

SPAGN Conference Participant Profile

Name: Julie Kramer

Organisation: Synovial Sarcoma Foundation

Role / Stakeholder Type: Patient, Healthcare Professional/Speaker

Country: USA



What is your connection to sarcoma or your sarcoma story?

I was diagnosed with stage 4 synovial sarcoma of the lung in 2014. I was given 3 months to live. After undergoing extensive treatments and 2 recurrences, I thankfully find myself NED for 9 years. Since then, I have spent my personal life advocating for this disease and providing peer support to patients in this community. I serve as the Community Engagement and Partnerships Manager at the Synovial Sarcoma Foundation to contribute to advancing research and treatment options as well as providing specialized support for the synovial sarcoma community.



What's most important to know about your organization?

The Synovial Sarcoma Foundation is dedicated to raising awareness, supporting patients and families, and accelerating research for a rare and often underfunded cancer. A key initiative is the Synovial Sarcoma Tumor Board, an international forum led by Dr. Ted Laetsch and hosted with Children's Hospital of Philadelphia (CHOP) and Penn Medicine, where experts collaborate on complex cases to expand treatment options for both children and adults. The foundation also funds the first-of-its-kind Synovial Sarcoma Registry and Biospecimen Repository, launched in 2023, which collects clinical, genomic, and biospecimen data to advance research and improve outcomes. By connecting patients, clinicians, and researchers, the foundation plays a critical role in driving collaboration, amplifying patient voices, and pushing toward more effective therapies.



What are you most interested in collaborating on?

Research, Awareness, Access, Partnerships, Patient Support





Your role in the organisation and main areas of involvement:

As the Community Engagement and Partnerships Manager, my role is to make patients and caregivers aware of the resources available within the community, both offered by the foundation as well as additional resources while offering compassionate support to all. I also look for other foundations to collaborate with that share the similar mission of driving research forward.



How can others best connect with you after the conference?

julie@synovialsarcoma.org; Instagram @synovial_sarcoma or @julie_kramer



One fun fact about you or something you are proud of:

I am a mom of a 3 year old boy who came into my life as a shocking miracle as I did not do egg preservation prior to chemotherapy.

