end of this Notebook (Section VIII, pages 3-4) will assist you in organizing your contact information. The Physician/Nurse Encounter Log (Section VIII, pages 5-8) is a good place to write down questions, responses, and notes. Make sure to include dates on all your entries, along with the names of the physician and nurse answering your questions. This will make up an important history to which you can refer later.

Bring a support person. Sometimes it can be difficult trying to listen, ask questions, and take notes at the same time. This can be particularly difficult during a stressful visit with the doctor. Consider bringing a trusted friend, family member, or other support person to your appointments. 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. Make sure this person knows in advance what his/her role will be during each visit.

SURVIVORSHIP CARE PLANNING

A report by the Institute of Medicine (IOM), From Cancer Patient to Cancer Survivor: Lost in Transition, recommends that each cancer patient receive a "survivorship care plan." Such a plan should summarize information critical to the individual's long-term care, such as the cancer diagnosis, treatment, and potential consequences; the timing and content of follow-up visits; tips on maintaining a healthy lifestyle and preventing recurrent or new cancers; legal rights affecting employment and insurance; and the availability of psychological and support services.

If you are newly diagnosed, a written treatment plan will enable you to work with your doctor to both determine the best treatment and develop ways to handle side effects and potential late effects. It also will be useful in coordinating your overall care. Upon completing treatment, you should request a formal consultation with your doctor and ask him/her for a Cancer Care Summary (a summary of your diagnosis and treatment) and a Survivorship Care Plan (a plan for follow-up care after primary cancer treatment).

Your Cancer Care Summary and Survivorship Care Plan should include, but are not limited to:

• Your cancer diagnosis, treatments received (including names of the drugs and dosages), and the potential known long-term effects;

• Specific information about the timing and content of recommended follow-up (for example, screening tests for recurrences and/or secondary cancers, follow-up visits with your oncologist, etc.);

• Recommendations about preventative practices and how to maintain health and well-being (for example, nutrition, exercise, and emotional support);
• Information on employment rights as a cancer survivor and access to health insurance; and
• Availability of emotional support services in the local community.

During the consultation, ask your doctor and/or nurse to explain the Cancer Care Summary and Survivorship Care Plan to you. It is important that you understand both plans. You should keep the plans in a safe place where you store other important personal documents and provide copies to all other healthcare providers who examine you in the months and years to come.

**Institute of Medicine Survivorship Planning Guide**


**LIVESTRONG Care Plan**

This free and easy-to-use program provides adult cancer survivors with information regarding the health risks they face as a result of cancer therapies. The good news for cancer survivorship is that the numbers are growing, with an estimated 12 million survivors living in the U.S. today. Unfortunately, cancer treatments are not without consequences, and many survivors are dealing with the long-term effects of treatments with little guidance. The Institute of Medicine (IOM) researched the state of care for cancer survivors and found that little support is available for survivors and healthcare providers in dealing with the medical and psychosocial problems that may arise post-treatment. The Livestrong Care plan is a program provided by the University of Pennsylvania and its OncoLink service [http://www.livestrongcareplan.org/](http://www.livestrongcareplan.org/).

**CureSearch for Children’s Cancer**

The Children's Oncology Group website, Cure Search, ([http://www.curesearch.org/](http://www.curesearch.org/)) is a wonderful resource for survivors of childhood cancers. In addition, childhood cancer survivors should encourage your healthcare team to review the extensive [guidelines for long-term care](http://www.survivorshipguidelines.org/) developed by the Children's Oncology Group.

**Long-Term Follow-up Clinic, University of Minnesota Physicians Cancer Care**

Today, there are more cancer survivors than ever before, thanks to early diagnosis and extraordinary treatment options. As you come through cancer diagnosis and treatment, you may have questions about your follow-up care and the side effects of treatment, both physical and emotional. The Long-Term Follow-Up Clinic at the University of Minnesota...
Medical Center, provides care to survivors of childhood and adult cancers. 
https://www.mhealth.org/care/services/cancer-survivor-program-adult

Annual Cancer Survivorship Conference – Minneapolis
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. RIS regularly promotes the program on our website and through our electronic newsletter, RIS Update.

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 or phone (651) 201-3608.

Cancer Survival Toolbox®
The Cancer Survival Toolbox is a free, self-learning audio program that has been developed by leading cancer organizations. It 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. (See http://www.canceradvocacy.org/toolbox/).

MEDICAL HISTORY
You will be asked to recount your medical history often. Important information that should be included in your medical history includes:

- Childhood illnesses;
- Traumas and injuries (broken bones, car accidents);
- History of medication use and any allergic reactions;
- Onset of menstrual period, menopause, or pre/post menopause;
- Allergies; and
- Your family’s medical history (illnesses of your blood relatives).

MEDICAL RECORDS
It is important for each of your care providers to have a complete copy of your medical record. In fact, if you are at the center of your care team, then it likely makes sense for you to have one, too. Throughout the course of your treatment, you or your support person and your doctors may refer back to parts of your medical record. It is recommended that you always ask for copies of lab values, results, tests, and other impressions as they are added to
your record. The average cancer patient can accumulate a thick medical record in a very short period of time.

Building your own “shadow” record (See Section VIII pages 13-14 for help) as your official hospital or clinic record grows makes a great deal of sense. Log sheets found in the back of this Notebook (Section VIII – Pages 5-7) will assist you in organizing and remembering your contacts with physicians and nurses.

Get in the habit of asking for copies of additions to your medical record before you leave each appointment. Then keep the most recent information in this section for easy reference when you or a specialist needs it in the future.

For more information and great resources about setting your own portable and personal medical records, see Section VIII, pages 13-14 of this Notebook.

MEDICINES AND COMPLEMENTARY MEDICINES

It is imperative that you keep detailed records of your medicines and complementary therapies, including vitamins, supplements, and herbs. High dosages of certain vitamins may have an adverse reaction when taken with certain medications. In addition, certain medications should not be taken together. A detailed record may assist physicians and pharmacists in devising your treatment plan.

The log sheets found in the back of this Notebook (Section VIII, pages 9-10) will assist you in organizing your medications. It may also be helpful to keep the pharmacy disclaimers and prescription information following the log sheet in your Notebook for future reference, should you, your loved one, or your healthcare team need the information later.

PERSONAL SUPPORT NETWORK

As a patient or caregiver, friends and family will often ask you what they can do to help. This section will help you to organize your personal support network.

Establish a Network Coordinator. Your network coordinator will be the main person your friends and family will contact to assist you. The network coordinator will also be the person who delivers patient information. The patient must establish boundaries regarding the amount of information they want to share. People will not know what you want or are comfortable sharing unless you tell them. Recognize that people who care about you may ask for more than you want to share. Your network coordinator can politely but firmly let
them know. Set expectations early by letting people know that you may be unable to return phone calls or e-mail during this difficult time. Your network coordinator will also be helpful in this area.

**Delegate tasks.** Remember that you do not have to personally do everything. You or your network coordinator can delegate non-essential tasks to others who want to help in some way. Keep a “honey do” list of things you need done (or may need done in the future). Some examples may be:

- Doing the laundry;
- Taking out the trash;
- Bringing dinner to the family on certain nights or coordinating Meals on Wheels;
- Going to the post office; and/or
- Picking up the dry cleaning.

If someone asks what s/he can do to help, you will have a list prepared to delegate the task. Remember that by delegating a task to a friend or other family member, you are allowing that person to feel good about contributing to your recovery.

In the back of this Notebook (Section VIII, pages 15 and 16), you will find sheets that will help you keep track of the various tasks you may choose to delegate, to whom they have been delegated, and when.
SECTION IV:
DOING YOUR OWN RESEARCH

Studies have shown that it is beneficial for patients to remain involved and proactive in their treatment. One way to be proactive is to learn as much as possible about sarcoma and, more specifically, to learn about the latest research being conducted concerning your particular sarcoma. The Internet is a wonderful tool in finding this kind of information, but at times it can be confusing and overwhelming. Also, one should be aware that there is a certain amount of inaccurate information on the Internet. Always keep that in mind and consider the source of the information you are reading, as there might be some bias to the content.

There are several sites that provide search tools that look for high quality, reliable medical articles on different cancers. Prior to beginning your search, it is helpful to identify keywords and alternatives to use in a search. Keep in mind that neoplasm and malignancy are just other terms for cancer, so perhaps use those words if you do not get search results using cancer or sarcoma. Search engines utilize Boolean logic (AND, OR, NOT) to refine searches. For instance, you might input “angiosarcoma AND chemotherapy” to further refine your desired search results. To help you get started, detailed below are several trustworthy sites that provide searches for abstracts and citations about cancer research. It may be easier to find these resources found in Section V of this Notebook or through links found on the RIS website: http://reininsarcoma.org/resources.

National Library of Medicine

PubMed is a service of the U.S. National Library of Medicine and the National Institutes of Health; it includes over 24 million citations from MEDLINE and other life science journals for biomedical articles and dates back to 1948. PubMed includes links to full-text articles and other related resources.
PubMed’s tutorial is located at http://www.nlm.nih.gov/bsd/pubmed_tutorial/m1001.html. The tutorial provides a very helpful and thorough explanation of how to search for journal literature using this site. It explains how to limit your search for specific dates or languages and also discusses the site’s preview feature. This allows you to refine your search after you see how many entries appear.

**National Cancer Institute**
https://www.cancer.gov/

The National Cancer Institute’s website provides a search engine for its bibliographic database named Cancer Topics. This database is updated monthly and contains more than 1.8 million citations and abstracts from over 4,000 different sources, including biomedical journals, proceedings, books, reports, and doctoral theses. The search page for the database (http://www.cancer.gov/cancertopics) allows you to define your search by subject, publication type and/or year, and language.

**Soft Tissue Sarcoma** is one of the topics that has a prepared search page. Each edition of the prepared search includes only those citations new that month. The last six editions (the last six months) are included on the site. A section on soft tissue sarcoma can be found at: http://www.cancer.gov/cancertopics/types/soft-tissue-sarcoma.


**Telephone Assistance**
NCI also offers telephone assistance at 1-800-4-CANCER (or 1-800-422-6237). Telephone assistance is available in English and Spanish to answer cancer-related questions, Monday through Friday, from 8:30 am to 8:00 pm Eastern Time.

**LiveHelp**
The NCI’s website also offers live online assistance with its LiveHelp service at https://livehelp.cancer.gov/app/chat/chat_launch. NCI Information Specialists on LiveHelp can give you information about cancer from the National Cancer Institute. However, they are not healthcare providers and do not provide medical advice. LiveHelp is not a substitute for talking with a healthcare professional. LiveHelp users are anonymous. LiveHelp is available from 8:00 am to 11:00 pm Eastern Time. If you prefer to contact them in Spanish, please visit http://www.cancer.gov/espanol/global/contactenos.
Medscape
http://www.medscape.com/oncology

Medscape, now a part of WebMD, is a leading online destination used by physicians and other healthcare professionals for trusted, timely medical information that supports them at the point-of-care. Medscape offers free, unlimited access to a vast network of resources tailored to areas of specialization. These include in-depth medical news, CME/CE, full-text journal articles, conference coverage, peer-reviewed clinical research, expert commentary features, discussion forums, and more.

To access most of the information on this site, you will need to register; registration is free and only takes a minute. You may register as patient/consumer. Membership includes specialty-focused clinical newsletters and e-mail alerts on breaking news, plus selected information from the industry, tailored to areas of clinical practice from the WebMD Professional service.

Your search will create a Search Results page that has a citation for each relevant article. Clicking on the article title will allow you to view the abstract for that particular article. Above most of the abstracts are icons, which can be used to either purchase a hard copy of the complete article text or to view the text in full online.

You also can search Medscape’s DrugInfo database, which contains comprehensive drug information that is searchable by drug name or disease. Click on the “DrugInfo” tab.

ACOR & CancerLinks—Sarcoma Cancer
The ACOR website (http://www.acor.org/) is specially designed to make searching the World Wide Web for information about sarcoma cancer faster and easier. The heart of ACOR is a large collection of cancer-related Internet mailing lists, which delivers over 1.5 million e-mail messages each week to subscribers across the globe. In addition to supporting the mailing lists, ACOR develops and hosts state-of-the-art Internet-based knowledge systems that enable people to find and use credible information relevant to their illnesses.

Rein in Sarcoma Foundation (RIS)
http://www.reininsarcoma.org/
The newly redesigned Rein in Sarcoma website is designed to provide support and offer resources located not only here in the Upper Midwest, but across the country. You will learn more about sarcomas, courses of treatment, medical centers specializing in the treatment of sarcomas, and clinical trials, as well as about organizations and travel assistance.
From the home page (www.reininsarcoma.org) you can quickly get to the help you need.
From the “What is the Sarcoma?” banner at the top of the homepage or the “Sarcoma Cancer” block on the page you will find:

- Specific information on soft tissue and bone sarcomas with links to:
  - Current news
  - Treatment Options
  - Resource links
  - Clinical Research Studies—links to sites providing current information on sarcoma-related clinical trials
  - Sarcoma Cancer Treatment Centers (nationwide)
  - Cancer Treatment Centers (nationwide)

From the “Patients and Families” banner or the “Support” block on the home page you will find:

- A new Patient Checklist
- Financial and Travel Assistance
- Legal Assistance
- Housing services during treatment
- Local and national support resources
- Resources for Caregivers
- Sarcoma Patient Support and Research Organizations (nationwide)
- Nutrition
- Sarcoma Survivor Stories
- Additional resources

Under the Get Involved banner and Latest News and Events block on the home page you will find:

- Volunteer Opportunities
- The RIS Events Calendar
- Latest information on current RIS support activities and programs
- Ways to donate and support Rein in Sarcoma
- You also can download the latest copy of the RIS Sarcoma Patient Notebook from the www.reininsarcoma.org home page.

Rein in Sarcoma Foundation Support Network Registration

Sign up on the website to receive our monthly RIS Update and additional information about RIS, including support activities for sarcoma patients and loved ones. Or use the printed registration form found in Section VIII of this Notebook.
Most Current Sarcoma Information
RIS provides a primary sarcoma aggregator of RSS feeds. This provides the latest news on many types of sarcomas and can be found on the Rein in Sarcoma website under “current sarcoma news”. RSS stands for Really Simple Syndication and is a technology used to simply publish and gather details of the very latest information on the Internet.

General Research
Be aware that through these general search engines, there will be little or no filtering of credible sites for sarcoma information.

Research – Anything!
www.refdesk.com/index.html

Dogpile
http://www.dogpile.com/
This is a meta search engine, meaning that it gets results from multiple search engines and directories and then presents them combined to the user. Dogpile currently gets its results from Google, Yahoo, MSN Search, Ask, About, MIVA, LookSmart, and more.

Yahoo and GoodSearch
If you use the Yahoo search engine, you might consider using it through GoodSearch. GoodSearch.com is a new Yahoo-powered search engine that donates half its advertising revenue, about a penny per search, to the charities its users designate—including Rein in Sarcoma. Use it just as you would any search engine and watch the pennies add up! To learn more, go to:
http://www.goodsearch.com/causes/search?utf8=%E2%9C%93&cause_query=Rein+in+Sarcoma&button

Google
Yes, there also is Google! While Google has become the largest and most accepted universal search engine, the content of Google is not generally filtered for accuracy, timeliness, or access.

Hopefully you will find these sites, and the information that they contain, helpful in your search for relevant sarcoma research and information. Be certain to share and discuss your findings with your doctor and other members of your healthcare team.

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SECTION V: RESOURCES

The speed at which information is exchanged on the Internet makes it impossible for us to guarantee that the sites listed below are still operational. If you discover that a link or site is no longer accurate, please let us know. Additionally, if you find a site that is particularly helpful, we would love to list it for others. All of the sites below and others can be reached through the Rein in Sarcoma website at www.reininsarcoma.org. If you know of additional helpful sites or have corrected updates on sites listed, please email info@reininsarcoma.org with suggestions and/or corrections.

ONLINE RESOURCES: SARCOMA INFORMATION & RESOURCES

National Cancer Institute: Sarcoma Resources
This site produces current aggregated results about sarcoma from the National Cancer Institute (NCI), the primary source of credible cancer information in this country.

http://www.cancer.gov/cancertopics/types/soft-tissue-sarcoma
The portal for soft tissue sarcoma on the NCI website.

http://www.cancer.gov/cancertopics/types/bone
The portal for bone sarcoma on the NCI website.

Sarcoma Cancer Links
www.acor.org/
The Association of Cancer Online Resources (ACOR) is a free online lifeline for everyone affected by cancer and related disorders. The heart of ACOR is a large collection of cancer-related Internet mailing lists, which delivers over a million e-mail messages weekly to subscribers across the globe. In addition to supporting the mailing lists, ACOR develops and
hosts state-of-the-art Internet-based knowledge systems that allow the public to find and use credible information relevant to their illnesses.

**Cancer.Net** – of the American Society of Clinical Oncology (ASCO)

[www.cancer.net](http://www.cancer.net)

Cancer.Net provides timely, oncologist-approved information to help patients and families make informed health care decisions. All content is subject to a formal peer-review process by the [Cancer.Net Editorial Board](http://www.cancer.net), composed of more than 150 medical, surgical, radiation, and pediatric oncologists, physician assistants, oncology nurses, social workers, and patient advocates. In addition, ASCO editorial staff reviews the content for easy readability. Cancer.Net content is reviewed on an annual and as-needed basis.


Sarcoma of specific organs: [http://www.cancer.net/cancer-types/sarcomas-specific-organs](http://www.cancer.net/cancer-types/sarcomas-specific-organs)


Find a Sarcoma Doctor: [http://www.cancer.net/find-cancer-doctor](http://www.cancer.net/find-cancer-doctor)

**Sarcoma and Bone Cancer Treatment Center**


The Center for Sarcoma and Bone Oncology at Dana Farber Cancer Institute in Boston has dedicated specialty expertise in the pathologic and radiologic assessment of sarcoma and in the application of novel soft tissue and bone reconstructive techniques. It offers access to the most promising new therapies. Dr. George Demetri, a physician at the Dana Farber Cancer Institute, is active in supporting this site.

**National Comprehensive Cancer Network (NCCN)**


The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 26 of the world's leading cancer centers, is dedicated to improving the quality, effectiveness, and efficiency of care provided to patients with cancer. For patients: [http://www.nccn.org/patients/](http://www.nccn.org/patients/)

NCCN Guidelines for Patients: Soft Tissue Sarcoma:


**Bone Tumor.org**

[http://bonetumor.org/](http://bonetumor.org/)

This is an extensive and comprehensive site on bone tumors, including bone sarcomas.
The Liddy Shriver Sarcoma Initiative
http://sarcomahelp.org/
Although The Liddy Shriver Sarcoma Initiative ceased operation at the end of 2014, its website remains—providing in-depth articles on various aspects of sarcoma.

OncoLink
http://www.oncolink.com/
OncoLink is a service of the Abramson Cancer Center of the University of Pennsylvania.
Bone Sarcoma:
http://www.oncolink.com/types/article.cfm?c=17&s=80&ss=817&id=9533
Soft Tissue Sarcoma:
http://www.oncolink.com/types/article.cfm?c=17&s=58&ss=811&id=9532

Rein in Sarcoma Foundation
www.reininsarcoma.org
Sarcoma Cancer Resources: Listings of local, national, and International resources; RSS aggregate feed of latest sarcoma research.

Find a Sarcoma Surgeon
Musculoskeletal Tumor Society’s mission is to advance the science of orthopaedic oncology and promote high standards of patient care. The Musculoskeletal Tumor Society is the recognized authority on all aspects of orthopaedic oncology and is an influential participant in policy-making for oncology services. Its website is patient-oriented with educational resources and a searchable orthopaedic oncology directory. Locate a sarcoma surgeon by city, state, and country.

Sarcoma Patients EuroNet Association (SPAEN)
http://www.sarcoma-patients.eu/
The International Network of Sarcoma, GIST, and Desmoid Patient Advocacy Groups was founded in 2009 with the aim of extending information services, patient support, and advocacy to patient organizations for the benefit of sarcoma patients across Europe. SPAEN has strong relationships with pharmaceutical companies.
NCI NATIONAL CANCER CENTERS & SARCOMA CANCER TREATMENT CENTERS

If you or a loved one has been diagnosed with sarcoma, please seek a specialist who sees a number of sarcoma patients each month. Consider visiting an NCI Cancer Center or a surgeon from the Musculoskeletal Tumor Society. The following is a list of medical centers the National Cancer Institute (NCI) has designated as Cancer Centers as of November 2016. This information is available with links and updated information in the Patients & Families Section of the Rein In Sarcoma website. Hospitals specializing in sarcoma are also listed.

The Sarcoma Alliance is another source for locating sarcoma specialist centers. This website provides comprehensive listings based on sarcoma cancer treatments.  
http://sarcomaalliance.org/sarcoma-centers/

We hope the following list makes finding a specialist easier to accomplish. For a comprehensive listing of NCI designated cancer centers, visit:  
http://cancercenters.cancer.gov/Center/CCList

ALABAMA

UAB Comprehensive Cancer Center  
University of Alabama at Birmingham  
Edward E. Partridge, M.D. Director  
1824 Sixth Avenue South  
Birmingham, Alabama 35294  
Main: (205) 975-8222  
Toll Free: 1-800-822-0933 (1-800-UAB-0933)

ARIZONA

Arizona Cancer Center  
University of Arizona  
Andrew S. Kraft, M.D. Director  
1515 North Campbell Avenue  
Tucson, Arizona 85724  
Administration: (520) 626-2548  
Patient Care/Appointments: 1-800-524-5928; (520) 694-2873 (694-CURE)  
http://azcc.arizona.edu/research/clinical-trials/teams/melanoma-sarcoma
**Institution designated Sarcoma Cancer Center by the Sarcoma Alliance**

### CALIFORNIA

<table>
<thead>
<tr>
<th>Institution</th>
<th>Director</th>
<th>Address</th>
<th>Phone Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chao Family Comprehensive Cancer Center</strong></td>
<td>Richard Van Etten, M.D., Ph.D.</td>
<td>101 The City Drive, Building 56, R. 81, Room 216L, Orange, California 92868</td>
<td>Appointments: (714) 456-8000, Physician Referral Service: 1-877-824-3627</td>
</tr>
<tr>
<td><strong>City of Hope Comprehensive Cancer Center</strong></td>
<td>Steve Rosen, M.D., FACP</td>
<td>1500 East Duarte Road, Duarte, California 91010</td>
<td>Main: (626) 256-4673, New Patient Services: 1-800-826-4673</td>
</tr>
<tr>
<td><strong>Jonsson Comprehensive Cancer Center</strong></td>
<td>Kenneth Dorshkind, Ph.D.</td>
<td>10833 Le Conte Avenue, Los Angeles, California 90095</td>
<td>Administrative Office: (310) 825-5268, UCLA Cancer Hotline: 1-888-662-8252</td>
</tr>
<tr>
<td><strong>Salk Institute Cancer Center</strong></td>
<td>Tony Hunter, Ph.D.</td>
<td>10010 North Torrey Pines Road, La Jolla, California 92037</td>
<td>Main: (858) 453-4100</td>
</tr>
<tr>
<td><strong>Sanford Burnham Prebys Medical Discovery Institute</strong></td>
<td>Garth Powis, Ph.D.</td>
<td>La Jolla, California 92037</td>
<td>Main: (858) 646-3100</td>
</tr>
<tr>
<td><strong>Stanford Cancer Institute</strong></td>
<td>Beverly S. Mitchell, M.D.</td>
<td>265 Campus Drive, Suite G2103, Stanford, California 94305</td>
<td>Referral Center: (650) 498-6000, Toll Free: 1-877-668-7535</td>
</tr>
<tr>
<td><strong>UC Davis Comprehensive Cancer Center</strong></td>
<td>Primo N. Lara, J., M.D.</td>
<td>4501 X Street, Suite 3003, Sacramento, California 95817</td>
<td></td>
</tr>
<tr>
<td><strong>UC San Diego Moores Cancer Center</strong></td>
<td>Scott M. Lippman, M.D.</td>
<td>3855 Health Sciences Drive, La Jolla, California 92093</td>
<td></td>
</tr>
</tbody>
</table>
**COLORADO**

**University of Colorado Cancer Center**
Dan Theodorescu, M.D., Ph.D. Director
13001 East 17th Place
Aurora, Colorado 80045
Adult Cancer Care: (720) 848-0300
Pediatric Cancer Care: (720) 777-6688
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

**CONNECTICUT**

**Yale Cancer Center**
Yale University School of Medicine
Peter G. Schulam, MD, PhD
Interim Director
333 Cedar Street Box 208028
New Haven, Connecticut
Patient Care: (203) 785-4191
Toll Free: 1-866-925-3226 (1-866-YALECANCER)

<table>
<thead>
<tr>
<th>New Patient Referral Office: (916) 703-5210</th>
<th>Appointments: (858) 822-6100</th>
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<tbody>
<tr>
<td>General Information: (916) 734-5959</td>
<td>General Information: 1-866-773-2703</td>
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<td><em>Institution designated Sarcoma Cancer Center by the Sarcoma Alliance</em></td>
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<table>
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<tr>
<th><strong>UCSF Helen Diller Family Comprehensive Cancer Center</strong></th>
<th><strong>USC Norris Comprehensive Cancer Center</strong></th>
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<tr>
<td>University of California at San Francisco</td>
<td>University of Southern California</td>
</tr>
<tr>
<td>Alan Ashworth, Ph.D., FRS Director</td>
<td>Stephen Gruber, M.D., Ph.D., M.P.H. Director</td>
</tr>
<tr>
<td>1450 3rd Street, Box 0128</td>
<td>1441 Eastlake Avenue</td>
</tr>
<tr>
<td>San Francisco, California 94115</td>
<td>Los Angeles, California 90089</td>
</tr>
<tr>
<td>Appointments &amp; Physician Referral Service::</td>
<td>General Information: (323) 865-3000</td>
</tr>
<tr>
<td>1-888-689-8273</td>
<td>Toll Free: 1-800-872-2273 (1-800-USC-CARE)</td>
</tr>
<tr>
<td>International Inquiries: 415-353-8489</td>
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<td><em>Institution designated Sarcoma Cancer Center by the Sarcoma Alliance</em></td>
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</table>

*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*
FLORIDA

Moffitt Cancer Center
Thomas Sellers, Ph.D., M.P.H. Center Director, Executive Vice President
12902 Magnolia Drive MCC-CEO
Tampa, Florida 33612
Main: (813) 745-4673 (813-745-HOPE)
New Patient/Physician Referral: 1-888-860-2778
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

GEORGIA

Winship Cancer Institute
Emory University
Walter J. Curran, M.D. Executive Director
1365C Clifton Road
Atlanta, Georgia 30322
Main: (404) 778-1900
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

HAWAII

University of Hawaii Cancer Center
Jerris R. Hedges M.D, MS, MMM Interim Director
701 Ilalo Street, Suite 600
Honolulu, Hawaii 96813
Main: (808) 586-3010

ILLINOIS

<table>
<thead>
<tr>
<th>Robert H. Lurie Comprehensive Cancer Center</th>
<th>The University of Chicago Comprehensive Cancer Center</th>
</tr>
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<tbody>
<tr>
<td>Northwestern University</td>
<td>Michelle M. Le Beau, Ph.D. Director</td>
</tr>
<tr>
<td>Leonidas Platanias M.D., Ph.D. Director</td>
<td>5841 South Maryland Avenue MC1140</td>
</tr>
<tr>
<td>303 East Superior Street</td>
<td>Chicago, Illinois 60637</td>
</tr>
<tr>
<td>Chicago, Illinois 60611</td>
<td>Pediatric Appointments: (773) 702-6808</td>
</tr>
<tr>
<td>Main: (312) 695-0990</td>
<td>Adult Appointments: 1-855-702-8222</td>
</tr>
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Appointments: 1-866-587-4322 (1-866-LURIE-CC)
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

## INDIANA

<table>
<thead>
<tr>
<th>Indiana University Melvin and Bren Simon Cancer Center</th>
<th>Purdue University Center for Cancer Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patrick J. Loehrer, Sr., M.D. Director</td>
<td>Timothy L. Ratliff, Ph.D. Director</td>
</tr>
<tr>
<td>535 Barnhill Drive</td>
<td>Hansen Life Sciences Research Building</td>
</tr>
<tr>
<td>Indianapolis, Indiana 46202</td>
<td>201 South University Street</td>
</tr>
<tr>
<td>Main: (317) 944-5000</td>
<td>West Lafayette, Indiana 47907</td>
</tr>
<tr>
<td>Appointments &amp; Referrals: (317) 944-0920</td>
<td>Main: (765) 494-9129</td>
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## IOWA

<table>
<thead>
<tr>
<th>Holden Comprehensive Cancer Center</th>
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<tbody>
<tr>
<td>University of Iowa</td>
</tr>
<tr>
<td>George J. Weiner, M.D. Director</td>
</tr>
<tr>
<td>200 Hawkins Drive</td>
</tr>
<tr>
<td>5970Z JPP</td>
</tr>
<tr>
<td>Iowa City, Iowa 52242</td>
</tr>
<tr>
<td>Appointments &amp; Referrals: (319) 356-4200</td>
</tr>
<tr>
<td>Cancer Information Service: 1-800-237-1225</td>
</tr>
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*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

## KANSAS

<table>
<thead>
<tr>
<th>The University of Kansas Cancer Center</th>
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<tbody>
<tr>
<td>University of Kansas</td>
</tr>
<tr>
<td>Roy A. Jensen, M.D. Director</td>
</tr>
<tr>
<td>3901 Rainbow Boulevard</td>
</tr>
<tr>
<td>Kansas City, Kansas 66160</td>
</tr>
<tr>
<td>Main: (913) 588-1227</td>
</tr>
<tr>
<td>Toll Free: 800-332-6048</td>
</tr>
</tbody>
</table>

*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance
KENTUCKY

Markey Cancer Center
University of Kentucky
B. Mark Evers, M.D. Director
CC140 Roach Building
800 Rose Street
Lexington, Kentucky 40536-0096
Main: (859) 257-4500
Toll Free: 1-866-340-4488

MAINE

The Jackson Laboratory Cancer Center
Edison T. Liu, M.D. President & CEO
600 Main Street
Bar Harbor, Maine 04609
Main: (207) 288-6000
Public Information: (207) 288-6051

MARYLAND

<table>
<thead>
<tr>
<th>Sidney Kimmel Comprehensive Cancer Center</th>
<th>University of Maryland Marlene and Stewart Greenebaum Cancer Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>Johns Hopkins University</td>
<td>22 South Greene Street</td>
</tr>
<tr>
<td>William G. Nelson, M.D., Ph.D. Director</td>
<td>Baltimore, Maryland 21201</td>
</tr>
<tr>
<td>401 North Broadway</td>
<td>Main and New Appointments: (410) 328-7904</td>
</tr>
<tr>
<td>Baltimore, Maryland 21231</td>
<td>Toll Free: 1-800-888-8823</td>
</tr>
<tr>
<td>Main: (410) 955-5222</td>
<td></td>
</tr>
<tr>
<td>Appointments &amp; Referrals: (410) 955-8964</td>
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MASSACHUSETTS

<table>
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<tr>
<th>Dana-Farber/Harvard Cancer Center</th>
<th>David H. Koch Institute for Integrative Cancer Research at MIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edward J. Benz Jr., M.D. Director</td>
<td>Massachusetts Institute of Technology</td>
</tr>
<tr>
<td>450 Brookline Avenue</td>
<td></td>
</tr>
</tbody>
</table>

Section V: Resources Page 9
Boston, Massachusetts 02215
Main: (617) 632-3000
Spanish Speakers: (617) 632-3673
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

Tyler Jacks, Ph.D. Director
77 Massachusetts Avenue, 76-158
Cambridge, Massachusetts 02139
Main: (617) 253-6403

MICHIGAN

The Barbara Ann Karmanos Cancer Institute
Wayne State University School of Medicine
Gerold Bepler, M.D., Ph.D. President & CEO
4100 John R
Detroit, Michigan 48201
Appointments: 1-800-527-6266 (1-800-KARMANOS)

University of Michigan Comprehensive Cancer Center
Theodore Lawrence, M.D., Ph.D. Director
1500 East Medical Center Drive
Ann Arbor, Michigan 48109
Cancer Answer Line: 1-800-865-1125
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

MINNESOTA

Masonic Cancer Center
University of Minnesota
Douglas Yee, M.D. Director
420 Delaware Street, S.E.
Minneapolis, Minnesota 55455
Cancer Information Line: (612) 624-2620
Patient Appointments: (612) 672-7422
http://www.cancer.umn.edu/
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

Mayo Clinic Cancer Center
Robert B. Diasio, M.D. Director
200 First Street, S.W.
Rochester, Minnesota 55905
Main: (507) 284-2511
http://www.mayoclinic.org/sarcoma/index.html
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

MISSOURI

Alvin J. Siteman Cancer Center
Washington University School of Medicine and Barnes-Jewish Hospital
Timothy J. Eberlein, M.D. Director  
660 South Euclid Avenue, Campus Box 8109  
St. Louis, Missouri 63110  
Main: (314) 747-7222  
Toll Free: 1-800-600-3606  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

**NEBRASKA**

**Fred and Pamela Buffett Cancer Center**  
University of Nebraska Medical Center  
Kenneth H. Cowan, M.D., Ph.D. Director  
985950 Nebraska Medical Center  
Omaha, Nebraska 68198  
Care Center: (402) 559-6500  
Medical Call Center – Physician & Service Referral: 1-800-922-0000

**NEW HAMPSHIRE**

**Norris Cotton Cancer Center at Dartmouth**  
Dartmouth-Hitchcock Medical Center  
Mark A. Israel, M.D. Director  
One Medical Center Drive  
Lebanon, New Hampshire 03756  
Administration: (603) 653-9000  
Cancer Help Line: 1-800-639-6918

**NEW JERSEY**

**Rutgers Cancer Institute of New Jersey**  
Rutgers Biomedical and Health Sciences  
Bruce Hafty, M.D. Interim Director  
195 Little Albany Street  
New Brunswick, New Jersey 08903  
Main: (732) 235-2465

**NEW MEXICO**
**University of New Mexico Cancer Center**  
Cheryl L. Willman, M.D. Director & CEO  
1201 Camino de Salud NE  
Albuquerque, New Mexico 87131  
Main: (505) 272-4946  
In New Mexico: 1-800-432-6806

**NEW YORK**

| **Albert Einstein Cancer Center** |
| Yeshiva University |
| I. David Goldman, M.D. Director |
| 1300 Morris Park Avenue |
| Bronx, New York 10461 |
| Main: (718) 862-8840 |

| **Memorial Sloan-Kettering Cancer Center** |
| Craig B. Thompson, M.D. President & CEO |
| 1275 York Avenue |
| New York, New York 10065 |
| General: (212) 639-2000 |
| Pediatric Appointments: (212) 639-5954 |

*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

| **Roswell Park Cancer Institute** |
| Candice S. Johnson, Ph.D. President & CEO |
| Elm & Carlton Streets |
| Buffalo, New York 14263 |
| Main: (716) 845-2300 |
| Physician Referral: 1-800-767-9355 (1-800-ROSWELL) |

*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

| **Laura and Isaac Perlmutter Cancer Center at NYU Langone** |
| Benjamin Neel, M.D., Ph.D. Director |
| 550 First Avenue |
| 1201 Smilow Building |
| New York, New York 10016 |
| Main: (212) 731-6000 |
| Physician Referral: 1-888-769-8633 |

| **Cold Spring Harbor Laboratory Cancer Center** |
| Bruce W. Stillman, Ph.D. President |
| 1 Bungtown Road |
| Cold Spring Harbor, New York 11724 |
| Main: (516) 367-8800 |

| **The Tisch Cancer Institute at Mount Sinai** |
| Steven J. Burakoff, M.D. Director |
**NORTH CAROLINA**

**Duke Cancer Institute**  
Duke University Medical Center  
Michael B. Kastan, M.D., Ph.D. Executive Director  
Box 2714, 2424 Erwin Road  
Durham, North Carolina 27710  
Consultation and Referral Service: 1-888-275-3853 (1-888-ASK-DUKE)  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

**The Comprehensive Cancer Center of Wake Forest University**  
Boris Pasche, M.D., Ph.D. Director  
Medical Center Boulevard  
Winston-Salem, North Carolina 27157  
Main: (336) 716-7971  
Appointments: (336) 716-WAKE  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

**UNC Lineberger Comprehensive Cancer Center**  
Norman E. Sharpless, M.D. Director  
450 West Drive, CB 7295  
Chapel Hill, North Carolina 27599  
Main: (919) 966-3036  
Information or Appointments: 1-866-869-1856

**OHIO**

**Case Comprehensive Cancer Center**  
Case Western Reserve University  
Stanton L. Gerson, M.D. Director  
11100 Euclid Avenue, Wearn 151  
Cleveland, Ohio 44106  
Main: (216) 844-8797

**The Ohio State University Comprehensive Cancer Center**  
James Cancer Hospital and Solove Research Institute  
Michael A. Caligiuri, M.D. Director  
460 West 10th Avenue  
Columbus, Ohio 43210  
Main: (614) 293-5066  
Toll Free: 1-800-293-5066
### OREGON

**Knight Cancer Institute**  
**Oregon Health and Science University**  
Brian J. Druker, M.D. Director  
3181 S.W. Sam Jackson Park Road  
Portland, Oregon 97239  
Cancer Institute: (503) 494-1617  
Health Care Services/OHSU Switchboard: (503) 494-8311  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

### PENNSYLVANIA

#### Abramson Cancer Center  
**University of Pennsylvania, Philadelphia**  
Chi V. Dang, M.D., Ph.D. Director  
3400 Spruce Street  
Philadelphia, Pennsylvania 19104  
Main: (215) 615-5858  
Medical Referrals: 1-800-789-7366  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

#### Fox Chase Cancer Center, Philadelphia*  
Richard I. Fisher, M.D., Ph.D. President & CEO  
333 Cottman Avenue  
Philadelphia, Pennsylvania 19111  
New Patient Appointments: (215) 728-2570  
Cancer Information Line: 1-888-369-2427 (1-888-FOX-CHASE)  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

#### Sidney Kimmel Cancer Center at Thomas Jefferson University  
Karen E. Knudsen, Ph.D. Director  
233 South 10th Street  
Philadelphia, Pennsylvania 19107  
Main: (215) 503-5692  
Hospital: (215) 503-4500  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

#### University of Pittsburgh Cancer Institute  
Nancy E. Davidson, M.D. Director  
5150 Centre Avenue  
Pittsburgh, Pennsylvania 15232  
Main: (412) 647-2811  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

#### The Wistar Institute Cancer Center  
Dario C. Altieri, M.D. Director  
3601 Spruce Street
SOUTH CAROLINA

Hollings Cancer Center
Medical University of South Carolina
Anthony J. Alberg, Ph.D., MPH Interim Director
86 Jonathan Lucas Street
Charleston, South Carolina 29425
Main: (843) 792-0700
Health Connection Line: 1-800-424-6872 (1-800-424-MUSC)
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance

TENNESSEE

<table>
<thead>
<tr>
<th>St. Jude Children’s Research Hospital</th>
<th>Vanderbilt-Ingram Cancer Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charles W. M. Roberts, M.D., Ph.D.</td>
<td>Jennifer A. Pietenpol, Ph.D. Director</td>
</tr>
<tr>
<td>Executive Vice President</td>
<td>691 Preston Research Building</td>
</tr>
<tr>
<td>262 Danny Thomas Place</td>
<td>Nashville, Tennessee 37232</td>
</tr>
<tr>
<td>Memphis, Tennessee 38105</td>
<td>Main: (615) 936-8422 (615-936-VICC)</td>
</tr>
<tr>
<td>General Information: (901) 595-3300</td>
<td>Toll Free: 1-877-936-8422 (1-877-936-VICC)</td>
</tr>
<tr>
<td>Appointments &amp; Referrals: 1-866-278-5833</td>
<td>*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance</td>
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<td>(1-866-2STJUDE)</td>
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TEXAS

<table>
<thead>
<tr>
<th>Cancer Therapy &amp; Research Center University of Texas Health Science Center</th>
<th>Harold C. Simmons Cancer Center University of Texas Southwestern Medical Center</th>
</tr>
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<tbody>
<tr>
<td>Ian M. Thompson, M.D. Executive Director</td>
<td>Melanie Cobb, Ph.D. Interim Director</td>
</tr>
<tr>
<td>7979 Wurzbach Road</td>
<td>2201 Inwood Road</td>
</tr>
<tr>
<td>Urschel Tower, Room U627</td>
<td>Dallas, Texas 75390</td>
</tr>
<tr>
<td>San Antonio, Texas 78229</td>
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<td><strong>Section V: Resources</strong></td>
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<tr>
<td><strong>Appointments &amp; Referrals:</strong> (210) 450-1000</td>
<td></td>
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<tr>
<td><strong>Cancer Information Line:</strong> 1-800-340-2872</td>
<td></td>
</tr>
<tr>
<td><strong>Main:</strong> (214) 645-4673 (214-645-HOPE)</td>
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<td><strong>Toll Free:</strong> 1-866-460-4673 (1-866-460-HOPE)</td>
<td></td>
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<tr>
<td><strong>Dan L. Duncan Cancer Center</strong></td>
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<tr>
<td>Baylor College of Medicine</td>
<td></td>
</tr>
<tr>
<td>C. Kent Osborne, M.D. Director</td>
<td></td>
</tr>
<tr>
<td>One Baylor Place</td>
<td></td>
</tr>
<tr>
<td>MS: BCM305</td>
<td></td>
</tr>
<tr>
<td>Houston, Texas 77030</td>
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<td><strong>The University of Texas</strong></td>
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<td><strong>MD Anderson Cancer Center</strong></td>
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<td>Ronald A. DePinho, M.D. President</td>
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<td>Toll Free: 1-877-632-6789 (1-877-MDA-6789)</td>
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| *Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

**UTAH**

**Huntsman Cancer Institute**  
**University of Utah**  
Mary C. Beckerle, Ph.D. Chief Executive Officer and Director  
2000 Circle of Hope  
Salt Lake City, Utah 84112  
Local: (801) 585-0303  
HCI Main: 1-877-585-0303  
*Institution designated Sarcoma Cancer Center by the Sarcoma Alliance*

**VIRGINIA**

**Massey Cancer Center**  
**Virginia Commonwealth University**  
Gordon D. Ginder, M.D. Director  
P.O. Box 980037  
401 College Street  
Richmond, Virginia 23298  
General Information: (804) 828-0450  
New Patients: (804) 828-5116

**University of Virginia Cancer Center**  
Thomas P. Loughran, Jr., M.D. Director  
6171 West Complex  
Charlottesville, Virginia 22908  
Main: (434) 924-3627  
Toll Free: 1-800-223-9173

**WASHINGTON**

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Section V: Resources Page 16
Fred Hutchinson/University of Washington Cancer Consortium
Gary Gilliland, M.D., Ph.D. President & Director
P.O. Box 19024, D1-060
Seattle, Washington 98109
SCCA - New Patients/Intake: (206) 288-1024
SCCA Main: (206) 288-7222

WASHINGTON - DISTRICT OF COLUMBIA

Georgetown Lombardi Comprehensive Cancer Center
Georgetown University
Louis M. Weiner, M.D. Director
3970 Reservoir Road, NW
Washington, District of Columbia 20007
Appointments: (202) 444-2223
CancerLine: 202-444-4000

WISCONSIN

University of Wisconsin Carbone Cancer Center
Howard Bailey, M.D. Director
1111 Highland Avenue, Rm. 7057
Madison, Wisconsin 53705
General Information: (608) 263-8600
Cancer Connect: 1-800-622-8922
GENERAL CANCER INFORMATION & RESOURCE SITES

American Cancer Society
www.cancer.org
The American Cancer Society is a nationwide community-based voluntary health organization dedicated to eliminating cancer through research, patient services, early detection, treatment and education.

American Society of Clinical Oncology (ASCO)
www.asco.org
Founded in 1964, the American Society of Clinical Oncology (ASCO) is the world's leading professional organization for physicians and oncology professionals caring for people with cancer. ASCO develops and publishes clinical practice guidelines, provisional clinical opinions (PCOs), and guideline endorsements, providing evidence-based recommendations to serve as a guide for doctors and outline appropriate methods of treatment and care.

Cancer Care.org
http://www.cancercare.org/
CancerCare is a national organization dedicated to providing free professional support services including counseling, support groups, educational workshops, publications, and financial assistance to anyone affected by cancer. All CancerCare services are provided by oncology social workers and leading cancer experts.

Macmillan Cancer Support
http://www.macmillan.org.uk
Macmillan Cancer Support is Europe’s leading cancer information charity, with up-to-date cancer information and practical advice and support for cancer patients, families, and caregivers.

Medscape
Hematology/Oncology Home Page (a product of WebMD)
Medscape is the leading online global destination for physicians and healthcare professionals worldwide. Its mission is to improve patient care with comprehensive clinical information and resources.

Minnesota Cancer Alliance
The Minnesota Cancer Alliance is a partnership of organizations and leaders across Minnesota dedicated to reducing the burden of cancer from prevention and detection to treatment, survivorship, and end-of-life care.

It enables cancer patients and their caregivers to:

- Connect to resources such as support groups, transportation, financial assistance, and palliative care.
- Find links to cancer information on treatment options, clinical trials, pain management, and much more.

**National Cancer Institute – Cancer Information & Support Networks**
http://www.cancer.gov/

**National Cancer Institute – General Information**
www.nci.nih.gov
1-800-4-CANCER
The National Cancer Institute (NCI) is the federal government’s principal agency for cancer research and training. It is part of the National Institutes of Health (NIH), which is one of 11 agencies that comprise the Department of Health and Human Services (HHS).

The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

**National Comprehensive Cancer Network (NCCN)**
www.nccn.org/patients/
The National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of 27 of the world’s leading cancer centers devoted to patient care, research, and education, is dedicated to improving the quality, effectiveness, and efficiency of cancer care so that patients can live better lives. Its website provides many resources for patients and caregivers.

**National Library of Medicine**
http://www.nlm.nih.gov/
Its website provides access to searchable databases, including PubMed/Medline, an archive of life science journals. PubMed includes links to full-text articles and other related resources.


Oncolink
http://www.oncolink.com/
Oncolink was the first cancer information website on the Internet, started in 1994, and remains one of the largest. This award-winning site is maintained by a group of oncology healthcare professionals who understand the need of patients, caregivers, and healthcare professionals. Oncolink’s content is continually updated and ranges from treatment and disease information for a newly diagnosed patient, support through the side effects of treatment, and into survivorship.

INTERPRETING PATHOLOGY REPORTS

The Doctor’s Doctor
www.thedoctorsdoctor.com/f_home.html
This site is run by pathologists to help patients understand their test results and diagnoses. The physicians on staff can interpret test results for you, in plain English. This will help you make informed healthcare decisions.

CANCER ADVOCACY ORGANIZATIONS

National Coalition for Cancer Survivorship (NCCS)
http://www.canceradvocacy.org/
NCCS advocates for quality cancer care for everyone touched by cancer and provides tools that empower people to advocate for themselves. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship, defining someone as a cancer survivor from the time of diagnosis and for the balance of his or her life.

SARC
http://www.sarctrials.org
SARC (Sarcoma Alliance for Research through Collaboration) is a nonprofit organization, based in Michigan, dedicated to the development and support of research for the prevention, treatment, and cure of sarcoma. Information regarding clinical trials is available on its website.
Sarcoma Foundation of America (SFA)
http://www.curesarcoma.org/
The mission of the Sarcoma Foundation of America (SFA), based in Maryland, is to advocate for sarcoma patients by funding research and increasing awareness about the disease. The organization raises money to privately fund grants for sarcoma researchers and conducts education and advocacy efforts on behalf of sarcoma patients. Its website has significant information on patient resources and research funding, along with a sarcoma patient registry.

DRUG INFORMATION

The Angiogenesis Foundation
www.angio.org
The Angiogenesis Foundation is the world's first and leading nonprofit organization dedicated to conquering disease by controlling the blood vessels that feed it.

MacMillan (UK)
Macmillan Cancer Support is Europe’s leading cancer information charity. This section of its website contains information about individual chemotherapy drugs. It includes information about how each drug is given and the possible side effects that may be experienced with each drug.

National Cancer Institute
http://www.cancer.gov/cancertopics/druginfo/alphabet
NCI’s drug information summaries provide consumer-friendly information about certain drugs that are approved by the U.S. Food and Drug Administration (FDA) to treat cancer or conditions related to cancer. For each drug, topics covered include background, research results, possible side effects, approval information, and ongoing clinical trials.

Rx List
www.rxlist.com
RxList is an online medical resource dedicated to offering detailed and current pharmaceutical information on brand and generic drugs. RxList was founded by pharmacists in 1995 and acquired by WebMD in 2004. Its knowledgeable staff continuously reviews and updates the site with articles written by pharmacists and physicians and data provided by credible and reliable sources like the FDA to ensure the most accurate and beneficial information is provided.
COMPLEMENTARY AND ALTERNATIVE MEDICINE

Memorial Sloan Kettering
This information resource, presented by Memorial Sloan Kettering’s Integrative Medicine Service, provides evidence-based information about herbs, botanicals, supplements, and more.

National Center for Complementary and Integrative Health (NCCIH)
https://nccih.nih.gov
The National Center for Complementary and Integrative Health (NCCIH) is the Federal Government's lead agency for scientific research on the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine.

University of Texas MD Anderson Integrative Medicine Center
The Integrative Medical Center offers therapies that reduce patients’ stress and anxiety and improve their physical, mental, and emotional well-being. It also publishes a regular newsletter and holds group classes for patients, caregivers, and the public. For those who want to learn more about complementary and integrative medicine, it has an online audio and video library, which includes introductions and talks about different therapies as well as meditation and music therapy sessions.

PATIENT AND FAMILY SUPPORT

ONLINE SARCOMA SUPPORT GROUPS: You are not alone in your sarcoma journey. Through the Internet, you can both connect with others who are facing sarcoma and reach out to your friends, family, and loved ones to help them and yourself as you face sarcoma.

ACOR Mailing Lists
http://www.acor.org
To get to sarcoma mailing lists, type sarcoma next to mailing list searches. At the time of this publication, there are seventeen sarcoma-related mailing lists.
Adult Bone Cancer Survivors
http://www.abc-survivors.net/
This site is for bone cancer survivors (primarily sarcoma). It is dedicated to the sharing of survival stories to give readers hope, and to communicating through its ABC Café support forum. The site provides good background, but is no longer active, transitioning to “archival mode” in 2010.

Ben’s Friends Rare Diseases
http://ben-rarediseases-community.trydiscourse.com
Ben’s Friends Rare Diseases is an online forum for individuals diagnosed with rare diseases or chronic illnesses. The mission at Ben’s Friends is to ensure that patients living with rare diseases or chronic illnesses, as well as their caregivers, family, and friends, have a safe and supportive place to connect with others like them. As of November 2016, over thirty groups exist, including one for synovial sarcoma. The site features open discussion, as well as recommendations for doctors and clinics.

CaringBridge
http://www.caringbridge.org/
CaringBridge offers free, easy-to-create websites that help connect friends and family when they need it most. You can create your own CaringBridge website.

Chemo Angels Support Network
http://www.chemoangels.net/
Chemo Angels is a volunteer organization dedicated to adding a ray of sunshine to the lives of those undergoing IV chemo treatment. The Chemo Angels Support Network believes that people going through the physical, emotional, and mental rigors of chemotherapy deserve some encouragement. Many Chemo Angel volunteers are cancer survivors themselves or people whose lives have been affected by cancer in some way. The common denominator is a desire to brighten the lives of cancer patients while they are going through this challenging time.

Facebook
Facebook offers several support groups for individuals dealing with sarcoma.

https://www.facebook.com/groups/synovialsarcomasupport/
This support group of over 600 members is specifically geared towards those with synovial sarcoma.
https://www.facebook.com/groups/sarcomasupportinitiative/
This group of over 1,500 members is open to all sarcoma types. It is a safe place to ask questions, vent, get support, and make friends.

Gilda’s Club
www.GildasClubTwinCities.org
Gilda’s Club Twin Cities is a 501(c)3 nonprofit and the local affiliate of the Cancer Support Community, a network of more than 57 supportive, free, and welcoming “clubhouses” where everyone living with cancer can come for social, emotional, and psychological support. Clubs are healing environments where individuals learn from each other with guidance from licensed professionals.
National Gilda’s Club (Cancer Support Community): http://www.gildasclub.com/

Sarcoma Alliance
http://www.sarcomaalliance.org/peer-to-peer/
The mission of the Sarcoma Alliance Peer-to-Peer Network is to facilitate positive relationships between individuals affected by sarcoma, so that they may find emotional support, encouragement, and information.

HEALTH INSURANCE COVERAGE

Affordable Care Act
https://www.healthcare.gov/
The Affordable Care Act provisions are now available in all 50 states either through local exchanges such in MNsure in Minnesota or through the National Health Exchange. The Act should provide you with more and better insurance options and with subsidized premiums if you have financial needs. Preexisting conditions, such as a sarcoma cancer diagnosis, no longer prevent you from getting coverage. Your options will differ depending on which state you are residing in and whether your state is collaborating with the federal legislation in setting up state-based Health Insurance Exchanges. Depending on acts of congress in 2017 these options may change, so it is important to keep abreast of state and national health care coverage and affordability issues as it may impact you.

In Minnesota, MNsure (www.mnsure.org/) is the single best site to find health insurance. With MNsure, you will find instant, easy access to coverage options, personalized assistance, side-by-side comparisons of your options, financial assistance, and enrollment information. Open
enrollment to sign up for or change coverage is now set for the three-month period from November 1 through January 31. Some health plans may have enrollment caps during this period, so it is important to enroll early in this timeframe to have the most options available to you. Consumers who experience a life-changing event (birth of a child or loss of employer coverage, for example) may purchase health insurance outside of the open enrollment period. Visit: www.mnsure.org/

Medicare
http://www.medicare.gov/
For persons who are 65 or older or who are eligible because of a disability, primary health care coverage is usually through Medicare. In addition, many obtain supplemental coverage including prescription drug coverage. Open enrollment to sign up for or change coverage without a health screen is now set for the three-month period from November 1 through January 31. Cancer patients should carefully examine the providers in the network covered by the health plan and whether the necessary cancer medications are covered by the prescription plan.

FINANCIAL AND OTHER ASSISTANCE IN MINNESOTA
These organizations provide direct financial support to families of cancer patients in the Minneapolis and St. Paul Metro areas, and in some cases, Minnesota-wide.

Angel Foundation of Minnesota
http://www.mnangel.org/
The Angel Foundation provides financial assistance for basic non-medical living necessities for cancer patients and their families in the seven-county Metro area, along with other support services. Grants are approved for rent and housing payments, food, utility bills, non-prescription medication expenses, childcare, bus passes, gas vouchers, and other basic non-medical needs and necessities. Patient grant requests must be made by a healthcare professional. For information, please have your healthcare professional call (612) 627-9000 or email grants@MNAngel.org. The Angel Foundation’s Facing Cancer Together program offers free education and support to families with children age 5-18 who have a parent with cancer.

Cancer Financial Resources
http://www.cancer.org/treatment/supportprogramsservices/app/resource-search
This is a general search engine of the American Cancer Society. It provides a comprehensive list of many resources, including financial and housing resources, based on ZIP code or home state.
Cleaning for a Reason  
http://www.cleaningforareason.org/  
Fighting cancer is difficult enough, but living with it is even tougher—and that's where Cleaning For A Reason steps in. As a nonprofit serving the entire United States and Canada, Cleaning For A Reason partners with maid services to offer professional house cleaning services to help women undergoing treatment for any type of cancer. It currently serves seventeen cities in Minnesota.

Hand in Hand: Suzanne R. Leider Memorial Assistance Fund  
http://sarcomaalliance.org/financial-assistance/  
The Hand in Hand Fund was created to help sarcoma patients find the treatment they need. 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. Although modest, Hand in Hand touches as many patients' lives as possible. Grants from the Fund are awarded each quarter. The grant maximum is currently $500. The Fund is administered by the Sarcoma Alliance.

Healthwell Foundation  
http://healthwellfoundation.org/  
The HealthWell Foundation provides financial assistance to eligible individuals to cover coinsurance, copayments, health care premiums, and deductibles for certain medications and therapies. If you've been prescribed a medication covered by insurance, but cannot afford the coinsurance or copayment required, the Healthwell Foundation may be able to assist you by paying for part of your costs associated with the medication.

The Pinky Swear Foundation  
http://www.pinkyswear.org/  
The Pinky Swear Foundation is a Minnesota-based 501(c)3 organization whose sole purpose is to improve the quality of life for children and their families struggling daily with cancer. The Pinky Swear Foundation (formally Miracles for Mitch) seeks to provide relief and respite for all families with cancer who are being treated in the state of Minnesota. The Foundation helps children being treated for cancer by partnering with Children's Hospital of Minneapolis, Children's Hospital of St. Paul, University of Minnesota Children's Hospital, Fairview, St. Mary's Medical Center in Duluth, and the Mayo Clinic. It works through each hospital's Social Worker network.
The Szott Foundation
http://szottfoundation.org/
The Szott Foundation is a Minnesota state nonprofit organization that provides financial support to replace lost income when a parent stays home from work to care for a child with cancer—the Gift of Time. Founded by David and Kathryn Szott, the Foundation has grown to provide support to several families in the Midwestern United States.

Spare Key
http://www.sparekey.org/
Spare Key is a Minnesota-based 501(c)(3) nonprofit that provides housing grant assistance (up to $1,200 towards a mortgage payment) to parents of children age 18 and under who have been hospitalized for serious medical conditions. It currently operates in Minnesota, North and South Dakota, and Wisconsin.

MISCELLANEOUS RESOURCES

Along Comes Hope
http://alongcomeshope.com
Along Comes Hope is a 501(c)3 nonprofit organization helping families of children with cancer. It provides financial assistance for travel associated with treatment, creative emotional support programs, and advocacy to promote policy changes, awareness, and education.

Angel Bears of Hope
http://angelbearsofhope.org
Angel Bears of Hope (ABOH) is an Illinois charitable organization that gives the gift of hope, one stuffed bear at a time. This group donates Angel Bears to patients suffering from life threatening diseases to give them hope and courage throughout their battle with cancer. The Angel Bear will be there with them during treatments, at night when they are alone, during tests, and any other time they need comfort.

Angels of Destiny
http://angelsofdestiny.net
Angels of Destiny is a nonprofit organization that gives the gift of an angel to people who are living with life-threatening illnesses. There is no cost to the recipients. The organization is now offering "Prayer Cloth Angels", which are made of cloth and prayed over specifically for the
recipient’s needs. This angel is perfect for recipients who are confined to bed, because the
angel can be pinned to bedding or hung over a bed.

**Beads of Courage**

[http://www.beadsofcourage.org](http://www.beadsofcourage.org)

Founded in 2005, Beads of Courage coordinates with health care workers at hospitals to help
children suffering from serious illness cope with their treatment through art. Specifically, Beads
of Courage has helped over 60,000 children in eight countries record, tell, and own their stories
using colorful beads as meaningful symbols of courage and hope along their treatment journey.
The Beads of Courage Program is available for children with cancer and blood disorders, as well
as other conditions, such as cardiac disorders, burn injuries, and chronic illnesses. All program
bead guides were developed with experts in the field (nurses, doctors, child-life specialists, and
social workers) so that each bead guide would reflect meaningful acknowledgement of a child’s
treatment journey.

**Blankets Sent With Love**

[http://blanketsswl.blogspot.com](http://blanketsswl.blogspot.com)
[https://www.facebook.com/blanketssentwithlove](https://www.facebook.com/blanketssentwithlove)

This organization will provide a handmade blanket to any adult in the UK diagnosed with
cancer.

**Bows & Ballcaps**

[http://www.bowsandballcaps.com](http://www.bowsandballcaps.com)

Bows & Ballcaps is a charitable organization dedicated to offering love and support to kids
fighting cancer, especially those who have lost their hair from their treatments. It was founded
in 2013 by then ten-year-old Hannah Grubbs, a girl who has been bald her entire life from
Alopecia Areata. Hannah lost her hair from alopecia before she was one-year-old, and she has
real-life, first-hand experience with what it’s like to live without hair. Her mission is to
encourage other kids to be comfortable and confident being bald, and to remind them that it is
what’s on the inside that really matters. Hannah’s message to the world is that we all have a
beautiful light inside of us that makes us unique and special.

Hannah has received so much generosity through the years from people who think she has
cancer that she wanted to pass it on—to actually come up with a charitable program
specifically dedicated to doing something for kids with cancer or Alopecia, like her. Now, she
can turn a random inquiry about why she doesn’t have hair into an opportunity to spread
the word about Bows & Ballcaps and help other children.
Bows & Ballcaps works to collect new bows, ballcaps, headbands, scarves, and various other headwear and accessories through donations from companies and individuals. Then, the organization distributes these items to kids with cancer either through children’s hospitals or organizations or by sending them directly to the children. All gifts come with special words of encouragement from Hannah.

**Brendan Pederson Foundation**
This organization gives free bibles to children fighting cancer in memory of a boy who fought terminal pediatric brain cancer.

**Canvas for Hope**
http://www.canvasforhope.com
https://www.facebook.com/canvasforhope/
This group paints and delivers at least 200 paintings to children and families affected by childhood cancer and other life-threatening illnesses on a yearly basis.

**CURE Bears for Hope and Love**
CURE Bears for Hope and Love sends teddy bears to children undergoing cancer treatment and spreads awareness about the prevalence of childhood cancer.

**Flashes of Hope**
http://flashesofhope.org
Founded in 2001 by the parents of a child with cancer, Flashes of Hope is a volunteer-driven organization solely focused on children's cancer. Every year, Flashes of Hope provides free portrait packages to 7,000 children in 55 cities across the country. Each family is presented with framed enlargements, proofs, and a CD of all the images. The portraits help the children see themselves in a new light. The images are not of sick kids, but of strong and beautiful children filled with hope. Volunteer stylists make every child feel special before stepping in front of the camera with family, friends, and often, a favorite nurse. A routine day quickly turns into a celebration of the love that surrounds them.

**The Gold Hope Project**
http://goldhopeproject.com
The Gold Hope Project is an international group of photographers that provides free portrait sittings for children diagnosed with pediatric cancer. Many families with ill children are emotionally, physically and financially strapped; it is the heart of The Gold Hope Project to take
at least one worry off their shoulders and gift them something magical—the smiles of their children frozen in time. The Gold Hope Project’s goal is to make sure that these already overburdened families have an everlasting documentation of the joy and whimsy of their children while simultaneously raising awareness of and funds for pediatric oncology research and treatment.

**Healing Helpers**
https://www.facebook.com/healinghelpers/about/?ref=page_internal
The mission of “Healing Helpers” is to provide a means of comfort for individuals as they cope with medical situations by making custom stuffed animals that relate to the person who adopts them—with ports, surgical scars, cochlear implants, etc.

**Hope Toys**
http://www.hopetoys.org
Hope Toys seeks to raise awareness of various disabilities, illnesses, birth defects, developmental conditions, injuries, and other medical conditions and disorders through toys and custom dolls for children who are bald, using a wheelchair, have an amputation, etc.

**Jars of Hope**
https://www.facebook.com/groups/974791335924503/
This group sends jars of toys to children battling any health issue, ages 3-12 (US only). The jars include various toys such as crayons, markers, tattoos, nail polish, bubbles, activity books, whistles, pens, pencils, matchbox cars, pirate dog tags, and more. The group then shares a photo of the child with Facebook followers.

**The Jessie Rees Foundation**
http://negu.org
Jessie Rees was a twelve-year-old girl who fought two brain tumors over the course of ten months. During her courageous fight, Jessie focused on helping other children receiving inpatient cancer care. This led to the creation of JoyJars, free 64 ounce plastic jars filled with toys and activities for kids 18 and under who have cancer, and her Never Ever Give Up (NEGU) message. During her lifetime, Jessie personally stuffed and sent over 3,000 JoyJars to children fighting cancer in homes and hospitals.
Kylee’s Dancing Angels  
**http://www.kyleesdancingangels.org**  
Kylee’s Dancing Angels is a non-profit foundation established in honor and memory of Kylee Brooke Webster, who lost her battle to sarcoma in October 2013. Through fundraising efforts and the establishment of partnerships with people and organizations that Kylee held close to her heart, Kylee’s Dancing Angels hopes to make a positive difference in the lives of others who have been diagnosed with sarcoma. Together, these organizations provide the financial means necessary to help sarcoma patients get to their “happy place”—a spot Kylee was always able to find when she had the opportunity to dance.

The Kylie Rowand Foundation  
**http://www.kyliestrong.org**  
The Kylie Rowand Foundation is dedicated to raising money and awareness for new, promising, less toxic treatments for childhood cancer. It also sends personalized care packages to children fighting cancer and provides financial assistance to some families.

Love Your Melon  
**https://www.loveyourmelon.com**  
Love Your Melon is a Minnesota-based apparel company founded by students at the University of St. Thomas. It is dedicated to giving a hat to every child battling cancer in America, as well as supporting nonprofit organizations that lead the fight against pediatric cancer. To request a hat for a child or family member battling cancer, go to:  
**https://www.loveyourmelon.com/pages/requestahat**.

Maer Bears  
**https://www.facebook.com/MaerBears/**  
This group donates handmade teddy bears and bunnies to children fighting cancer.

Peach’s Neet Feet  
**https://www.peachsneetfeet.com**  
This organization provides custom, hand-painted shoes to children living with disabilities and fighting serious illnesses.

Sweet Dreams for Kids  
**http://sweetdreamsforkids.org**  
Sweet Dreams for Kids is a family-run organization that has donated over 10,000 new pajamas to various hospitals in Minnesota and other Children’s Hospitals around the country.
Sunshine Snail Mail
https://www.facebook.com/SunshineSnailMail/
Sunshine Snail mail has card senders from all over the world who send cards to children with cancer, as well as their siblings.

Wally’s Smile
http://www.wallyssmile.org
Wally’s Smile provides comfort and a smile by delivering free care packages to adults, children, and dogs fighting cancer. Currently, Wally’s Smile ships within the United States only; for those interested in international shipping, please inquire at info@wallyssmile.org.

HOUSING  (for patients and families in treatment away from home)

Hope Lodge
http://www.cancer.org/treatment/supportprogramservices/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 may be in another city. Not having to worry about where to stay or how to pay for lodging allows guests to focus on getting well. Hope Lodge provides a nurturing, home-like environment where guests can retreat to private rooms or connect with others. As of 2016, there are 31 Hope Lodge locations throughout the United States. Accommodations and eligibility requirements may vary by location. ACS also lists other housing options with special discounts for patients and caregivers.

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

Ronald McDonald House
http://www.rmhc.org/ronald-mcdonald-house
Many families travel far from home and spend several weeks or months to get treatment for their seriously ill children—a long time to be away or to divide a family. And, for children facing a serious medical crisis, nothing seems scarier than not having mom and dad close by for love and support. 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. Ronald McDonald Houses are located throughout the country including:
Ronald McDonald House of Rochester, MN  (850 2nd Street SW)
Ronald McDonald House of the Twin Cities  (818 Fulton Street SE)
Ronald McDonald House at Children's Hospitals and Clinics  (2525 Chicago Avenue South)

Amschwand Sarcoma Cancer Foundation Housing Program – Houston, Texas
The Amschwand Foundation maintains three apartments specifically for sarcoma patients and their caregivers. The apartments are conveniently located near the MD Anderson Cancer Center and are provided at no cost.

LEGAL ASSISTANCE

Cancer Legal Line
http://www.cancerlegalline.org
Cancer Legal Line is a nonprofit that provides free legal consultation to cancer patients. Cancer Legal Line can help with estate planning, tax issues, foreclosure proceedings, and more. General questions: (651) 917-9000 or Email: info@cancerlegalline.org

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: http://aircharitynetwork.org/
Serving the Midwest: http://www.angelflightcentral.org/
To request assistance: 877-621-7177
Air Charity Network (ACN) is the largest charitable air transportation organization in the world. With more than 7,500 volunteer general aviation pilots, Air Charity Network is the largest volunteer pilot organization in the nation and the only charitable aviation organization in the United States offering access within all 50 states.

Angel Airlines for Cancer Patients
http://www.angelairlinesforcancerpatients.org/
The mission and purpose of Angel Airlines for Cancer Patients is to ensure that no cancer patient is denied access to distant specialized medical evaluation, diagnosis, or treatment for lack of means for long-distance commercial airline transportation.
Corporate Angel Network
www.corpangelnetwork.org
Patient line: 914-328-1313
The sole mission of the Corporate Angel Network is to help cancer patients access the best possible treatment for their specific type of cancer by arranging free travel to treatment across the country using empty seats on corporate jets. This not only improves the patients’ chances of survival, but at the same time reduces their emotional stress, physical discomfort, and financial burden.

National Patient Travel Center
http://www.patienttravel.org/
The National Patient Travel Center provides information about all forms of charitable, long-distance, medically-related transportation and provides referrals to all appropriate sources of help available in the national charitable medical transportation network.

RECREATION

Camp Kesem
http://campkesem.org/minnesota/about-us
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 currently organize the Minnesota summer camp. Camp is free for children whose parents have cancer and is held every summer with two one-week sessions. Similar camps are located in about thirty states including Wisconsin and Illinois. For more national information visit: http://campkesem.org/
National phone referral: (260) 225-3736 (260-22-KESEM)

Camp Mak-A-Dream
http://www.campdream.org
Camp Mak-A-Dream is operated by the Children’s Oncology Camp Foundation. It 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, just 65 miles east of Missoula.

Faith’s Lodge
www.faithslodge.org
Faith’s Lodge is a nonprofit organization located in northwestern Wisconsin that provides an opportunity for families with seriously ill children to retreat to the Northwoods for some fun and relaxation. To stay at Faith’s Lodge, each family must receive a referral from a member of its healthcare team, faith community, a mental health practitioner, or an approved support organization.

WISH FULFILLMENT ORGANIZATIONS

These organizations provide chronically or seriously ill children and their families the opportunity to have a dream come true. Wishes usually fall into one of three categories: trips, celebrity meetings, or special items. Most organizations listed below grant wishes to children between the ages of 3 and 18; exceptions are noted in our listing below. It is important to let the child choose his or her wish, apart from the influence of others, because most organizations allow a child to have only one wish granted.

Rein in Sarcoma does not endorse any of the organizations listed, nor guarantee that individuals will qualify for the services they provide. Please contact each organization for their specific guidelines. A more comprehensive listing of wish fulfillment organizations, both in the U.S. and abroad, can be found on the Rein in Sarcoma website. www.reininsarocma.org.

FOR CHILDREN AND YOUNG ADULTS

Believe in Tomorrow National Children’s Foundation
www.believeintomorrow.org
410-744-1032
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
678-290-2955
This organization provides a seaside family retreat for children with cancer and their families at no charge.

Make-a-Wish Foundation
www.wish.org
800-722-WISH
The Make-a-Wish Foundation grants wishes to children, 18 and under, with life-threatening medical conditions.

**Marty Lyons Foundation**
www.martylyonsfoundation.org
(212) 977-9474
This foundation provides wishes to children ages 3-17 who have been diagnosed with terminal or chronic life-threatening illnesses.

**Memories of Love**
www.memoriesoflove.org
800-625-1566
The Memories of Love vacation is provided to parents who are living with a life-threatening medical condition. The focus is on helping them create joyful family memories for themselves and their children. The vacation includes six days in Orlando, plus tickets to local theme parks, food vouchers, and $200 for out-of-pocket expenses.

**Planet Cancer for Young Adults**
http://myplanet.planetcancer.org/
Planet Cancer was an online community for young adults with cancer. The organization approached the disease with a sense of humor and included a "cancertainment" section with amusing essays including "Top 10 Signs You've Joined a Cheap HMO."

Planet Cancer was founded by Heidi Schultz Adams, a young adult cancer survivor who was diagnosed at 26 with Ewing's sarcoma, to help young adult cancer patients overcome isolation and connect with other cancer survivors in their age group. It was acquired by the Lance Armstrong Foundation in 2009.

**Ulman Cancer Fund for Young Adults**
http://www.ulmanfund.org/
888-393-FUND (3863)
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)**
www.childswish.com
800-518-8019
USSA is a nonprofit Christian organization that coordinates with other agencies to grant terminally ill and disabled children and youth the outdoor adventure of their dreams.

**Wish Fulfillment Organizations for Adults**

**Compassion Partners**  
(407) 396-5320 or (407) 396-6065 (no website available)  
Compassion Partners provides admission to several parks in central Florida, including Disney Theme Parks, Sea World, Universal Studios Orlando, and Busch Gardens. Passes are available to those facing a life-threatening or terminal illness and their family members.

**The Dream Foundation**  
[www.dreamfoundation.org](http://www.dreamfoundation.org)  
1-888-437-3267  
The Dream Foundation grants final wishes to terminally ill adults over the age of 18 and their families by providing end-of-life Dreams that offer inspiration, comfort, and closure.

**Reeling and Healing Midwest**  
[www.reelingandhealing.org](http://www.reelingandhealing.org)  
866-237-5725  
This non-profit organization hosts several fly-fishing retreats for women and men with cancer throughout the year. It offers a retreat for family, friends, and caregivers once a year, as well.

**Second Wind Dreams**  
[www.secondwind.org](http://www.secondwind.org)  
678-624-0500  
Second Wind Dreams is a non-profit organization that grants wishes to older adults living in eldercare facilities or in hospice care. It has granted wishes throughout the United States, Canada, and India.

**STRESS MANAGEMENT**

Acute and chronic stress is a reality for those facing sarcoma cancers. Distress is not an emotion to be avoided or denied; it is a messenger, a signal that our coping methods are not working.

**HeartMath Institute**  
The HeartMath Institute is an internationally recognized nonprofit research and education organization dedicated to helping people reduce stress, self-regulate emotions, and build energy and resilience for healthy, happy lives.

**Mayo Clinic: Stress Management**
http://www.mayoclinic.com/health/meditation/HQ01070

*Meditation: A simple, fast way to reduce stress*

Meditation can wipe away the day's stress and bring inner peace. See how you can easily learn to practice meditation whenever you need it most. If stress has you anxious, tense, and worried, consider trying meditation. Spending even a few minutes in meditation can restore your calm and inner peace.

Anyone can practice meditation. It's simple and inexpensive, and it doesn't require any special equipment. And you can practice meditation wherever you are—whether you're out for a walk, riding the bus, waiting at the doctor's office, or even in the middle of a difficult business meeting.

**MIT Medical: Sleep, Mindfulness Meditation, Relaxation, and Stress Reduction**
http://medweb.mit.edu/wellness/resources/downloads.html

This website, provided by the Massachusetts Institute of Technology (MIT)'s healthcare system, provides print and audio downloads to help you overcome insomnia, reduce stress, and improve sleep quality. Here is a sample of the resources provided:

**Sleep better:** For help with insomnia and other sleep problems

- Improve the quality of your sleep
  - "Cheat Sleep" pamphlet
  - Sleep tips: 5 techniques for better sleep
  - Free white noise website
- Bedtime: Fall asleep more easily by following this guided relaxation at bedtime.
  - Bedtime relaxation
  - Unwind
  - Rest
- Daytime: Yoga nidra ("yogic sleep") is a refreshing form of relaxation and an alternative to the 20-minute power nap.
  - Yoga nidra

**Relaxation and Stress Reduction**
MIT Community Wellness offers a relaxation tip line at 617-253-CALM (2256). The line is available 24 hours a day and features a guided three-minute relaxation exercise you can use any time.

- **Relax: Guided Meditation**
- **Revive Yourself: Energizing Breath**
- **Music for Relaxation: Naive**
- **Music for Relaxation: Clouds**
- **Introduction and Gentle Yoga**
- **Guided Visualization for Relaxation**
- **Progressive Relaxation: Release Muscle Tension**

**My Health Planner**

[http://www.thenewmedicine.org/health_planner.html](http://www.thenewmedicine.org/health_planner.html)

My Health Planner provides a personal plan for health and well-being. It is designed by the University of Minnesota Center for Spirituality and Healing and based on the Twin Cities Public Television series, The New Medicine.

**University of Minnesota Center for Spirituality and Healing**

[http://www.takingcharge.csh.umn.edu](http://www.takingcharge.csh.umn.edu)

The Center for Spirituality and Healing is a nationally recognized leader in integrative therapies and healing practices. Its website provides accurate and credible information to help individuals enhance their wellbeing, explore complementary and integrative healing practices, and navigate the healthcare system. Some of the resources provided include the following:

- Mindfulness Based Stress Reduction (MBSR) courses
- Taking Charge of Your Health website with personal planner: [http://www.takingcharge.csh.umn.edu/](http://www.takingcharge.csh.umn.edu/)
- Graduate courses, including Meditation and Advanced Meditation, Reiki Healing, and Integrative Psychotherapy

**BOOKS AND VIDEOS**


The Rein in Sarcoma website provides a selection of suggested readings and videos on many key issues.
Clinical Research Studies

Clinical trials are important in studying all aspects of medicine, not just cancer. All new treatments (drugs and medical devices) must go through clinical trials before being approved by the Food and Drug Administration for general use.

Clinical trials are usually conducted in distinct phases. Each phase is designed to answer specific questions. There are advantages and disadvantages to taking part in each phase of a clinical trial. Phase I trials generally assess the safety of the drug or treatment, while Phase II trials look at the effectiveness of a treatment. Phase III trials compare the safety and effectiveness of a treatment against the current standard treatment.

**Phase I** trials are the first studies that use people as participants. The treatment has already been tested in a laboratory setting and on animals, but these studies cannot always predict how a human subject will react to treatment and the side effects that may occur. These studies usually involve a small number of participants and are usually reserved for patients who do not have other good options left.

In **Phase II** trials, doctors are assessing how the cancer responds to a treatment. This may include the shrinkage of a tumor, or it may be an increase in the time before a cancer returns. Larger numbers of patients are used in Phase II trials than Phase I. Generally, placebos are not used in these trials.

**Phase III** trials usually include several hundred patients and are often conducted in more than one location at a time. Patients are chosen to receive either the new treatment or the standard treatment. Usually the trials are “double blind,” meaning neither the doctor nor the patient knows which treatment the patient is receiving.

Information on clinical trials available can be found several places. There is no one place to get information on all the government and private clinical studies being conducted, and new studies are continually starting.

**The National Cancer Institute (NCI)**

[http://cancernet.nci.nih.gov/clinicaltrials](http://cancernet.nci.nih.gov/clinicaltrials)

This website provides the Physician Data Query (PDQ), which is a comprehensive database of cancer information. It contains a database of both open and closed clinical trials. There are
step-by-step instructions on searching the database for clinical trials. The general public can also call the NCI’s Cancer Information Service (1-800-4-CANCER) to request a customized search of the PDQ database.

**The National Institutes of Health (NIH)**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

The NIH maintains an even larger database of clinical trials, but not all of them are cancer-specific. ClinicalTrials.gov is a registry of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov offers information about a trial's purpose, who may participate, trial locations, and phone numbers for obtaining more information. This information should be used in conjunction with advice from healthcare professionals. ClinicalTrials.gov currently contains over 60,000 trials sponsored by the National Institutes of Health, other federal agencies, and private industry. Studies listed in the database are conducted in all 50 States and in 161 countries. ClinicalTrials.gov receives over 40 million page views per month—50,000 visitors daily. At the time of this publication, over 1,000 sarcoma trials were listed, including 400 that were recruiting for participants.

**CenterWatch Clinical Trials Listing Service**

[www.centerwatch.com](http://www.centerwatch.com)

CenterWatch offers several services and resources specifically for patients. Its Clinical Trial Listing Service provides patients unbiased information on clinical trials, with a clinical trial database that contains thousands of currently enrolling trials. Information on drugs and new medical therapies are available to review. CenterWatch also provides patients with health and educational resources about clinical trials and other health information.

**Midwest Sarcoma Trials Partnership**

[http://www.midwestsarcoma.org](http://www.midwestsarcoma.org)

A partnership of sarcoma medical oncologists from Northwestern University, the University of Iowa, the University of Minnesota, the University of Wisconsin, Mayo Clinic, and Washington University in St. Louis collaboratively develop investigator-initiated studies for patients with sarcoma in the Midwest, Arizona, and Florida. These trials are also listed at [www.clinicaltrials.gov](http://www.clinicaltrials.gov).
RESOURCES FOR CAREGIVERS

American Academy of Family Physicians
This website provides an article about caregiver care and support.

The Caregiver Action Network (CAN)
http://caregiveraction.org/
The Caregiver Action Network is the nation’s leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer’s disease. CAN (the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

CaringInfo
http://www.caringinfo.org/
InfoLine: 800-658-8898
CaringInfo (formerly Caring Connections) is a program of the National Hospice and Palliative Care Organization. Since its inception, the program has provided the general public a toll-free InfoLine, a multilingual InfoLine, and free educational materials, including advance directives, to better understand all aspects of end-of-life care—advance care planning, caregiving, grief, hospice, pain and palliative care.

Jack’s Caregiver Coalition
www.jackscaregiverco.org
612-547-6929
Jack’s Caregiver Coalition exists to serve the male caregiver. Its ultimate goal is to help men build their own support systems with three primary tools: informal get-togethers; a project-based support community; and a network of resources.

FOR PATIENTS WHO ARE PARENTS, TOO
As is always the case, being both a patient as well as the parent of a young child or adolescent can make a diagnosis of cancer all the more difficult. Coping with your own fears and
unanswered questions can be overwhelming in itself, but trying to do this while also helping your child to understand his or her role in your treatment plan can be doubly difficult.

Fortunately, there are a number of resources available to assist the parenting patient in talking with his/her child. The following section has a list of the many resources available as well as places to go for support. Generally speaking, try to be as honest as you can with your child, but stay age-appropriate in what you share and how you share it. In fact, you may involve your child in helping you to draft questions for your doctor at your next appointment.

Make sure to reinforce to your child that while you are sick and may start to look and feel different, this does not mean that your love for your child will change. As such, encourage your child to be as involved in your care to the extent s/he wants to be and is capable. For younger children, perhaps suggest s/he assist you in documenting your new journey through the use of photographs, handmade pictures, illustrations, videos, or journals.

Most of all, remember that your child loves you. As a result, s/he may experience a variety of emotions as a result of your diagnosis. Keep him/her involved and think about ways that s/he can feel supportive of you during this difficult time.

**Non-profit Educational and Support Organizations for Children and Their Families:**

**Kids Konnected**
[www.kidskonncected.org](http://www.kidskonncected.org)
949-582-5443

Kids Konnected is founded under the premise that when a parent gets cancer, the entire family is affected. Children facing similar fears and experiences can be helped by others in a similar situation. Resources offered include quarterly newsletters, support groups, children's camps, online chat rooms, and other events.

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SECTION VII: THE REIN IN SARCOMA FOUNDATION

OUR MISSION
The Rein in Sarcoma Foundation is dedicated to educating the public and the medical community about sarcomas. The Foundation also supports sarcoma patients and their loved ones and funds research to develop new treatments and a cure for sarcoma cancers.

The Rein in Sarcoma Foundation (RIS) primarily serves the Upper Midwest sarcoma community and is one of a number of regional sarcoma organizations across the country started by patients and their loved ones. The organization was founded by Karen Wyckoff shortly before her death from synovial sarcoma in 2001.

Since then, her friends and family and, increasingly, sarcoma patients, survivors, and the families of those who have died of this disease, have worked to keep her vision alive. In 2004, The Rein in Sarcoma Foundation was created as a Minnesota nonprofit organization to build on the work that Karen had begun.

We have taken major steps forward in the fight against sarcoma. We have expanded our work in the Upper Midwest to support research that is focused on finding a cure for sarcoma cancers. We have increased physician and public awareness of these cancers and have increased our support for survivors, loved ones, and those who have lost someone to sarcoma. Over the past 15 years, we have raised over 1.6 million dollars to support the activities of the RIS Foundation.

In 2014, the Rein In Sarcoma Foundation went through a review process with the Charities Review Council of Minnesota. In December, the Council announced that Rein in Sarcoma met all twenty-seven of the Council’s Accountability Standards, and it 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.


“The Rein in Sarcoma Foundation is dedicated to overcoming the devastation of sarcoma. It has three strategies: Education, patient support, and research.”

**Education**

Our signature educational program is the RIS Red Flags of Sarcoma campaign. Its goal is to significantly reduce the amount of late and misdiagnosed sarcoma cancers. While most cancers are diagnosed within four months of the onset of symptoms, sarcomas take fourteen months to be correctly identified. Earlier diagnosis could increase survival rates by as much as 20%.

Through RISF advocacy, sarcoma diagnostic education has been added to the University of Minnesota (U of MN) Medical School’s curriculum. Public and professional printed materials have been developed. Our medical advisory team consists of doctors from the U of MN and Children’s Hospitals and Clinics, Mayo Clinic and Health Partners. Together, they are working to educate primary medical professionals throughout the Upper Midwest. In addition, RIS has released a YouTube video: Sarcoma Cancers: From “Never Heard of It” to “I Caught It Early,” which has been viewed by thousands. During the 2016-17 medical school year we awarded five sarcoma scholarships—three at the U of MN and two at the Mayo Clinic Medical School. The scholars learn about sarcoma and coordinate programs during the year to educate their peers and other physicians about sarcoma.

**Patient Support**

In support of sarcoma patients and their caregivers and loved ones, we publish this *RIS Patient Starter Notebook*. The Notebook is a comprehensive and supportive resource provided at no charge to newly-diagnosed sarcoma patients in Minnesota and throughout the country. This sixth edition was published in November of 2016 with updates by doctors from the University of Minnesota, Children’s Hospitals and Clinics, and The Mayo Clinic. We owe a debt of

“I had gone to three different doctors and had three different surgeries before we finally discovered that, in fact, it was sarcoma cancer... So let’s change the sarcoma story.”

- Lisa Griebel, sarcoma survivor
gratitude to the Amschwand Sarcoma Cancer Foundation, which developed a similar guide in 2005 and gave us permission to build upon it.

In the fall and winter, RIS also hosts Gatherings for patients, survivors, and loved ones throughout the Twin Cities metropolitan area. To learn more about RIS Gatherings, check on www.reininsarcoma.org or call 651-486-9114.

Research

To date, RIS has provided seed grants of over 1.5 million dollars for sarcoma research at the University of Minnesota. This has led to an additional 6 million dollars in external peer review sarcoma funding from private and public sources. As a result, sarcoma research and clinical faculty at the U of MN have quadrupled in the last ten years.

In 2016, RIS awarded new grants to the University of Minnesota Masonic Cancer Center, totaling $125,000. A complete description of these and other grants made by the Foundation can be found on the Rein in Sarcoma website by clicking “About” in the masthead.

THE REIN IN SARCOMA PARTY

The annual Rein in Sarcoma Party in the Park is held in late July at Cafesjian’s Carousel and Como Park Visitor’s Center in St. Paul, MN. Our objective is to create a lively, affordable, family-oriented, fun evening for folks of all ages. Activities for children include unlimited free rides on the Cafesjian’s Carousel (the genesis of the word "rein" in our organization’s name). The event also has a variety of entertainers and a large silent auction with over 200 items. The 2016 Party, with more than 1500 people from five states in attendance, raised over 70,000.

Prior to the public fundraiser, RIS hosts a free picnic at the Como Park picnic grounds for sarcoma patients, survivors, and their families and friends. More than 500 people, including 80 sarcoma patients and survivors, attended the 2016 picnic. The Party in the Park is scheduled annually on the last Monday evening of July.

“Curing sarcomas and comforting the patients and families who are affected by this dreaded cancer requires a multi-faceted approach and collaboration across broad areas of expertise. The RIS support of activities within the University of Minnesota Cancer Center has had an impressive impact on improving the lives of affected patients and has moved us remarkably closer to finding a cure.”

– Denis Clohisy, M.D. Head, Department of Orthopaedic Surgery, University of Minnesota
While the over 1.5 million dollars raised by RIS since 2001 is significant, the money is only a small part of our story.

It is the story of all who came to celebrate life and hope with the dedicated doctors, nurses and volunteers. One survivor recounted: “My wife and I shared a table with another survivor my age and her husband. Sharing our stories over dinner energized me, gave me more hope, and helped me release anxiety.”

It also is the story of one family of five with no direct sarcoma connection. They came to volunteer, in part, to teach their children the important lesson of commitment to a community, and of joining together to address an orphan disease.

It also is the story of a newly-diagnosed sarcoma patient who sat in fear at a recent RIS Gathering. She turned to the sarcoma survivor next to her, who had the same type of sarcoma cancer she is now battling, and asked, “And how long have you been dealing with the wretched disease?” He responded, “Twenty-one years.” Tears of joy filled her face as she found both support and hope sitting in front of her.

We are the story of each sarcoma survivor who brings a new level of energy and hope to all those touched by sarcoma. Research, fellowship, support, and caring are a powerful mix. That excitement is leading to plans in 2017 and beyond for more patient support, more research, and new ways to communicate with medical personnel about sarcoma cancers.

None of this would have been possible without the efforts of hundreds of volunteers and the support of more than 2,000 contributors, supporters, corporate sponsors, sarcoma patients, and loved ones.

“I do not know what death is, but someday I too will die. Hopefully, I will leave behind a better world for my passing. I hope that when I die, I will be able to look back on a life that was fulfilling and was spent living, not waiting to die.”

- From an essay written by Karen Wyckoff in high school, four years before her sarcoma diagnosis.
Rein in Sarcoma
Support Network Registration Form

Please complete the form below to register with the Rein in Sarcoma support network. You also may register online at www.reininsarcoma.org. You will be provided with updates on new support resources, along with invitations to support functions and volunteer opportunities (if you desire). This information will not be shared with any outside organization without your specific permission. Thank you for the privilege of assisting you in your journey.

Please Print:
Your name: ____________________________________________________________
Address: ______________________________________________________________________
City: ____________________________ State: _______ ZIP: ____________
Phone (area code) ____________________/_____________________________
Your e-mail address: __________________________________________________________

Your connection with sarcoma cancers (check all that apply)

☐ Sarcoma patient or survivor –
   If yes, please tell us the type of diagnosed sarcoma: __________________________
   Approximate date of initial sarcoma diagnosis: __________________________

☐ Loved one of a sarcoma patient - Relationship: __________________________
   If appropriate, provide sarcoma patient's name: __________________________
   If appropriate, provide sarcoma patient's e-mail address: __________________________

☐ Person who has lost someone to sarcoma cancer
   Name of loved one: ____________________________ Date of death: __________
   Relationship: ____________________________

Your comments or special concerns: ____________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
SECTION VIII: CONTACT INFORMATION AND LOGS

CONTACT INFORMATION
(Section VIII, pages 3-4)
Your contact information is one of the most useful sections of your Notebook, and it is important to keep it readily available. The sheets following include suggested contacts, but you also may want to include personal contacts such as utilities, banks, childcare providers, schools, babysitters, spouse’s work, parent’s work, etc.

Make sure you keep detailed notes of your conversations, including the date and name of the person with whom you spoke. Do not hesitate to ask them to explain or spell out information you do not understand.

LOGS
(Section VIII, pages 5-19)
This section provides structure to the patient or caregiver to assist in keeping track of temperature, reactions to treatments, diet, nausea, mouth sores, and more. The purpose is to keep accurate detail of your experiences in order to facilitate sharing with your doctor. The more s/he knows, the better s/he can determine the right course of treatment for you.

The following logs are included in this Section:

- Physician/Nurse Encounter Log            Pages 5-7
- Pharmacy Log Sheet                      Pages 9-10
- Diet Log                                Pages 11-12
- Medical Records and Medical History     Page 13-14
- “To Do” List for Your Support Network   Page 15-16
- Wong – Baker FACES Pain Rating Scale    Page 17
- Symptoms Log                           Pages 18
Notes....
## Important Contact Information

### Emergencies

| Name: __________________________ | Name: __________________________ |
| Address: ________________________ | Address: ________________________ |
| City/St/Zip: ____________________ | City/St/Zip: ____________________ |
| Home: __________________________ | Home: __________________________ |
| Cell: __________________________ | Cell: __________________________ |
| Work: __________________________ | Work: __________________________ |
| Fax: ___________________________ | Fax: ___________________________ |
| Email: __________________________| Email: __________________________|

### Doctors

| Name: __________________________ | Name: __________________________ |
| Hospital: ______________________ | Hospital: ______________________ |
| Phone: __________________________| Phone: __________________________|
| Fax: ___________________________ | Fax: ___________________________ |
| Comment: _______________________ | Comment: _______________________ |
| Email: __________________________| Email: __________________________|

### Nurses

| Name: __________________________ | Name: __________________________ |
| Doctor: _________________________ | Doctor: _________________________ |
| Hospital: ______________________ | Hospital: ______________________ |
| Phone: __________________________| Phone: __________________________|
| Fax: ___________________________ | Fax: ___________________________ |
| Comment: _______________________ | Comment: _______________________ |

### Pharmacy Information

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<td>Email: __________________________________</td>
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<td>Reference #: _____________________________</td>
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</table>
## Physician/Nurse Encounter Log

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<tr>
<th>Date</th>
<th>Question</th>
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Section VIII: Contact Information and Logs Page 5
## Physician/Nurse Encounter Log

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### Physician/Nurse Encounter Log

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Notes:
MEDICINES AND COMPLEMENTARY THERAPIES

It is imperative that you keep detailed records of your medicines and complementary therapies, including vitamins, supplements, and herbs. High dosages of certain vitamins may have an adverse reaction when taken with certain medications. In addition, certain medications should not be taken together. A detailed record may assist physicians and pharmacists in devising your treatment plan.

The following log sheet will assist you in organizing your medications. It also may be helpful to keep the pharmacy disclaimers and prescription information following the log sheet in your Notebook for future, easy reference should you, your loved one, or your healthcare team need the information later.

Pharmacy Information Log

Name: ___________________________  Name: ___________________________

Phone: ___________________________  Phone: ___________________________

Medicines & Complementary Therapies

<table>
<thead>
<tr>
<th>Name (Generic/Brand)</th>
<th>Dosages</th>
<th>Used For</th>
<th>Prescription Number</th>
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### Pharmacy Information Log

Name: ___________________________  Name: ___________________________

Phone: ___________________________  Phone: ___________________________

### Medicines & Complementary Therapies

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<th>Name (Generic/Brand)</th>
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**DIET LOG**

Good nutrition is important. This is especially true for persons with serious illnesses such as cancer. As is always the case, any changes to one’s diet should be made in consultation with a qualified doctor.

This log was created as a means by which to assist the interested cancer patient in keeping better track of what is consumed. A well-balanced diet is ideal, but keep in mind that during the course of your treatment, any food may be better than none at all. Make sure to talk with your doctor about your diet. S/he can suggest nutrition goals based on your individual circumstances.

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<th>DATE</th>
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<th>DRINK</th>
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### Diet Log (Continued)

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**MEDICAL RECORDS**

It is important for each of your care providers to have a complete copy of your medical record. In fact, if you are at the center of your care team, then it likely makes sense for you to have one, too. Throughout the course of your treatment, you (or your support person) and your doctors may refer back to parts of your medical record. As such, it is recommended that you always ask for copies of lab values, results, tests, and other impressions as they are added to your record. The average cancer patient can accumulate a pretty thick medical record in a very short period of time. Because of this, building your own “shadow” record as your official hospital or clinic record grows makes a great deal of sense.

Get in the habit of asking for copies of additions to your medical record before you leave each appointment. Then keep the most recent information in this section for easy reference when you or maybe another specialist needs it in the future.

Many health plans in Minnesota and elsewhere are now developing and using Electronic Medical Records (EMR). You should have access to these. Check with your health plan.

**MEDICAL HISTORY**

You will be asked to recount your medical history often.

Important information that should be included:

- Childhood illnesses;
- Traumas and injuries (broken bones, car accidents);
- History of medication use and any allergic reactions;
- Onset of menstrual period, menopause or pre/post menopause;
- Allergies; and
- Your family’s medical history (illnesses of your blood relatives).

**PORTABLE AND PERSONAL MEDICAL RECORDS (PMR)**

In the long term, it may be very helpful to have a personal portable health care record that you can develop in conjunction with your healthcare providers. Healthcare records need to be concise yet complete. They are particularly useful as you transition care from your home to the ER or hospital, from your specialist to a generalist, and from doctor to doctor. Such
medical records need to be easily accessible and are ideally Web-based. To be effective, they also need to be updated on a regular basis to reflect changes in your condition.

You've probably seen your chart at your doctor's office. In fact, you may have charts at several doctors' offices. If you've been in the hospital, you have a chart there, too. To keep track of all this information, it's a good idea to keep your own records.

What kind of information would you put in a personal health record? You could start with:

- Your name, birth date, blood type, and emergency contact;
- Date of last physical exam;
- Dates and results of tests and screenings;
- Major illnesses and surgeries, with dates;
- A list of your medicines, dosages, and how long you've taken them;
- Any allergies;
- Any chronic diseases; and
- Any history of illnesses in your family.

Options:

- **Microsoft HealthVault** helps you gather, store, use, and share health information for you and your family: [https://www.healthvault.com/us/en/overview](https://www.healthvault.com/us/en/overview)
- **Medline Plus** offers an overview of Personal Health Records along with links and resources: [www.nlm.nih.gov/medlineplus/personalmedicalrecords.html](www.nlm.nih.gov/medlineplus/personalmedicalrecords.html)

Also inquire with your health plan or medical provider to see if the Electronic Medical Records (EMR) that you may have access to can meet these needs.
To Do List

*(See Section III – Pages 4 and 5 for more information)*

<table>
<thead>
<tr>
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<th>Comments</th>
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To Do List

(See Section III – Page 3 for more information)

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<th>Delegated To (and the phone number where they can be reached)</th>
<th>Comments</th>
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Wong-Baker FACES Pain Rating Scale

The Wong-Baker FACES Pain Rating Scale was created by Dr. Donna Wong in order to better assess pain in children. Since its creation, the FACES Scale has been widely used by doctors and nurses in assessing the pain of both children and adults in a variety of settings.

The FACES scale is included in your Sarcoma Survivor Starter Notebook in an effort to assist you in better assessing and documenting your own pain throughout your treatment course. Today, doctors and nurses recognize the importance of controlling pain to the greatest possible extent. As such, it is important to let your doctor and/or nurse know about your own experiences, so that s/he can assist you in developing the best treatment plan.

**Instructions:** Each face is for a person who either feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 1 hurts just a little bit. Face 2 hurts a little more. Face 4 hurts even more. Faces 6 and 8 hurt a whole lot. Face 10 hurts as much as you can imagine, although you do not have to be crying to feel this bad.

Choose the face that best describes how you are feeling each day. Make sure to note your experience (on the log included in your Notebook if you prefer). This will be important information to share with your care provider at your next visit.

The FACES Pain Rating Scale was developed and copyrighted by Wong D.L., Hockenberry-Eaton M., Wilson D., Winkelstein M.L., Schwartz P.: Wong’s Essentials of Pediatric Nursing, ed. 6, St. Louis, 2001, p. 1301. Its use for anything other than for, by or with patients is not allowed without express written consent of the original authors.
# Symptom Log

<table>
<thead>
<tr>
<th>DATE</th>
<th>TEMP</th>
<th>NAUSEA</th>
<th>MOUTH SORES</th>
<th>PAIN</th>
<th>OTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Indicate: None</td>
<td>Indicate: None</td>
<td>See FACES Pain Scale on page 15</td>
<td>Any other symptoms should be noted here to be shared with your doctor or nurse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mild (some upset stomach)</td>
<td>Mild (some soreness)</td>
<td>Moderate (vomited some)</td>
<td>Moderate (interfered with eating)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe (unable to keep food/drink down)</td>
<td>Severe (unable to eat b/c mouth)</td>
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</tbody>
</table>

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Section VIII: Contact Information and Logs Page 18
SUPPORT NETWORK REGISTRATION FORM

Please complete the form below to register with the Rein in Sarcoma support network. You also may register online at www.reininsarcoma.org or linking through the QR code above from your “smart” phone. You will be provided with updates on new support resources, invitations to support functions, and volunteer opportunities (if you desire). If you provide us an email address, you will also receive the monthly RIS Update, a highly informative electronic newsletter. This information will not be shared with any outside organization without your specific permission. Thank you for the privilege of assisting you in your journey.

Please Print
Your name: ____________________________________________

Address: ________________________________________________

City: _____________________________ State: _______ ZIP: __________

Phone (area code) _______ / ___________________ Cell Phone: ______________________

Your e-mail address: __________________________________________

Your connection with sarcoma cancers (check all that apply)

• Sarcoma patient or survivor –
  If yes, please tell us the type of diagnosed sarcoma: ____________________________
  Approximate date of initial sarcoma diagnosis: ____________________________

• Loved one of a sarcoma patient - Relationship: ________________________________
  If appropriate, provide sarcoma patient's name: ____________________________
  If appropriate, provide sarcoma patient's e-mail address: ______________________

• Person who has lost someone to sarcoma cancer
  Name of loved one: ____________________________ Date of death: __________
  Relationship: ____________________________________________

Your comments or special concerns: ____________________________________________

________________________________________________________________________
Help us to improve this
RIS Sarcoma Patient Starter Notebook

1. Overall, how would you rate this Notebook?
   Excellent _____ Very Good _____ OK _____ Fair ____ Poor_____

2. What do like most about the Notebook? __________________________
   __________________________________________________________
   __________________________________________________________

3. Which Section was most helpful? ____________________________
   Why? ______________________________________________________
   __________________________________________________________

4. Which Section was the least helpful? ________________________
   Why? ______________________________________________________
   __________________________________________________________

5. What would you like to see included in the next edition of the
   Notebook? _________________________________________________
   __________________________________________________________
   __________________________________________________________

6. Have you visited the Rein in Sarcoma website? (www.reininsarcoma.org)
   Yes _____ No ______
   If yes, what did you like best about the website? ______________
   __________________________________________________________
   __________________________________________________________

7. How could Rein in Sarcoma better serve you? ________________
   __________________________________________________________
   __________________________________________________________

8. Other comments about the Notebook or Rein in Sarcoma:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

Would you like to be informed about upcoming Rein in Sarcoma
events and receive our email newsletter?
If so please provide your contact information.

Name: _____________________________________________________
Address:

City: __________________ State: _____ ZIP: __________
Phone: (area code): _______ Cell: _______________________
Email: ________________________________________________