RARE BUT RELENTLESS

NEW PATIENT GUIDE

A practical starting point for navigating a rare or ultra-rare sarcoma diagnosis

START HERE

You do not need to understand everything at once. Focus first on confirming the diagnosis, finding experienced sarcoma specialists, and understanding the decisions in front of you.

Relentless Research for the Rarest Cancers.

1. First Steps

An ultra-rare cancer diagnosis can bring a lot of information at once. This guide is designed to help you take the next steps, connect with experienced specialists, understand your options, and prepare for important treatment decisions.

A SIMPLE FIRST-WEEK PRIORITY LIST

1. Confirm the exact diagnosis and subtype.
2. Connect with a sarcoma-specialized team.
3. Make sure biopsy and surgery are planned by that team whenever possible.
4. Understand what treatment is being recommended, why, and what the tradeoffs are.
5. Keep your records, questions, and specialist recommendations organized.

2. Confirm Your Exact Diagnosis & Get Surgery Right

Sarcoma is not one disease. It includes many different subtypes, each with its own biology, behavior, treatment considerations, molecular features, and potential clinical-trial options.

Because rare sarcomas can sometimes look similar under the microscope, identifying the exact subtype can be critical. Ask whether your diagnosis has been reviewed by a pathologist who specializes in sarcoma and whether appropriate molecular or genomic testing has been performed.

Before Surgery

Whenever possible, confirm the diagnosis and have your case reviewed by an experienced sarcoma team before the tumor is removed. The first biopsy and surgery should be carefully planned; an unplanned or incomplete removal can sometimes complicate later treatment or require additional surgery.

[ ] Is my exact sarcoma subtype confirmed?

[ ] Has my pathology been reviewed by a sarcoma specialist?

[ ] Has appropriate imaging and staging been completed?

[ ] Has my case been reviewed by a multidisciplinary sarcoma team?

[ ] Is my surgeon experienced in treating sarcoma in this location?

[ ] Is the goal of surgery complete removal with appropriate margins?

KEY MESSAGE

Whenever possible, get the first operation right and avoid preventable repeat surgery.

3. Find an Experienced Sarcoma Team

Because sarcomas are rare, care at a dedicated sarcoma center can be especially valuable. Your team may include medical oncology, surgical or orthopedic oncology, radiation oncology, sarcoma pathology, radiology, and genetics or molecular specialists when appropriate.

Selected High-Volume U.S. Sarcoma Centers

- **MD Anderson Cancer Center** - Houston, TX
- **Mayo Clinic** - Rochester, MN
- **UCLA Sarcoma Program** - Los Angeles, CA
- **Dana-Farber Cancer Institute** - Boston, MA
- **Memorial Sloan Kettering Cancer Center** - New York, NY
- **Sylvester Comprehensive Cancer Center / University of Miami** - Miami, FL

Selected Leading International Referral Centers

- **Princess Margaret Cancer Centre** - Toronto, Canada
- **The Royal Marsden** - London, UK
- **Gustave Roussy** - Paris/Villejuif, France
- **Vall d'Hebron University Hospital / VHIO** - Barcelona, Spain
- **Istituto Nazionale dei Tumori** - Milan, Italy
- **NCT Heidelberg / Heidelberg University Hospital** - Heidelberg, Germany

Selected Pediatric Sarcoma Centers

- **Memorial Sloan Kettering Kids** - New York, USA
- **Dana-Farber/Boston Children's** - Boston, USA
- **St. Jude Children's Research Hospital** - Memphis, USA
- **Children's Hospital of Philadelphia** - Philadelphia, USA
- **Princess Maxima Center** - Utrecht, Netherlands

These are selected referral centers, not a ranking. The right center depends on your exact subtype, age, tumor location, treatment needs, and available expertise.

Know Who Is Coordinating Your Care

When several specialists or institutions are involved, ask which physician is responsible for coordinating the overall plan. Make sure the medical oncologist, surgeon, radiation oncologist, and outside consultants are communicating - especially when recommendations differ.

Ask for Navigation & Practical Support

A patient navigator or oncology social worker may help with appointments, insurance, financial assistance, transportation, lodging, work or disability concerns, and emotional support. If care or a trial requires travel, ask about available assistance programs.

4. Records, Second Opinions & Care Coordination

Gather What MyChart May Not Cover

MyChart may contain routine notes, labs, and reports, but some materials needed for expert review or a second opinion often must be requested separately.

- Actual CT, MRI, PET, and other imaging files - not just written reports
- Pathology slides, tumor blocks, and original biopsy material
- Complete molecular/genomic testing reports, including outside-lab reports
- Operative reports and treatment summaries from outside institutions
- The location where your tumor tissue is stored

Before a second opinion, ask the receiving center exactly what it needs and whether it can request materials directly.

Consider a Second Opinion

A second expert opinion can add confidence in the diagnosis and treatment plan, especially before major or irreversible decisions. Consider one when the diagnosis is ultra-rare or uncertain, before surgery when possible, when specialists disagree, or before major chemotherapy, radiation, or clinical-trial decisions.

5. Understand Treatment, Risks & Fertility

Before treatment begins, understand not only what is recommended, but why, what benefit is expected, and what the short- and long-term risks may be.

[ ] What is the goal of treatment - cure, reducing recurrence risk, controlling disease, or symptom relief?

[ ] How much benefit is this treatment expected to provide?

[ ] If possible, what is the absolute expected benefit?

[ ] What happens if I do not receive this treatment?

[ ] Are there reasonable alternatives?

[ ] How will we know whether treatment is working?

Understand the Tradeoffs

- Common short-term side effects and serious toxicities
- Possible effects on the heart, kidneys, lungs, nerves, bone marrow, or other organs
- Long-term or permanent effects and cumulative toxicity
- Secondary cancer risk
- Fertility effects
- Quality-of-life impact

MEDICATION & SUPPLEMENT CHECK

Tell your oncology team about every medication, vitamin, supplement, or herbal product you take. Some can interact with cancer treatment.

Protect Fertility Before Treatment

Some chemotherapy drugs and radiation treatments can temporarily or permanently reduce fertility. If having biological children in the future may be important - or you are unsure - ask about fertility preservation before treatment begins whenever possible.

- Sperm banking
- Egg freezing
- Embryo freezing
- Other fertility-preservation approaches depending on age and treatment

Ask for an urgent referral to a fertility-preservation specialist or reproductive endocrinologist.

LIVESTRONG Fertility

Cancer-specific fertility preservation information and support.

https://livestrong.org/how-we-help/livestrong-fertility/

Keep Questions and Follow-Up Organized

Keep a running question list, bring someone to important appointments when possible, take notes, and record visits when permitted. Near the end of treatment, ask for a written treatment summary and surveillance plan covering scans, late effects, organ monitoring, fertility, and secondary-cancer considerations.

6. Molecular Testing & ctDNA

Ask About Molecular Testing

Molecular profiling can sometimes help confirm the diagnosis, identify biomarkers or therapeutic vulnerabilities, and uncover research or clinical-trial opportunities.

[ ] Has comprehensive molecular testing been performed?

[ ] Are any findings relevant to treatment or clinical trials?

[ ] Are there research studies or registries for my tumor type?

[ ] Is tumor tissue available for future testing or research?

Caris Life Sciences

One example of comprehensive molecular profiling used in oncology.

https://www.carislifesciences.com/

Ask About Genetic Counseling

Tumor molecular testing and inherited genetic testing are different. Ask whether your diagnosis, age, personal history, or family history suggests that meeting with a cancer genetic counselor would be helpful.

Ask About Circulating Tumor DNA (ctDNA)

ctDNA is a blood-based approach that looks for small fragments of tumor DNA in the bloodstream. In some settings it may provide additional information about treatment response, molecular residual disease, or possible recurrence.

Tumor-informed tests such as Signatera are personalized using an individual patient's tumor tissue. Ask whether ctDNA is appropriate for your diagnosis and how it should be interpreted alongside imaging and clinical follow-up.

IMPORTANT

A negative ctDNA result does not necessarily mean no cancer is present.

Signatera / Natera Sarcoma Information

Tumor-informed ctDNA information for sarcoma.

https://www.natera.com/oncology/signatera-advanced-cancer-detection/clinicians/signatera-sarcoma/

7. Explore Clinical Trials

Clinical trials can be particularly important for ultra-rare cancers, where disease-specific treatment options may be limited. Discuss trials early rather than assuming they are only an option after every standard treatment has been exhausted.

- Disease-specific trials
- Sarcoma basket trials
- Biomarker-driven studies
- Trials available at other institutions
- Whether your tumor biology may qualify you even if your exact diagnosis is not specifically named

Bring potentially relevant trials to your oncologist and ask whether you may qualify and whether the study makes sense for your situation.

ClinicalTrials.gov

The U.S. government registry and search tool for clinical studies around the world.

https://clinicaltrials.gov/

Sarcoma Foundation of America Clinical Trial Matching

Sarcoma-focused trial information and matching support.

https://curesarcoma.org/support-resources/sarcoma-clinical-trials/

8. Use AI as a Medical Information Assistant

AI can help organize and understand a complicated cancer journey, especially when multiple specialists, institutions, reports, and treatment opinions are involved.

High-Value Uses

- Build and update a medical timeline or living medical summary
- Summarize clinical notes, pathology, imaging, and molecular reports
- Compare recommendations from different doctors and identify where they agree or differ
- Track treatments, scans, test results, medications, and side effects
- Prepare questions and identify unanswered issues before appointments
- Find research papers or potentially relevant clinical trials to discuss with your care team
- Create a concise summary for a second opinion or new specialist

Cross-Check and Collaborate

Use AI to identify questions and areas worth investigating - not to determine which doctor is right. Ask for sources, check important claims against original research or trusted medical sources, and bring relevant findings back to your physicians.

AI SHOULD START CONVERSATIONS, NOT MAKE DECISIONS

AI can misunderstand records, miss context, or provide incorrect information. Never start, stop, or change treatment based only on AI.

AI Resources

ChatGPT

General-purpose AI that can help organize information, explain medical concepts, and prepare questions.

https://chatgpt.com/

BelongAI Dave - Cancer Mentor

Cancer-focused AI support for patients and caregivers.

https://belong.life/belong-ai-cancer-mentor-app/

Claude

General-purpose AI that can be useful for reviewing long documents, research papers, and notes.
https://claude.ai/

9. Community & Support

Rare cancers can feel isolating. Connecting with patients, caregivers, and organizations that understand sarcoma can provide practical and emotional support.

Sarcoma Foundation of America

Education, support resources, research updates, and community programs.
https://curesarcoma.org/support-resources/

Sarcoma Alliance

Support groups, patient resources, and second-opinion assistance.
https://sarcomaalliance.org/

Smart Patients Sarcoma Community

Online discussion community for sarcoma patients and caregivers.
https://www.smartpatients.com/site/communities/sarcoma

SARC Patient Advocacy Directory

Directory of sarcoma advocacy and support organizations.
https://sarctrials.org/patient-resources/patient-advocacy-directory/

CancerCare

Professional counseling, support groups, and oncology social-work resources.
https://www.cancercare.org/diagnosis/sarcoma

Look for Your Exact Subtype

Facebook groups and online communities often exist for individual sarcoma subtypes or specific gene fusions. Search your exact diagnosis plus terms such as "support group," "patients," or "Facebook group." Even a small community can help you connect with someone who has faced similar decisions.

Sarcoma Stories Podcast

Sarcoma Stories - Sarcoma Foundation of America

Patient, survivor, and caregiver stories. Listen on Spotify.

https://open.spotify.com/show/6Og2JjUIp5sCaVtafS8m7V

ONLINE COMMUNITY NOTE

Patient experiences can be valuable for support and practical questions, but they are not medical evidence. Bring treatment suggestions, supplements, medications, or trial ideas back to your medical team before acting on them.

10. Printable Checklists

Medical Records & Materials Checklist

[ ] Actual CT/MRI/PET imaging files

[ ] Imaging reports

[ ] Pathology report

[ ] Pathology slides / tumor blocks

[ ] Original biopsy material

[ ] Complete molecular/genomic testing reports

[ ] Operative reports

[ ] Treatment summaries

[ ] Current medication and supplement list

[ ] Location where tumor tissue is stored

[ ] Outside-hospital records

[ ] Contact information for key physicians

Questions to Ask Your Doctor

[ ] What is my exact diagnosis and sarcoma subtype?

[ ] Has my pathology been reviewed by a sarcoma-specialized pathologist?

[ ] What is my stage and what imaging was used to determine it?

[ ] Is my case being reviewed by a multidisciplinary sarcoma team?

[ ] Who is coordinating my overall care?

[ ] What is the goal of the recommended treatment?

[ ] What is the expected absolute benefit, if it can be estimated?

[ ] What are the short-term and long-term risks?

[ ] Could this treatment affect fertility? Should preservation happen first?

[ ] What happens if I do not receive this treatment?

[ ] Are there reasonable alternatives?

[ ] Has comprehensive molecular testing been performed?

[ ] Is genetic counseling appropriate for me?

[ ] Is ctDNA monitoring appropriate for my diagnosis?

[ ] Are there relevant clinical trials now or later?

[ ] What is the surveillance plan after treatment?

[ ] What late effects or organ monitoring should I expect?

YOU DON'T HAVE TO NAVIGATE THIS ALONE

Focus on getting the diagnosis right, finding experienced specialists, understanding your options, asking informed questions, and building a team you trust. Take the process one decision at a time and use the people and resources around you.

MEDICAL DISCLAIMER

This guide is intended for educational and informational purposes only. It does not provide medical advice, diagnosis, or treatment recommendations and should not replace individualized guidance from qualified healthcare professionals.

Resource links are provided for convenience and do not constitute endorsement of any specific institution, company, test, service, or treatment.