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Patients Launch First-Ever Solitary Fibrous Tumor Foundation to Tackle Critical Gaps in Rare Cancer Care

Debuting during Sarcoma Awareness Month, the new nonprofit aims to eliminate patient isolation, drive research, and build global resources for a disease with zero FDA-approved treatments.

[CHICAGO / IL] — July 26, 2026 — The Solitary Fibrous Tumor Foundation (SFTF) today announced its launch as the first patient- and supporter-led nonprofit organization dedicated entirely to Solitary Fibrous Tumor (SFT), an ultra-rare sarcoma. The announcement comes during Sarcoma Awareness Month, observed globally each July.

SFT is diagnosed in fewer than one in one million people worldwide, with an estimated 300 to 400 new cases in the United States each year. The disease is notoriously unpredictable; between 10% and 30% of patients experience a recurrence or metastasis—often 10, 20, or even 30 years after initial tumor removal—leaving patients in a lifelong state of surveillance. Despite these complex timelines, the community currently faces a severe systemic vacuum:

- **Zero** FDA-approved treatments specific to SFT.
- **No** dedicated National Comprehensive Cancer Network (NCCN) clinical guidelines.
- **Nearly 40 percent** of patients report being misdiagnosed during their medical journey.

Until now, no dedicated foundation has existed to serve this community. SFTF was formed after five SFT patients met in person for the first time at the SARC and ASCO conferences in Chicago in May 2026.

> "When I was diagnosed with SFT in 2006, and again in 2021, I quickly realized there was no guide, no community, and no organization fighting specifically for us," said Steve McBee, founder of SFTF and an SFT patient for two decades. "This spring in Chicago, five of us recognized that SFT patients needed a stronger, more organized voice—and that we were ready to build it. The SFTF grew from that shared resolve: to connect patients, accelerate research, and turn isolation into collective strength."
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> "What struck us at our first meeting was how, due to the dearth of resources for SFT patients, each of us had to go through the process of educating ourselves about SFT alone, with little ability to share what we learned with others. SFTF exists to ensure the next patient doesn't have to start from zero. Even our launch date was chosen by design—July 26 (7/26) is a

> quiet nod to the NAB2-STAT6 gene fusion that defines our disease. We wanted every single detail of this foundation to reflect the community we are building."

Founded by McBee and Dina Rollman, the foundation is guided by a founding board of dedicated patient advocates including Steve Ducos, Marvin Schuldiner, Bethany Lucas, Sydney Zacher, and Joe Zacher. SFTF's work centers on three gaps identified directly by patients: isolation, knowledge, and research funding.

The foundation:

- Publishes a plain-language patient guide at curesft.org/patient-guide covering diagnosis, risk assessment, treatment pathways, and long-term surveillance.
- Refers newly diagnosed patients to the Horowitz Solitary Fibrous Tumor Initiative (HSFTI) at the University of Miami's Sylvester Comprehensive Cancer Center, which operates the field's leading SFT patient registry.
- Builds peer connection among a patient population that is geographically scattered — many treating physicians see only one or two SFT cases in a career.
- Advocates on insurance access, clinical trial awareness, and long-term care policy specific to ultra-rare cancer patients.

The Solitary Fibrous Tumor Foundation is a 501(c)3 non-profit organization (EIN 42-3546399) registered in Illinois, incorporated June 26, 2026. With its federal 501(c)(3) tax-exempt determination pending, the foundation is actively accepting financial contributions to accelerate its patient programs and core initiatives. Patients, caregivers, and allies looking to volunteer, collaborate, or donate can find more information at `curesft.org`.

About the Solitary Fibrous Tumor Foundation

The Solitary Fibrous Tumor Foundation builds the trusted resources, research connections, and organized voice that people living with Solitary Fibrous Tumor deserve. Founded by patients, it brings together patients, caregivers, clinicians, researchers, and advocates so that no one affected by SFT has to navigate the disease alone. Learn more at curesft.org.

Media Contact

Steve McBee, Co-Founder

Solitary Fibrous Tumor Foundation

media@curesft.org | (479) 283-6124

curesft.org

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