SPAGN Conference Participant Profile

Name: Karin Arndt

Organisation: Deutsche Sarkom-Stiftung

Role / Stakeholder Type: Patient, Patient Advocate

Country: Germany

What is your connection to sarcoma or your sarcoma story?

Following a poorly performed diagnosis and subsequent surgery, I received the diagnosis in 2005: clear cell sarcoma that had metastasized to the lymph nodes and had a very poor prognosis. I connected with other patients and searched for the reasons behind the incorrect treatment. I helped establish the sarcoma division of the predecessor organization "Das Lebenshaus". I am a founding member and, until recently, a board member of the current German Sarcoma Foundation.

What's most important to know about your organization?

"Das Lebenshaus" was one of the founders of SPAEN. Even today, key positions are held by German patient representatives who play a significant role in the global development of SPAGN. The German Sarcoma Foundation, a joint organization of patients and physicians, now has nearly 6,000 registered patients or relatives and approximately 700 physicians. We participate in research and inform patients and physicians through our patient hotline, website, newsletter, events, and social media.

What are you most interested in collaborating on?

Partnerships, Patient Support, Networking with organizations on the topic of research on clear cell sarcoma

Sarcoma
Patient Advocacy
Global Network

Your role in the organisation and main areas of involvement:

I am involved daily with our patient hotline, advising and connecting patients. I am involved in all sarcoma research projects of our organization and the National Centers for Tumor Diseases in Germany. Since the founding of the patient advisory board for research at the German Cancer Research Center in Heidelberg, I have been an active member. My primary concern there was to represent our rare type of cancer. Through my involvement, I also have personal contact with many sarcoma specialists in Germany. I am a co-organizer of the annual Sarcoma Tour in Essen, where in 2025 patients donated a total of just over €280,000 for sarcoma research.

How can others best connect with you after the conference?

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

Driven by my very poor prognosis and numerous relapses, I took up pottery during my first rehabilitation: "I wanted at least something of me to remain if I was going to die," and pottery also helped me push away the negative thoughts. I gave many particularly beautiful pieces to my doctors. Through my involvement, I've had the opportunity to meet many patients and doctors, many of whom have enriched my life and are now good friends. Some patients say I saved their lives—that makes me happy.