

Newly Diagnosed with Synovial Sarcoma?

Being diagnosed with synovial sarcoma can turn your world upside down. Because this cancer is so rare, you may have never heard of it before, and finding reliable information can feel overwhelming. We want you to know one thing first: you are not alone.

The Synovial Sarcoma Foundation was created by patients and families who understand this journey. Our mission is to accelerate research, improve treatment options, and ensure every person diagnosed with synovial sarcoma has access to trusted information, expert resources, and a supportive community.

What is Synovial Sarcoma?

Synovial sarcoma is a rare type of soft tissue sarcoma that develops in deeper tissues such as muscles, tendons, ligaments, and connective tissue, often near joints. Despite its name, it does not originate from synovial tissue (the lining of joints); it was named because the cancer cells can resemble synovial cells under a microscope.

Because synovial sarcoma is rare, research, treatment options, and patient resources have historically been limited. Receiving care from physicians and medical teams experienced in treating sarcoma can be an important part of navigating this diagnosis. The Synovial Sarcoma Foundation works to advance research, increase awareness, and improve outcomes for everyone affected by this disease.

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Your First Steps After **Diagnosis**

Find An Experienced Sarcoma Team

Not every surgeon or oncologist regularly treats sarcoma. Ask your doctor:

- Do you specialize in sarcoma?
- How many patients with synovial sarcoma do you treat each year?
- Will you discuss my case at a multidisciplinary tumor board?
- Do I need other doctors on my team (medical oncologist, radiation oncologist, oncologic surgeon)?
- Should I seek a second opinion at a sarcoma specialty center?

Confirm the Right Testing

Ask whether your tumor has received:

- Pathology review
- Molecular testing, including confirmation of the SS18::SSX fusion

Additional biomarker testing is important if your tumor has spread (is metastatic), difficult to completely remove by surgery, or recurs. In these cases, ask your doctor whether you should have:

- HLA typing (to determine if you are HLA-A*02 positive)
- Your tumor tested for MAGE-A4 and other biomarkers

These results may affect treatment options and clinical trial eligibility.

Learn About Your Treatment Options

Every patient's treatment plan is different. Depending on your individual situation, treatment may include:

- Surgery
- Radiation therapy
- Chemotherapy
- Targeted therapies
- Clinical trials

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Ask your doctor to explain:

- Why this treatment is recommended
- The goal of treatment
- Expected side effects
- How treatment may affect your daily life

Questions to Ask Your Oncologist

We encourage every newly diagnosed patient to bring our Questions to Ask Your Doctor guide to their first oncology appointment.

Topics include:

- Understanding your diagnosis
- Biomarker testing
- Clinical trials
- Fertility preservation
- Managing treatment side effects
- When to seek emergency medical care

Understanding Biomarker & Molecular Testing

One of the most important conversations to have early is about biomarker testing. Biomarker and molecular testing can provide important information about your tumor and may help identify treatment options, including eligibility for certain therapies or clinical trials.

The Synovial Sarcoma Foundation encourages patients to ask about:

- **SS18::SSX fusion confirmation:** This is important to confirm the diagnosis of synovial sarcoma
- **MAGE-A4 testing:** A tumor marker that may help determine eligibility for newer treatments, including the FDA-approved therapy Tecelra® for eligible patients with synovial sarcoma.

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- **HLA typing (HLA-A*02):** HLA (human leukocyte antigen) testing may determine whether you are eligible for certain cellular therapies including Tecelra®.
- **NY-ESO-1 testing:** A tumor marker that may help determine eligibility for certain clinical trials and investigational T-cell therapies targeting NY-ESO-1.

This testing is typically performed through specialized laboratories and must be ordered by your medical team. In some cases, a biopsy may not provide enough tissue for every test, and additional testing may need to be performed using tissue from surgery.

The Importance of Surgery

For many patients with localized synovial sarcoma, surgery plays a critical role in treatment. The goal of surgery is to remove the tumor completely with negative margins, meaning there is a clear border of healthy tissue around the tumor to reduce the chance of cancer cells being left behind. For some patients with small tumors that have not spread, surgery may be the only treatment that is required. For other patients with tumors that are larger or have spread, chemotherapy and/or radiation therapy is used before or after surgery.

Because synovial sarcoma is rare and surgery can be complex, it is important to have your case reviewed by a team with experience treating sarcoma.

If there are concerns about achieving clear margins or the complexity of your surgery, seeking a second opinion at a multidisciplinary sarcoma specialty center where you can see a surgeon, radiation oncologist, and medical oncologist with expertise in the treatment of sarcoma may be helpful.

Treatment Beyond Surgery

Depending on your individual diagnosis, your care team may recommend additional treatments before or after surgery, such as radiation therapy and/or chemotherapy. These treatments are often used to help reduce the risk of recurrence by targeting any microscopic cancer cells that may remain after surgery.

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Your treatment plan will depend on several factors, including tumor size, location, stage, surgical results, and your overall health. Working with a multidisciplinary sarcoma team can help ensure all treatment options are considered.

Chemotherapy

Chemotherapy is one of the treatment options that may be used to treat synovial sarcoma, particularly for larger, higher-grade tumors, tumors that are difficult to completely resect, or when the cancer has spread (metastasized).

Your treatment team may recommend chemotherapy at different points in your care, including:

- **Before surgery (neoadjuvant therapy):** To help shrink the tumor or treat cancer cells that may have spread.
- **After surgery (adjuvant therapy):** To help eliminate any remaining microscopic cancer cells and reduce the risk of recurrence.
- **For metastatic or unresectable disease:** To help slow disease progression and manage symptoms.

The chemotherapy regimen most commonly used as a first-line treatment for synovial sarcoma is **doxorubicin (Adriamycin®) and ifosfamide**. This combination may help shrink tumors and slow the growth of cancer in some patients. Treatment is typically given in cycles, and your oncologist will determine the schedule and number of cycles based on your individual situation, treatment goals, and how your body responds.

If synovial sarcoma does not respond to first-line chemotherapy or returns after treatment, your care team may consider other chemotherapy options or therapies, such as:

- **Afamitresgene autoleucel (Telecrā®):** A newer cell therapy that is FDA approved for patients with specific HLA-types and biomarker expression (MAGE-A4). This treatment engineers your immune system to try and attack synovial sarcoma cells.
- **Pazopanib (Votrient®):** A medication approved for soft tissue sarcomas that works by damaging cancer cell DNA and may help slow tumor growth.

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- **Trabectedin (Yondelis®):** A medication approved for soft tissue sarcomas that works by damaging cancer cell DNA and may help slow tumor growth.
- **Gemcitabine (Gemzar®) and docetaxel (Taxotere®):** A chemotherapy combination that may be used for some patients with soft tissue sarcomas, including synovial sarcoma.
- Some patients may be offered a second treatment with **ifosfamide and/or doxorubicin** if the tumor initially responded and it has been a long time since first-line treatment.

Because synovial sarcoma is rare, treatment decisions should be personalized based on factors such as your tumor characteristics, stage, previous treatments, and overall health. Working with a sarcoma-experienced oncology team can help ensure all available treatment options are considered.

Clinical Trials

Research is changing rapidly.

Clinical trials may provide access to promising new therapies and help advance treatment for future patients.

Ask your care team:

- Am I eligible for a clinical trial?
- Could I qualify in the future?
- Are there trials available outside my treatment center?

The Synovial Sarcoma Foundation regularly shares updates on clinical trials, emerging therapies, and research advancements. You can find a list of active clinical trials and current therapies on our website at:

synovialsarcoma.org/clinical-trials-and-therapies

You're Not Alone

The Synovial Sarcoma Foundation provides programs designed specifically for people affected by synovial sarcoma.

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Patient Education

Stay informed through educational webinars featuring leading sarcoma specialists covering treatment advances, research updates, survivorship, and more.

International Synovial Sarcoma Tumor Board

Have your case reviewed by an international multidisciplinary team of sarcoma experts through our monthly virtual Tumor Board, bringing together specialists from leading institutions to discuss complex cases and treatment options. For more information on how to present your case, visit:

synovialsarcoma.org/synovial-sarcoma-tumor-board

Synovial Sarcoma Registry & Biorepository

By participating in our SSF Registry & Biorepository, you can help researchers better understand synovial sarcoma and accelerate discoveries that lead to improved treatments. This initiative, developed in collaboration with Children's Hospital of Philadelphia (CHOP), and Penn Medicine, is creating one of the world's most comprehensive collections of clinical data and biospecimens dedicated to this disease. To learn more and register, visit:

synovialsarcoma.org/synovial-sarcoma-registry

Synovial Sarcoma Foundation Patient Profile

Your experience matters. Understanding the journeys of people diagnosed with synovial sarcoma helps identify challenges, improve care, and advance research. Through our ongoing global patient survey we collect firsthand insights from patients about diagnosis, treatment, recurrence, and survivorship. With more than 200 responses and growing, this information helps researchers and clinicians better understand this rare disease and the needs of our community.

Complete your patient profile:

synovialsarcoma.org/synovial-sarcoma-patient-survey

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Community Support

Connect with other patients and caregivers through our online community, educational events, and patient stories. Hearing from others who have walked this path can provide encouragement, practical advice, and hope. To join our Synovial Sarcoma Foundation Community Group, visit:

facebook.com/share/g/1C1Q8Qf2G1

Research Updates

Stay informed about emerging therapies, clinical trials, scientific discoveries, and advocacy efforts that are advancing the future of synovial sarcoma care.

Additional Resources and Support

A synovial sarcoma diagnosis affects more than just your physical health. Navigating appointments, treatment decisions, insurance, finances, and the emotional impact of cancer can feel overwhelming. You don't have to do it alone.

In addition to the Synovial Sarcoma Foundation, several trusted organizations offer resources and support for patients and families.

Synovial Sarcoma Foundation

The Synovial Sarcoma Foundation is dedicated exclusively to advancing research, improving treatment options, and supporting patients and families affected by synovial sarcoma. Our resources include:

- Disease-specific education and patient resources
- Research updates and clinical trial information
- Educational webinars featuring sarcoma experts
- The International Synovial Sarcoma Tumor Board
- The Synovial Sarcoma Registry & Biorepository
- Patient and caregiver community support
- Opportunities to participate in research

To learn more, visit **synovialsarcomafoundation.org**

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Sarcoma Alliance

The Sarcoma Alliance provides support, guidance, and resources specifically for people affected by sarcoma. Programs include:

- Financial assistance for eligible patients seeking a second opinion
- Peer-to-peer support
- Support groups
- Educational resources to help patients better understand their diagnosis and treatment options

To learn more, visit sarcomaalliance.org

Triage Cancer

Triage Cancer provides free education and resources to help people affected by cancer navigate the practical and financial challenges that may come with a diagnosis. Resources include information about:

- Health insurance
- Employment rights
- Disability benefits
- Medical leave
- Financial concerns
- Legal protections

To learn more, visit triagecancer.org

Sarcoma Patient Advocacy Global Network (SPAGN)

SPAGN is a global network connecting sarcoma patient advocacy organizations around the world. Through collaboration, education, and advocacy, SPAGN works to ensure that people affected by sarcoma have access to information, support, and a stronger collective voice.

To learn more, visit sarcoma-patients.org

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Sarcoma Foundation of America

The Sarcoma Foundation of America (SFA) supports sarcoma research, education, advocacy, and patient resources. Their work focuses on improving outcomes for people affected by sarcoma by advancing research, increasing awareness, and supporting the sarcoma community.

To learn more, visit **curesarcoma.org**

Your Hospital's Nurse Navigator or Patient Navigator

Many cancer centers have nurse navigators or patient navigators who can help connect you with resources specific to your institution and community.

Ask your care team:

"Is there a nurse navigator or social worker who can help me understand what resources are available?"

They may be able to assist with:

- Financial assistance programs
- Transportation and lodging resources
- Insurance questions
- Social work support
- Counseling services
- Nutrition support
- Fertility preservation referrals
- Rehabilitation services
- Local support groups
- Symptom management resources

Remember: Asking for support is an important part of your care. Your medical team, the Synovial Sarcoma Foundation, and the broader sarcoma community are here to help you navigate this journey.

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How You Can **Help Advance Research**

Every patient has the opportunity to make a difference.

Whether by participating in research, enrolling in our Clinical Registry, donating tissue through our Biorepository, or sharing your experience, your involvement helps accelerate discoveries that benefit the entire synovial sarcoma community.

Stay Connected

Visit **synovialsarcomafoundation.org**

Explore:

- Educational resources
- Clinical trial information
- Research updates
- Patient stories
- Webinars
- Events
- Support programs
- Ways to participate in research

Remember

Synovial sarcoma is rare, but you are not alone.

Receiving care from a team experienced in sarcoma, asking questions, and ensuring appropriate biomarker and molecular testing are important steps in making informed treatment decisions. The Synovial Sarcoma Foundation is here to support you with trusted information, expert-led educational resources, groundbreaking research initiatives, and a community that understands what you're going through every step of the way.

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