Sarcoma

The purpose of this guide is to help patients and families find sources of information and support. This list is meant to provide links to authoritative, up-to-date information sources for patients, families, and caregivers.

The materials in this guide can be found at the Patient Education Resource Center (PERC) in the University of Michigan Comprehensive Cancer Center B2 lobby. Visit us online at: http://www.mcancer.org/support/learning-about-cancer/education-resource-center

Brochures, Fact Sheets

- CancerCare. Treatment Update: Gastrointestinal Stromal Tumors. An online version is also available at: http://www.cancercare.org/publications/136-treatment_update_gastrointestinal_stromal_tumors


Books

- Ronald DeMatteo; George D. Demetri; Marina Symcox. 100 questions & answers about gastrointestinal stromal tumors (GIST). Sudbury, MA: Jones and Bartlett Publishers, 2006.

Audiovisual Resources

- Cancercare Connect Workshops
  - Living with Gastrointestinal Stromal Tumors: Treatment Update
  - Treatment Update on Soft Tissue Sarcoma

Available at: www.cancercare.org/connect_workshops

→ Go to “Browse Workshops”
→ Select sarcoma from “by Diagnosis” in the pull down menu

These workshops are available as a downloadable mp3 or viewable online as a webcast.
• Liddy Shriver Sarcoma Video Series
  www.youtube.com/teamsarcoma
  Series of one-minute videos on sarcoma topics including diagnosis, caregiving, biopsy, treatment essentials, metastases, clinical trials, and survivorship.

• What’s New in Sarcoma Care and Treatment, with Dr. Robert Maki
  American Society of Clinical Oncology
  www.cancer.net/multimedia/videos
    → Select Treatments, Tests, and Procedures
    → Click on the Sarcoma title

Web Resources

• American Cancer Society
  http://www.cancer.org
    → Click on: "Learn About Cancer"
    → Select from the drop down list under “Select a Cancer Type”
      o Bone Cancer
      o Gastrointestinal Stromal Tumors
      o Sarcoma – Adult Soft Tissue Cancer
    → Click “GO” button

• American Society of Clinical Oncology - Sarcoma
  www.cancer.net/patient/cancer+types/sarcoma
  Detailed overview of sarcoma, including statistics, medical illustrations, risk factors, symptoms, diagnosis, staging and treatment.

• Liddy Shriver Sarcoma Initiative
  http://sarcomahelp.org/
  In-depth website on all sarcoma subtypes. Printable patient materials. Detailed guides on over 15 sarcoma subtypes.

• National Cancer Institute
  www.cancer.gov
  Cancer resources, including general information on sarcoma as well as staging, treatment options, statistics and clinical trials.
    → Click on “S” under “Find a Cancer Type”
    → Click on various sarcoma types
- **OncoLink Sarcoma Information**  
  [www.oncolink.org](http://www.oncolink.org)  
  Detailed information for patients of Ewing’s Sarcoma, Osteosarcoma,  
  Rhabdomyosarcoma and other soft tissue sarcomas, sarcoma of the bone  
  and sarcoma of the soft tissue.  
  → Click on “Cancer Types”  
  → Click on “Sarcomas” from the drop down menu

- **Sarcoma Alliance**  
  Patient information for sarcoma patients, including general information,  
  treatment guidelines, clinical trials, complementary therapies, and personal  
  tools for dealing with sarcoma.

- **Sarcoma Foundation of America**  
  Includes materials on general sarcoma information, how sarcoma develops,  
  statistics, and treatment. Information on sarcoma subtypes as well.

**University of Michigan Resources**

- **The University of Michigan Comprehensive Cancer Center**  
  Multidisciplinary Sarcoma Clinic  
  This clinic offers a collaborative approach in treating soft tissue and bone  
  sarcomas.

**Email Groups (Online Communities)**

- **The Association of Cancer Online Resources** hosts a number of email  
  discussion groups for adult sarcoma patients and families.  
  o **SARCOMA** is an email discussion group for Sarcoma patients  
    and families.  
  o **SARCOMA-MED** is an email discussion group for medical  
    questions about Sarcomas.  
  o **L-M-SARCOMA** is an email discussion group for  
    Leiomyosarcoma patients and families.  
  o **L-SARCOMA** is an email discussion group for Liposarcoma  
    patients and families.  
  o **DESMOID** is an email discussion group for Desmoid Tumor  
    patients and families.

Subscribe to these online communities at:  
Organizations

- Sarcoma Alliance
  (415) 381-7236

- The Life Raft Group (for GIST patients)
  [https://liferaftgroup.org/](https://liferaftgroup.org/)
  (973) 837-9092

- GIST Support International
  (215) 340-9374