



# Sarcoma & Rare Disease Patient Resources

If you have recently been diagnosed with soft tissue sarcoma (STS), it's important to ask your doctor what type you have, since there are more than 50 types of STS. Epithelioid sarcoma (ES) is a rare type of STS that accounts for less than 1 percent of STS.

There are resources and support services that exist for patients and caregivers within the broader STS category. The list below provides an overview of some of the sarcoma, general cancer and rare disease resources that may provide you with additional information and support.

To learn more about any of the patient groups or resources listed, please contact the organization directly for details.

## Sarcoma Patient Resources

### Northwest Sarcoma Foundation

Offers hope, education and support to sarcoma patients and their families in the Pacific Northwest. In addition to providing patient grants, the organization invests in research to improve cure rates for sarcomas.

**Website:** [www.nwsarcoma.org](http://www.nwsarcoma.org)  
**Facebook:** @NWSarcoma  
**Twitter:** @nwsarcoma  
**Instagram:** @nwsarcoma  
**YouTube:** [www.youtube.com/channel/UCdt8XKdYmLMA4VICUb3yw4Q/featured](http://www.youtube.com/channel/UCdt8XKdYmLMA4VICUb3yw4Q/featured)  
**Phone:** (458) 201-3126  
**Email:** [info@nwsarcoma.org](mailto:info@nwsarcoma.org)

### Rein in Sarcoma

Dedicated to educating the public and medical community about sarcomas, supporting sarcoma patients and their loved ones, and funding research directed toward developing new treatments and finding a cure for sarcoma cancers. Offers a Rein in Sarcoma Patient Starter Notebook that provides support, hope, information and valuable resources for the newly diagnosed sarcoma patient.

**Website:** [www.reininsarcoma.org](http://www.reininsarcoma.org)  
**Facebook:** @ReinInSarcomaFoundation  
**Twitter:** @reininsarcoma  
**Instagram:** @reininsarcoma  
**YouTube:** [www.youtube.com/user/reininsarcoma](http://www.youtube.com/user/reininsarcoma)  
**Phone:** 1-844-727-2662  
**Email:** [admin@reininsarcoma.org](mailto:admin@reininsarcoma.org)

### Sarcoma Alliance

Strives to improve the lives of people affected by sarcoma through accurate diagnosis, improved access to care, guidance, education and support. Provides a list of links to Financial Assistance Resources.

**Website:** [www.sarcomaalliance.org](http://www.sarcomaalliance.org)  
**Facebook:** @sarcomaalliance  
**Twitter:** @SarcomaAlliance  
**Phone:** (415) 381-7236  
**Email:** [info@sarcomaalliance.org](mailto:info@sarcomaalliance.org)

## Sarcoma Alliance for Research Through Collaboration (SARC)

A non-profit organization dedicated to the development and support of research for the prevention, treatment, and cure of sarcomas. They are researchers and investigators at sarcoma centers working together with pharmaceutical and biotech companies to achieve breakthroughs in patient outcomes.

**Website:** [www.sarctrials.org](http://www.sarctrials.org)  
**Twitter:** @SARCTrials  
**Phone:** (734) 930-7600  
**Email:** [sarc@sarctrials.org](mailto:sarc@sarctrials.org)

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## Sarcoma Coalition

A collaborative of sarcoma advocacy groups from around the country working toward a common purpose: to provide resources and support for those dealing with sarcoma – from patients and their families to allies in the research community.

**Website:** [www.sarcomacoalition.org](http://www.sarcomacoalition.org)  
**Email:** [sarcomacoalition@sarctrials.org](mailto:sarcomacoalition@sarctrials.org)

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## Sarcoma Foundation of America (SFA)

Advocates for sarcoma patients by funding research and by 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.

**Website:** [www.curesarcoma.org](http://www.curesarcoma.org)  
**Facebook:** @CureSarcoma  
**Twitter:** @CureSarcoma  
**Phone:** (301) 253-8687  
**Email:** [info@curesarcoma.org](mailto:info@curesarcoma.org)

## Cancer Support Groups

### CancerCare

A national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

**Website:** [www.cancercare.org](http://www.cancercare.org)  
**Facebook:** @cancercare  
**Twitter:** @cancercare  
**Instagram:** @cancercarepics  
**YouTube:** [www.youtube.com/user/cancercareinc](http://www.youtube.com/user/cancercareinc)  
**LinkedIn:** [www.linkedin.com/company/cancercare](http://www.linkedin.com/company/cancercare)  
**Phone:** 800-813-HOPE (4673)  
**Email:** [info@cancercare.org](mailto:info@cancercare.org)

## Cancer and Careers

Empowers and educates people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events.

**Website:** [www.cancerandcareers.org](http://www.cancerandcareers.org)  
**Facebook:** @CancerandCareers  
**Twitter:** @CancerAndCareer  
**Instagram:** @cancerandcareers  
**YouTube:** [www.youtube.com/user/cancerandcareers](http://www.youtube.com/user/cancerandcareers)  
**LinkedIn:** [www.linkedin.com/company/cancer-and-careers](http://www.linkedin.com/company/cancer-and-careers)  
**Phone:** (646) 929-8032  
**Email:** [cancerandcareers@cew.org](mailto:cancerandcareers@cew.org)

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## Cancer Legal Resource Center (CLRC)

Founded in 1997 by the Disability Rights Legal Center to address the legal issues faced by people with cancer. They are committed to providing information and resources about cancer-related legal issues to members of the cancer community across the nation.

**Website:** [www.thedrhc.org/cancer/](http://www.thedrhc.org/cancer/)  
**Facebook:** @CancerLegalResourceCenter  
**Twitter:** @CancerLegalHelp  
**Phone:** (866) 843-2572  
**Email:** [CLRC@drhcenter.org](mailto:CLRC@drhcenter.org)

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## Cancer Support Community (CSC)

The largest professionally-led non-profit network of cancer support worldwide and is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. This global network of 175 locations delivers more than \$50 million in free support services to patients and families.

**Website:** [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)  
**Facebook:** @CancerSupportCommunity  
**Twitter:** @CancerSupportHQ  
**Instagram:** @cancersupporthq  
**YouTube:** [www.youtube.com/user/CancerSupportComm](http://www.youtube.com/user/CancerSupportComm)  
**LinkedIn:** [www.linkedin.com/company/cancer-support-community](http://www.linkedin.com/company/cancer-support-community)  
**Phone:** 1-202-659-9709  
**Phone:** 1-888-793-9355 (Toll-Free Cancer Support Helpline)

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## LIVESTRONG

Fights for the more than 32.6 million people around the world affected by cancer. They provide direct services to anyone affected by cancer; connect people and communities with the services they need; and call for state, national and world leaders to help fight this disease.

**Website:** [www.livestrong.org](http://www.livestrong.org)  
**Facebook:** @livestrong  
**Twitter:** @livestrong  
**YouTube:** [www.youtube.com/user/livestrongarmy](http://www.youtube.com/user/livestrongarmy)  
**Phone:** (877) 236-8820  
**Email:** [livestrong@livestrong.org](mailto:livestrong@livestrong.org)

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## National Coalition for Cancer Survivorship (NCCS)

Advocates for quality cancer care for all people touched by cancer. Offers free resources for patients and caregivers on various issues for people living with, through and beyond cancer, including a Cancer Survival Toolbox.

**Website:** [www.canceradvocacy.org](http://www.canceradvocacy.org)  
**Facebook:** @cancersurvivorship  
**Twitter:** @canceradvocacy  
**YouTube:** <https://www.youtube.com/user/CancerSurvivorship>  
**Phone:** (877) 622-7937  
**Email:** [info@canceradvocacy.org](mailto:info@canceradvocacy.org)

# Rare Disease Patient Resources

## Global Genes

A leading rare disease advocacy and education organization with global reach to the worldwide rare community of patients, caregivers, advocates and clinical partners.

**Website:** [www.globalgenes.org](http://www.globalgenes.org)

**Facebook:** @globalgenes

**Twitter:** @GlobalGenes

**Instagram:** @globalgenes

**Phone:** (949) 248-7273

**Email:** [globalgenes@globalgenes.org](mailto:globalgenes@globalgenes.org)

## National Organization for Rare Disorders (NORD)

A patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 280 patient organization members, is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient services.

**Website:** [www.rarediseases.org](http://www.rarediseases.org)

**Facebook:** @NationalOrganizationforRareDisorders

**Twitter:** @RareDiseases

**YouTube:** [www.youtube.com/user/raredisorders](http://www.youtube.com/user/raredisorders)

**LinkedIn:** [www.linkedin.com/company/national-organization-for-rare-disorders/](http://www.linkedin.com/company/national-organization-for-rare-disorders/)

**Phone:** (203) 744-0100

**Email:** [orphan@rarediseases.org](mailto:orphan@rarediseases.org)

**Visit [ESsentialsforES.com](http://ESsentialsforES.com) for more epithelioid sarcoma information and resources.**

*This document is intended for educational purposes only. Treatment advice should be provided by your doctor. Please direct questions to your doctor or healthcare professional.*

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### References

About Soft Tissue Sarcoma: What Is a Soft Tissue Sarcoma? American Cancer Society. Updated April 6, 2018. Accessed January 9, 2019. Available at: <https://www.cancer.org/cancer/soft-tissue-sarcoma/about/soft-tissue-sarcoma.html>

Armah, H.B. Arch Pathol Lab Med. 2009;133(5):814–819. Available at: <https://www.archivesofpathology.org/doi/full/10.1043/1543-2165-133.5.814>