



# About Sarcoma

## WHAT IS SARCOMA?

Sarcoma is a rare cancer of the connective tissues. It appears in a variety of tissue structures, including nerves, muscles, fat, joints, and bone, collectively referred to as the body's connective tissues. Most frequently, sarcomas are found in the limbs, where the majority of the body's connective tissue resides. Tumors are often hidden deep in the body or within tissues, thus making it difficult for an early diagnosis.

## WHO IS AFFECTED BY SARCOMA?

Sarcoma is a rare cancer with more than 17,000 new cases and over 7,500 deaths each year in the United States. At any one time, more than 225,000 patients and their families are struggling with sarcoma. It is disproportionately prevalent in children, accounting for 15-21% of all childhood cancers.

## HOW IS SARCOMA TREATED?

Sarcomas are sometimes treatable by surgery, or by surgery with chemotherapy and/or radiation, but much of the time they are resistant to all these approaches—thus there is a need for new therapeutic options. Adding to the difficulties in fostering new drug development, there are over 130 subtypes of sarcomas, with varying degrees of molecular and histologic characterization. This means that an already rare group of diseases is further broken down into increasingly smaller subsets of patients.

## WHY IS SARCOMA AWARENESS SO IMPORTANT?

Due to its rarity and limited public knowledge of the disease, sarcoma is often referred to as a "forgotten cancer." The sarcoma community works tirelessly to raise more awareness in order to highlight the extraordinary challenges that sarcoma patients face and to demonstrate the need for new sarcoma therapies.

This lack of awareness and understanding creates obstacles in efforts to foster research and drug development. It also creates obstacles for patients to get appropriately diagnosed and treated. Most clinicians will not see more than one patient with a sarcoma in their entire career, if any. This means patients may be presenting to a care provider without the skills needed to identify, diagnose, or treat their disease.

By the time a patient engages with a sarcoma specialist and receives an accurate diagnosis, the sarcoma is often at a relatively advanced stage. This can make the sarcoma more challenging to treat, and contributes to poorer overall outcomes for patients.

## WHAT IS THE ROLE OF SARCOMA FOUNDATION OF AMERICA?

Sarcoma Foundation of America (SFA), a 501(c)(3) nonprofit charitable organization, advocates 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 researchers and conducts education and advocacy efforts on behalf of sarcoma patients. SFA also interacts with public, private for-profit, and private non-profit entities to educate and raise awareness about the treatment needs of sarcoma patients. SFA engages with sarcoma patients, care partners, specialists and other stakeholders to develop innovative resources to empower patients to be knowledgeable partners in shared decision making with their care teams. The organization conducts independent research about the unique experiences of sarcoma patients to inform the future direction of scientific efforts and develop programming to support the growing needs of the sarcoma community.