Spence Family
Synovial Sarcoma Foundation

OUR MISSION

Transform the synovial sarcoma treatment landscape by driving groundbreaking research, expanding clinical resources, and fostering a strong patient and caregiver community.

Our story, community *and services*

In January 2022, Chas and Laura Spence's 16-year-old son, Callan, was diagnosed with synovial sarcoma. Multiple specialists said his tumor was inoperable. Only CHOP offered a real plan. That gap, between what patients need and what exists, became the reason the Spence family built the infrastructure themselves.

They were later joined by Nathan Imperiale, whose husband, Eddie Cohen, was diagnosed with synovial sarcoma in 2023. Together they founded the Synovial Sarcoma Foundation, a national research and advocacy platform built by families who refused to wait.



Laura, Callan and Chas Spence.

650+
members in our private, moderated Facebook group

11
leading sarcoma clinicians and researchers on our Medical Advisory Board

1st
place, SPAGN 2026 Advocacy in Action Award

Our milestones

What our families and partners have built since 2022

DEC 2022
The Spence family commits $600,000 to research at CHOP and Penn Medicine.

JAN 2023
The Tumor Board first meets.

JUN 2023
The Registry and Biorepository opens.

FEB 2025
SSF formally launches as a foundation.

MAR 2025
SSF co-hosts the first national virtual conference on synovial sarcoma.

DEC 2025
The registry enrolls its 100th patient.

MAY 2026
SSF wins first place at SPAGN.

SEP 2026
The pediatric TumorGlow trial launches.

OCT 2026
New funding at Dana-Farber and Northwestern.

Community and services

Survivors and families lead our support for patients and clinicians

OPEN RECORDS

Open-source patient journeys

Callan's and Eddie's sites

To show the newest treatment options patients are pursuing, we publish open-source sites that follow each patient's journey in detail.

Every record and treatment decision is shared openly, so other families and their doctors can learn from each step.



3D TUMOR LOCATOR

SCAN FOR CALLAN'S SITE

COMMUNITY LEAD



Julie Kramer

Director of Community Engagement

Julie is a survivor, so every family who reaches us talks with someone who has lived through this disease.

PEER SUPPORT

Private Facebook group

Private and moderated

Patients and caregivers ask questions and share updates. Only members see the posts.

- Moderators keep it free of spam.

ADVOCACY



Ambassador Program

Led by Jonathan, age nine

Ambassadors turn their experience with synovial sarcoma into advocacy. They share their stories and help other families find support.

CLINICAL CARE



International Tumor Board

Led by Dr. Ted Laetsch of CHOP

Each month, sarcoma specialists worldwide review complex cases together.

- Any oncologist can bring a case.

CARE GUIDANCE

Finding expert care

Care Guide, Center Locator, Trial Finder

Our Care Guide covers diagnosis and treatment. A locator maps sarcoma centers. The trial finder lists 26+ recruiting trials.

RESEARCH — Launching soon

AI-assisted research tool

Ask the Research Hub

Ask a question in your own words. Answers draw only on research we have checked, with a link to every source.

AN IDEA TO BORROW

Build the infrastructure your patients need instead of waiting for it, and open it to the world.

Families can reach our team directly

Write to us at
community@synovialsarcoma.org

Instagram @synovial_sarcoma
Facebook @synovialsarcomafoundation
X @curesynovial
LinkedIn @synovialsarcomafoundation

synovialsarcoma.org
Scan to visit