SOLITARY FIBROUS TUMOR FOUNDATION

Patient-led. Science-guided. Collaborative.

curesft.org

CTOS 2026 · PATIENT ADVOCACY POSTER

Break the NAB2::STAT6 Fusion

Building the Research Path for Solitary Fibrous Tumor

SFTF connects the SFT patient community with investigators, clinicians and industry to accelerate research.

FIRST SFT PATIENT PRIORITIES SURVEY

101	17	2 of 90
voices	**countries**	**only treated on a clinical trial** (self-reported)

97%

What matters: systemic therapy in advanced SFT

The top-rated research question of 17. Treatment-changing questions ranked highest.

71%

What falls short: trial information is unmet

Access to research was rated the need furthest from being met.

84%

Research-ready: volunteered for a research role

31 for a registry · 21 for tissue donation · 26 as patient advisors

WHAT IS SFT

One fusion. Anywhere in the body. Fewer than 1 in a million.

NAB2::STAT6	<1 in 1M	Any site
A single defining driver	**Diagnosed each year**	**Brain to pelvis**
The fusion that defines SFT gives researchers one clear target.	No single centre sees enough patients to study it alone.	Patients are scattered across specialties, and prognosis relies on risk models.

No approved therapy yet targets the fusion. Be the team that breaks it.

You bring the science. SFTF brings the patients, the tissue & data and the questions that matter to the patients.

QUESTIONS SFTF WANTS ANSWERED

01 Why do some SFTs stay stable while others recur or metastasize?

02 How do NAB2::STAT6 fusion variants affect disease behavior?

03 Can circulating tumor DNA be used to monitor SFT?

Methods and limitations. Online survey, 143 items, n = 90. Self-selected convenience sample recruited through existing SFT networks. 75 of 90 respondents identified as White; 46% reported brain or meningeal disease, above published site distributions. Results describe these respondents.



FROM SURVEY TO ACTION

Patients told us what matters. They volunteered to participate. SFTF is building the infrastructure to connect them with research.

38 volunteers mobilized in our first eight weeks

- ✓ Research conversations underway with clinicians and scientists at leading sarcoma centers in the U.S. and Europe
- ✓ Medical and Scientific Advisory Boards in development

WORK WITH US IN 2027

We are looking for investigators, trial sponsors, biobanking partners and SFT experienced Centers of Excellence.

- ✓ Patient registry
- ✓ Tissue donation
- ✓ Trial protocol review
- ✓ Expert center directory

Scan to contact SFTF

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