

# SPAGN Conference Participant Profile

**Name:** Stéphanie Anzellotti

**Organisation:** Cum Cura

**Role / Stakeholder Type:** Patient Advocate, Caregiver

**Country:** Belgium

## What is your connection to sarcoma or your sarcoma story?

My story began over ten years ago, when my husband was diagnosed with a desmoid tumor. My deeper involvement started later, when my son was diagnosed with sarcoma.

## What's most important to know about your organization?

What is most important about our organization is that we create a warm and easy-to-access community for people affected by rare tumors like sarcoma. We support patients, their families, and healthcare professionals by sharing clear information and bringing people together. Our goal is to help people feel less alone and improve their quality of life. A key part of our work is the buddy program. Our buddies are volunteers with their own experience as patients or relatives. They listen, share their experience, and offer support in a kind and respectful way. We carefully match people so they can talk to someone who truly understands their situation.

## What are you most interested in collaborating on?

Awareness, Access, Patient Support

## Your role in the organisation and main areas of involvement:

As a volunteer, I am part of the board and help manage the daily operations of our organization. I am responsible for communication and marketing, and I act as a moderator in our online community. I am also active as a patient advocate, support our buddy program, and contribute to research initiatives.

## How can others best connect with you after the conference?

LinkedIn

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

My sarcastic humor :-) But not everyone likes it.

