ADULT SOFT TISSUE SARCOMAS: A GUIDE FOR PATIENTS

Table of contents

1) What is adult soft tissue sarcoma

Malignant tumors of the connective tissues are called soft tissue sarcomas. The normal connective tissue of the body include, fat, blood vessels, nerves, bones, muscles, deep skin tissues, and cartilage. Sarcomas are divided into two main groups, bone sarcomas and soft tissue sarcomas. Soft tissue sarcomas are further sub-divided based on the type of presumed cell of origin found in the tumor. Sarcomas can develop in children and adults. Overall, soft tissue sarcoma is a rare form of cancer. It comprises approximately one percent of all cancers diagnosed. According to the National Cancer Institute, there are approximately 11,280 new cases of soft tissue sarcoma in the United States each year and approximately 3,900 people die of the disease each year. About 40 percent occur in the lower limb. Fifteen percent develop in the hands and arms, another 15 percent in the head and neck and 30 percent in the shoulders, chest, abdomen, or hips.

Soft tissue sarcomas can invade surrounding tissue and can metastasize (spread) to other organs of the body. Secondary tumors are referred to as metastatic soft tissue sarcoma, because they are part of the original cancer and are not a new disease. Some tumors (e.g. lipoma, which is frequently found as a superficial smooth and mobile lump) of the soft tissue are benign (non-cancerous) and are rarely life threatening.

2) How rare is Soft tissue sarcoma?

Sarcomas account for about 1% of all adult tumors and are made up of over 80 different histological subtypes. Due to its rarity, it is crucial for patients to seek a cancer center specialized in the treatment of their disease.

Among soft tissue, liposarcomas are one of the most common subtypes; however, liposarcomas are also a group of diseases, each with their own unique biology and response to systemic therapy.

Sarcomas are relatively more common among children than in adults. Between 1,500 and 1,700 U.S. children are diagnosed with a bone or soft tissue sarcoma each year making up about 15 percent of pediatric cancers (compared to that 1 percent of adult cancers), but pediatric cancers themselves are rare and make up only 1 percent of cancer cases. It has been estimated that one in 304 men and women will be diagnosed with cancer

of the soft tissue during their lifetime. The SEER (Surveillance Epidemiology and End Results) data indicates that about a third of soft tissue cancers over half of bone sarcomas are diagnosed in people under 45 years of age. In comparison, less than one-tenth of all cancers occur in this age group.

The median age of all cancer diagnoses in the U.S. is 66 years, whereas it is 58 years for soft tissue cancers. Thus, the average age of sarcoma diagnosis is considerably younger than the age of most cancer diagnoses. Because many sarcoma patients are young, with the exception of their sarcoma they are relatively healthy. They should be ideal candidates for research studies, as they are less likely to have other health issues which may compromise the ability to try intensive treatments.

Overall, one in every 150 families will include someone who is battling or who has battled with sarcoma.

3) What are the principal subtypes of soft tissue sarcomas?

Liposarcoma

Liposarcoma is the most commonly diagnosed tumor of the soft tissue. These tumors usually develop in the deep fatty tissue. They most commonly occur in the thigh, behind the knee, the groin, the gluteal area or behind the abdominal cavity (retroperitoneum). Liposarcomas are usually malignant (cancerous) and rarely arise from a pre-existing lipoma, which is a non-cancerous tumor. They are most commonly found in adults between 30 and 60 years old and are slightly more common in men than women. The tumor can invade surrounding tissues, while metastases to the lymph nodes occur only in approximately 10% of patients.

The most common are well-/de-differentiated liposarcoma, which are characterized by amplifications in *CDK4* and *MDM2*. These tend to present as large primary tumors and local control can be a major challenge. The second group is myxoid liposarcoma characterized in the majority of cases by a specific chromosomal translocation t(12;16). These tumors tend to present with lower limb primaries and metastasize to unusual locations for sarcomas, such as pleural, pericardial and bone. The third subtype, pleomorphic, is very rare

and these tumors have a complex karyotype, with many genetic gains and losses. They tend to have an aggressive clinical course.

Fibrosarcoma

Fibrosarcomas usually occur in the arms or legs or on the trunk but can occur in any of the soft tissues. They can occur around scars, muscles, nerves, tendons, and around the lining of the bone (periosteum). Local recurrence after surgery is common. Fibrosarcomas typically invade local tissues and can metastasize through the bloodstream to the lungs. Less than 5% of patients will experience metastases to the lymph nodes.

Dermatofibrosarcoma Protuberans

This lesion can be found on the back or abdomen. In the early stages the tumor remains under the skin and the skin surface appears dark red-violet. If untreated, the tumor can break through the skin forming an open wound. It has a tendency to recur, but rarely metastasizes. Treatment consists of wide surgical excision.

Malignant Fibrous Histiocytoma

Malignant fibrous histiocytomas are the most commonly diagnosed soft tissue sarcoma in patients between the ages of 50 and 70. It is twice as common in men than women.

Synovial Cell Sarcoma

Synovial cell sarcoma usually occurs in young adults. They are most commonly found in the arms or legs next to a joint. They are usually found around the joint capsule but rarely invade the joint itself. The most common site is adjacent to the knee. They are also commonly found near the foot, ankle and hand. Unlike other soft tissue sarcomas, synovial cell sarcomas are often painful. Treatment usually consists of radical excision with radiation and chemotherapy or amputation combined with chemotherapy.

Epithelioid Sarcomas

Epithelioid sarcomas typically occur in the hand or foot of young adults. They appear like small nodules, which sometimes merge together. Spreading to lymph nodes occurs in approximately 20% of patients. Because of their proximity to the joints, surgical excision can be difficult and often amputation is the surgery of choice for long-term survival.

Rhabdomyosarcomas

Cancerous tumors in the striated or skeletal muscle are one of the most common types of soft tissue sarcoma, and account for about half the soft tissue sarcomas diagnosed in children. There are several different types, including pleomorphic, alveolar, embryonal and botryoid.

- *Embryonal Rhabdomyosarcoma:* This is the most common type of rhabdomyosarcoma, and is diagnosed most frequently in children under the age of 10. It can be found anywhere in the body, butoften occurs in the head and neck especially around the eye. Chemotherapy is very effective in these tumors. There is a high cure rate in these tumors when combination therapy is used (i.e. surgery and/or radiation combined with chemotherapy).
- *Alveolar Rhabdomyosarcoma:* This tumor is extremely aggressive and typically occurs in adolescents and young adults. Tumors metastasize widely at an early stage. Alveolar rhabdomyosarcoma almost always is associated with a translocation between two genes (PAX3 or PAX7 and FOX01). Treatment includes radiation and chemotherapy as well as surgery for some cases. Localized alveolar rhabdo responds fairly well to treatment.
- *Botryoid Rhabdomyosarcoma:* These lesions usually occur in children at the average age of 7. They generally occur in the genital region and urinary tract. They appear as a swollen lumpy mass.
- *Pleomorphic Rhabdomyosarcoma:* This tumor occurs most commonly in people over 30 years of age. It commonly affects males on their extremities but not exclusively. Because it grows in the skeletal muscle, it usually is deep in the limb. Tumors can arise at many sites within the same muscle group and grow very rapidly. The tumor spreads through the bloodstream although in approximately 15% of cases the tumor spreads through the lymphatic system. Rhabdomyosarcoma is often widely spread at the time of diagnosis. Treatment generally consists of surgery and combination chemotherapy (multiple drugs used).

Leiomyosarcoma (Smooth Muscle Tumor) and Uterine Sarcoma

Leiomyosarcomas are cancerous tumors of the smooth muscle. They most commonly occur in the organs (e.g., gastrointestinal tract and the uterus). The average age of patients is 60 years. Of the tumors occurring in the GI tract 61% occur in the stomach, 29% in the small bowel, and 10% in the colon. Symptoms of GI or uterine leiomyosarcomas are significant bleeding and pain. Metastases occur in more than half of patients. Leiomyosarcomas of the retroperitoneum and the vena cava are found mostly in women. The growth of the tumors can accelerate during pregnancy. Metastases usually occur in the lungs except in GI tumors, which often metastasize in the liver. Treatment for uterine leiomyosarcoma is total abdominal hysterectomy.

Gastrointestinal Stromal Tumor (GIST)

GIST develops in the stroma, the supporting connective tissue, of the stomach and intestines. It is now often treated with the biological agent Gleevec. Gleevec is a biologic agent that works by shutting down the activities of gtenes that apparently are needed for the tumor's growth. In particular, it targets a gene called c-kit that produces inappropriate amounts of an enzyme that promotes the tumor growth.

Extraosseous Tumors

There are three types of Extraosseous tumors. They are giant cell tumors, osteosarcomas, and Ewing's sarcoma. These are bone sarcomas, which are found in the soft tissue. They have very similar characteristics as their bone sarcoma variation, Extraosseous Ewing's sarcomas respond well to radiation therapy.

Myxoma

Myxomas occur in men and women averaging the age of 50. They are most often found in the arms and legs. Tumors can be small nodules or very large tumors. They do not metastasize; however, they do spread locally. Treatment is usually wide local excision.

Vascular Sarcomas

- *Hemangioendothelioma: this is* a very rare vascular (containing many blood vessels) tumor, which can be malignant. They occur in men and women but rarely in children. One variety of this tumor occurs in younger males and typically arises on the hand and tends to recur locally.
- *Angiosarcomas: a*ngiosarcomas represent 1% of all sarcomas. One-third of the cases occur on the skin, one-fourth of the cases occur in the soft tissue or organs such as breast, liver, heart and lungs. Tumors arising in the liver are observed in adults exposed to insecticides or plastics. Angiosarcomas of the breast typically occur in young or middle aged women. Additionally some angiosarcomas occur at the site of previous radiation therapy or in chronically lymphedematous tissues. Tumors metastasize widely. The most common forms of treatment are surgical resection and chemotherapy.
- *Hemangiopericytoma: h*emangiopericytomas are typically found in the thigh, retroperitoneum or near the kidneys.

Malignant Schwannoma

Malignant Neurilemomas usually develop in young to middle aged adults, most commonly in males. They occur in the peripheral nerves. Half of these tumors occur in people with Von Recklinghausen's disease or multiple neurofibromatosis. The spreading of these tumors occurs in the surrounding soft tissue forming a nodular tumor. Metastases can occur through the bloodstream. Tumors can be painful, tender and sometimes nerve function is affected. Treatment is generally wide resection of the nerve in either direction. Radiation therapy and chemotherapy can be used as well.

Alveolar Soft-Parts Sarcoma

This is a very rare tumor that typically occurs in female adolescents and young adults. It is usually a slow growing tumor found in the extremities and commonly metastasizes to the lung. The typical form of treatment is wide resection of the lesion.

Kaposi's sarcoma

Kaposi ’s sarcoma is a disease in which cancerous cells are found in the tissues under the skin or mucous membranes that line the mouth, nose and anus. There are three groups of patients for Kaposi’s sarcoma. The first group typically includes older men of Jewish, Italian or Mediterranean heritage. This type of Kaposi’s usually progresses slowly over 10-15 years. Patients commonly develop a bluish lesion on the front of the lower leg, which typically spreads to multiple lesions. After some time the disease can spread to other organs. The second group of Kaposi’s sarcoma occurs in patients who have received organ transplant. Due to the Immunosuppressive treatment following a transplant, patient’s immune systems are weakened thus are more susceptible to infection. The third group of Kaposi’s sarcoma is found in AIDS patients. Due to the weakened immune system cause by the HIV virus, Infections and other diseases such as Kaposi’s can invade the body. Kaposi’s sarcoma in people with AIDS usually spreads more quickly and can be found in many parts of the body. Surgery, locoregional chemotherapies and radiation therapy represent the treatment for Kaposi’s sarcoma; however, when lesions have spread to the organs, chemotherapy is often used as well.

4) Where does soft tissue sarcoma occur?

Extremity and superficial trunk sarcomas are the most common site for soft tissue sarcomas and make up 60% of all adult cases. Patients present with a lump, which is usually painless.

Retroperitoneal sarcomas usually present with an abdominal mass, with half reporting pain at presentation. Patients can present with a large tumour due to the space available in the retroperitoneum for the tumour to grow and often require complex surgical intervention.

Viscera sarcomas present with signs and symptoms particular to the organ of origin. For example, GIST can present as upper abdominal pain in 40–50% of cases. Sarcomas of the uterus often present with painless vaginal bleeding as occurs with other uterine malignancies. Head and neck sarcomas can arise from bone, cartilage or the soft tissues of the head and neck. They can present as a lump, with problems relating to compression of the surrounding anatomy such as the orbit or pharynx. Surgery and radiotherapy are difficult because of the proximity of important anatomy in this area.

5) What are the causes of soft tissue sarcoma?

It is not clear why some people develop sarcoma; however, 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 some herbicides and clorphenols have increased risk of soft tissue sarcoma. Researchers also know that people exposed to high doses of radiation are at a greater risk for developing soft tissue sarcoma. Researchers are also studying genetic abnormalities and chromosome mutations as possible causes for soft tissue sarcoma. People with certain inherited diseases such as neurofibromatosis, tuberous sclerosis, familial adenomatous polyposis, (FAP; Gardner syndrome), Li-Fraumeni syndrome. Werner syndrome, Nevoid basal cell carcinoma syndrome (Gorlin syndrome). Other risk factors for soft tissue sarcoma include the following: past treatment with radiation therapy for certain cancers; being exposed to certain chemicals, such as thorium dioxide, vinyl chloride, or arsenic; finally, having swelling (lymphedema) in the arms or legs for a long time.

6) What are the symptoms of soft tissue sarcoma?

Since these tumor are so rare, it can be difficult to establish the diagnosis. Most general practitioners will only see two to three sarcoma patients in their career. Consequently, there can be a delay in the diagnosis of sarcomas. In addition, because there are so many subtypes, the histological diagnosis can also be challenging. An experienced multidisciplinary team should treat sarcoma patients. Due to the rarity, heterogeneity and widespread anatomic primary sites these tumors are very challenging to treat. Early on, soft tissue sarcoma rarely causes any symptoms. Because soft tissue is very elastic, the tumors can grow quite large before they are felt by the patient. The first symptom is usually a painless lump. As the tumor grows and begins to press against nearby nerves and muscles, pain or soreness can occur.

7) How soft tissue sarcoma is diagnosed?

Soft tissue sarcomas can only be diagnosed by a surgical biopsy. A biopsy is an outpatient procedure, which removes a small amount of tissue from the tumor suitable for being analyzed under a microscope. The type of biopsy will be based on the size of the tumor and where it is in the body. There are three types of biopsy that may be used. The incisional biopsy is the (surgical) removal of a small portion part of the lump; the core biopsy is the removal of as small piece of tumor tissue by using a wide needle; finally, the excisional biopsy is the removal of the entire lump. All soft tissue sarcomas are either first reported or reviewed by a specialist sarcoma pathologist, who is a pathologist who regularly reports soft tissue tumors.

8) How soft tissue sarcoma is staged?

The process used to find out if cancer has spread within the soft tissue or to other parts of the body is called staging. Staging of soft tissue sarcoma is also based on the grade and size of the tumor, whether it is superficial (close to the skin's surface) or deep, and whether it has spread to the lymph nodes or other parts of the body. The information gathered from the staging process determines the stage of the disease. It is important to know the stage in order to plan treatment. The following tests and procedures may be used in the staging process: chest x-rays, ultrasound scan (US), computerized tomography (CT) scan, magnetic resonance imaging (MRI), positron emission tomography (PET) scan.

Stage I soft tissue sarcoma (includes stages IA and IB)

In **stage IA**, the tumor is low-grade (likely to grow and spread slowly) and 5 centimeters or smaller. It may be either superficial (in subcutaneous tissue with no spread into connective tissue or muscle below) or deep (in the muscle and may be in connective or subcutaneous tissue). In **stage IB**, the tumor is low-grade (likely to grow and spread slowly) and larger than 5 centimeters. It may be either superficial (in subcutaneous tissue with no spread into connective tissue or muscle below) or deep (in the muscle and may be in connective or subcutaneous tissue).

Stage II (includes stages IIA and IIB)

In **stage IIA**, the tumor is mid-grade (somewhat likely to grow and spread quickly) or high-grade (likely to grow and spread quickly) and 5 centimeters or smaller. It may be either superficial (in subcutaneous tissue with no spread into connective tissue or muscle below) or deep (in the muscle and may be in connective or subcutaneous tissue). In **stage IIB**, the tumor is mid-grade (somewhat likely to grow and spread quickly) and larger than 5 centimeters. It may be either superficial (in subcutaneous tissue with no spread into connective tissue or muscle below) or deep (in the muscle and may be in connective or subcutaneous tissue).

Stage III

In stage III, the tumor is either: high-grade (likely to grow and spread quickly), larger than 5 centimeters, and either superficial (in subcutaneous tissue with no spread into connective tissue or muscle below) or deep (in the muscle and may be in connective or subcutaneous tissue); or any grade, any size, and has spread to nearby lymph nodes.

Stage IV

In stage IV, the tumor is any grade, any size, and may have spread to nearby lymph nodes. Cancer has spread to distant parts of the body, such as the lungs.

9) How soft tissue sarcoma is treated?

The treatment of soft tissue sarcomas is multimodal and coordinated by a multidisciplinary team including several different specialists (surgeon, radiologist, medical oncologist, radiotherapist, etc). In fact, soft tissue sarcomas are generally managed using surgery, radiation and chemotherapy or a combination of them depending on tumor size, location, extent and grade (growth rate) of the tumor.

The surgical team works in collaboration with the oncologists to plan treatment as required per agreed local network treatment protocols. Individuals work together with the same aims and clinical understanding of the condition and its management to create a multi-disciplinary team approach.

Many soft tissue sarcoma are discovered incidentally following excision of a lump, with no prior suspicion that it could be a sarcoma. Very often, this initial excision is inadequate and further treatment is required. The treatment of soft tissue sarcoma of the limbs or trunk is surgical excision of the primary tumour with an adequate margin of normal tissue around it. The surgical management of retroperitoneal sarcomas may require not only the removal of the primary tumor, but also of surrounding viscera (i.e. kidney, colon, etc.) in order to achieve microscopically-free resection margins.

In limb soft tissue sarcomas, the extension of surgery can be grouped as follows:

Wide local excision: Removal of the tumor along with some normal tissue around it. For tumors of the head, neck, abdomen, and trunk, as little normal tissue as possible is removed.

Limb-sparing surgery: Removal of the tumor in an arm or leg without amputation, so the use and appearance of the limb is saved. Radiation therapy and / or chemotherapy may be given first to shrink the tumor. The tumor is then removed in a wide local excision. Tissue and bone that are removed may be replaced with a graft using tissue and bone taken from another part of the patient's body, or with an implant such as artificial bone.

Isolated limb perfusion (ILP) is another option aimed at achieving a limb sparing surgical treatment. ILP is a procedure that sends chemotherapy directly to an arm or leg in which the cancer has formed. The flow of blood to and from the limb is temporarily stopped with a tourniquet, and anticancer drugs are put directly into the blood of the limb. This sends a high dose of drugs to the tumor.

Amputation: Surgery to remove part or all of a limb or appendage, such as an arm or leg. Amputation is rarely used to treat soft tissue sarcoma of the arm or leg.

Lymphadenectomy: A surgical procedure in which lymph nodes are removed and a sample of tissue is checked under a microscope for signs of cancer. This procedure is also called a lymph node dissection.

Radiation therapy or chemotherapy may be given before or after surgery to remove the tumor. When given before surgery, radiation therapy or chemotherapy will make the tumor smaller and reduce the amount of tissue that needs to be removed during the surgical procedure. Treatment given before surgery is called neoadjuvant therapy. When given after surgery, radiation therapy or chemotherapy will kill remaining cancer cells. Treatment given after the surgery, to lower the risk that the cancer will come back, is called adjuvant therapy.

Radiation therapy uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing. There are two types of radiation therapy: the external radiation therapy uses a machine outside the body to send radiation toward the cancer; the internal radiation therapy uses a radioactive substance sealed in needles, seeds, wires, or catheters that are placed directly into or near the cancer. The intensity-modulated radiation therapy (IMRT) is a peculiar type of 3-dimensional (3-D) radiation therapy that uses a computer to make pictures of the size and shape of the tumor. Thin beams of radiation of different intensities (strengths) are aimed at the tumor from many angles. This type of external radiation therapy causes less damage to nearby healthy tissues.

In the metastatic setting, doxorubicin has been the backbone of palliative therapy for 40 years. Recently, a number of drugs have been approved for metastatic disease including pazopanib, trabectedin and eribulin. In selected patients, molecules that specifically target certain genes expressed by the cancer cells are also being used, such as in patients with gastrointestinal stromal tumor (GIST).

10) Sarcoma Treatment Guidelines

Several international guidelines provides a source of information to help patients and health professionals make informed decisions about the care of patients with soft tissue sarcomas.

The NCCN (National Comprehensive Cancer Network) creates guidelines, which outline the standards of care for different types of cancer. These guidelines provide treatment recommendations for healthcare providers to follow when treating a particular type of cancer.

The NCCN Clinical Practice Guidelines in Oncology for Sarcoma are available at:

http://www.nccn.org/professionals/physician_gls/f_guidelines.asp?button=I+Agree#site

The ESMO (European Society of Medical Oncology) guidelines for soft tissue and visceral sarcomas are available at: http://www.esmo.org/Guidelines/Sarcoma-and-GIST

11) What is recurrent soft tissue sarcoma?

Recurrent adult soft tissue sarcoma is cancer that has recurred (come back) after it has been treated. The cancer may come back in the same soft tissue or in other parts of the body. Depending on the anatomical site of recurrence (in the site of primary tumor or in distant organs) and its size, different treatment strategies can be considered.

12) What is the prognosis of patients with soft tissue sarcoma?

Five-year survival is between 50% and 60% for soft tissue sarcomas as a group; however, there is wide variation depending on anatomical site and histological features. The prognosis for patients with limb and trunk soft tissue sarcoma is based on five factors: patient's age, the presence of metastases at the time of presentation, the size of the tumour, its depth and histopathological grade.

13) Is there a relationship between soft tissue sarcoma, trauma and physical exercise?

No link has been established between exercise and sarcoma. Nevertheless, exercise can help in many ways (by reducing stress and depression, relieving constipation, reduce the risk of blood clots and osteoporosis). There is no evidence that weight puts anyone at risk of getting sarcoma. However, obese people tend to have more complications after surgery.

During or after treatment you may benefit from **physical therapy**, **rehabilitation** and/or **occupational therapy**. Therapists will help determine your needs. You may need to regain strength, mobility and endurance; learn to use a prosthetic or assistive device; and/or focus on skills of everyday living. Ask your health-care team before starting or resuming other exercise and physical activities. Then go slow. As you recover, think of exercise and other physical activities that work your heart and lungs, and strengthen bones as well as muscles.

14) What are Clinical Trials?

The best way to improve cancer treatment is through the clinical trial process. This process sets up a rigorous set of scientific questions and the criteria needed to answer them. Clinical trials require resources, in the form of funding, and patients. Without patients willing to enroll on trials for new treatments, it isn't possible to determine whether new treatments are indeed better than the current standard therapy. Contrary to children, only less than 10 percent of adults with cancer enroll on clinical trials. Considering that many sarcomas do not have standard treatments that work well, one would think that patients would be clamoring for clinical trials. On the contrary, many sarcoma trials have closed without obtaining results due to low patient accrual. Medical research is done through studies called clinical trials. Cancer clinical trials may be for new treatments, for new methods of screening or diagnosis, for new supportive care agents, or for quality of life. There are several medical and psychological benefits of being on a clinical trial, including: you are being treated with the latest treatments; your physician will be following your progress more closely as clinical trials require more data collection; you will have the knowledge that you helped in the development of better treatments. Importantly, clinical trials are not only options of last resort and come in many phases of the disease.

15) Complementary and Alternative Medicine

"Complementary" and "integrative" medicine are used *in addition* to standard medicine. "Alternative medicine" refers to treatments that are alternatives to western medicine, also known as conventional or standard medicine. The actual treatment may be the same. The difference is whether patients use them

instead of, or in addition to, conventional medicine. Common ones include acupuncture, massage, chiropractic, meditation, yoga, herbal medicine, dietary supplements, and art and music therapy.

Patients should inform their health-care providers about all treatments they use. Some vitamins and herbal supplements, for example, may interfere with prescription drugs, chemo or radiation. Many treatments once considered alternative are now commonly found in large hospitals and cancer centers. Some chemotherapy drugs came from plants or animals originally, such as paclitaxel from the Pacific yew tree, trabectedin from sea squirts, and doxorubicin from a bacterium.

The NIH (National Institutes of Health) offers comprehensive information, including safety, research, clinical trials on alternative medicines, as well as how to talk to health-care providers. Treatments are listed alphabetically at: http://nccam.nih.gov

16) What can be done to raise awareness of soft tissue sarcomas?

Many patient groups in conjunction with sarcoma specialists are trying to raise awareness of these rare and complex diseases. As a collective group, all rare cancers account for approximately 25% of cancers but the outcomes for patients with rare cancers are worse than those for patients with more common cancers. There is a need for more research and more research funding for rare cancers, including sarcomas.

17) Sarcoma Working Group at IOV – Padova

The Sarcoma Working Group at the Veneto Institute of Oncology includes experts from different specialties (surgery, pathology, medical oncology, radiation oncology) devoted to the assistance of adult patients with soft tissue sarcomas. This multidisciplinary team provides care to adult soft tissue sarcoma patients during all the stages of the disease, ranging from the initial diagnosis to the treatment of the advanced phase. The core group has a wide range of external collaborators from other specialties, including vascular surgery, urology, orthopedics, etc. The central role of this multidisciplinary group is to discuss every single patient and to develop the overall treatment plan. Besides conventional treatments (surgery, radiation, systemic

therapies), the group can offer also highly specialized treatments such as intraperitoneal chemotherapy, limb perfusion and electrochemotherapy. Through a weekly meeting, the Working Group stimulates discussion among different specialists involved in patient care and offers suitable patients the possibility to ben enrolled in major international clinical trials. Patients can be referred for clinical evaluation and multidisciplinary discussion using the following ways: telephone (+39 049.8215757), email (melanoma.sarcomi@iov.veneto.it).