

the general public about the risks of Sarcoma, as well as the latest advancements in detection and treatment. The organization participates in professional medical meetings and sits on local, regional, and national cancer committees to create awareness about the disease. The SFA represents the interests of Sarcoma patients with regard to access to clinical trials, innovative treatments or a second opinion at a multi-disciplinary cancer center.

### Research Advocacy

SFA advocates for increased research funding for Sarcoma from both the public and private sectors. We work with government institutions, for-profit and non-profit cancer organizations, and industry to improve the level of awareness, interest, and investment in translational research for Sarcoma. These efforts ensure that Sarcoma receives attention from government and other entities that have the ability to support scientific research into Sarcoma.

### Research Grants

SFA raises funds to support translational research grants focused on discovering and developing new and effective therapies to treat and eradicate Sarcoma. The organization has also partnered with the American Society for Clinical Oncology to support an Advanced Clinical Research Award and multiple Young Investigator Awards. For more information, please visit [www.curesarcoma.org](http://www.curesarcoma.org)



**Sarcoma Patient Registry**  
2966 South Church St. #293  
Burlington, NC 27215  
Tel: 866-501-6780

**Sarcoma Foundation of America**  
National Headquarters  
9884 Main Street  
Damascus, MD 20872  
Tel: 301-253-8687

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# Sarcoma Foundation of America Patient Registry

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Sarcoma is a cancer of the connective tissue (i.e., bone, muscles, fat, nerves and tendons) that affect approximately 12,000 Americans each year. The Sarcoma Foundation of America (SFA) has developed the Sarcoma Patient Registry to gather detailed information on the almost 100 Sarcoma subtypes and patients who have this rare cancer. The goal of the patient registry is to collect, catalogue, and analyze Sarcoma data on a national level in order to create a valuable research tool for understanding different forms of the disease. We invite you to participate in our efforts to make the Sarcoma Patient Registry information as accurate and comprehensive as possible.

### Outlining Your Patient History

As a Sarcoma patient your story is important. The history you share provides useful information to advance our understanding of Sarcoma. The Sarcoma Patient Registry collects and manages this data about Sarcoma patients, helping physicians and researchers in every facet of patient care, from investigating the cause of cancer, to making the diagnosis, and tracking the effectiveness of different treatments. When you participate, you contribute to the larger picture by:

- Helping produce a better understanding of Sarcoma
- Adding to the improved care of future patients
- Helping to extend and improve the lives of Sarcoma patients
- Allowing the natural history of Sarcoma to be studied

## Participating in the Sarcoma Patient Registry

### Am I Eligible To Participate?

You are eligible to participate if you have been diagnosed with Sarcoma. You are eligible regardless of prognosis, disease stage at diagnosis, current treatment or treatment plans.

### Why Should I Participate?

You will have the pleasure of knowing that you have contributed in helping others better understand Sarcoma. If you choose, you can also be confidentially notified about current or future clinical trials. Your participation will aid you and other Sarcoma patients in future years.

### How Do I Register?

When a patient decides to participate, there are three ways to register:

- Request an information packet by contacting the patient registry toll-free at (866) 501-6780
- E-mail the patient registry at [SFA@registrypartners.com](mailto:SFA@registrypartners.com)
- Complete an online SFA member registration at [www.curesarcoma.org](http://www.curesarcoma.org)

### When Should I Register?

It is most beneficial to register as soon as possible following diagnosis. Patients' participation in the Sarcoma Patient Registry can help provide a sense of control when dealing with this cancer. This is an opportunity to share your unique experience of battling Sarcoma. Registration usually requires less than 30 minutes of the patient's time.

## Frequently Asked Questions

### What About Confidentiality?

The Sarcoma Patient Registry staff protects the privacy and records of the participants. The patient registry staff has been trained on privacy and confidentiality issues and pledges to maintain each patient's rights. All patient registry information is stored at a location secured by biometric access, is subject to monthly access audits, and meets the criteria identified by Sarbanes-Oxley standards.

### How Does The Registry Work?

The Sarcoma Patient Registry is defined as a systematic collection of data on the occurrence, treatment

if applicable, physician-reported outcomes, and characteristics of Sarcoma, with the purpose being to assess and control the impact of the disease. Once your Medical Release Form is signed and returned to the patient registry, the patient registry staff will request copies of your medical records in order to collect the data, code and collate the information, and routinely analyze the data to assess clinical practice, patterns of care, and continuous quality improvement initiatives. Your identity is never disclosed or used during these activities.

Once you are registered, you or your managing physician will receive a follow-up letter every six months with a few questions regarding your disease status and treatment so we can keep your information current in the patient registry database.

### Who Is Managing The Sarcoma Patient Registry?

The Sarcoma Foundation of America (SFA) founded and funded the Sarcoma Patient Registry. The patient registry is managed by SFA leadership with all data and records securely held in Burlington, North Carolina.

SFA was incorporated as a nonprofit corporation in the State of Maryland and received 501(c)(3) status from the IRS on June 18, 2001. The SFA is a tax-exempt charity/community foundation.

## About SFA

### Our Mission

The mission of the Sarcoma Foundation of America is to advocate for increased research to find new and better therapies with which to treat patients with Sarcoma. The organization raises money to privately fund grants for Sarcoma researchers and conducts education and advocacy efforts on behalf of Sarcoma patients.

### Education And Awareness

SFA educates legislators, federal and state agency officials, health and research communities and

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