

SPAGN Conference Participant Profile

Name: Lina Vissenaeken

Organisation: Cum Cura VWZ

Role / Stakeholder Type: Patient, Patient Advocate, Company representative, Founder

Country: Belgium



What is your connection to sarcoma or your sarcoma story?

I was diagnosed with osteosarcoma in 2006. At that time, my biggest and only wish was to see my children, who were 8 and 11, grow up to adulthood. Thirteen years later, I reached that milestone, and my sense of gratitude was overwhelming. I felt a strong need to give back and support other sarcoma patients — that's how Cum Cura was born. Since then, I've met so many inspiring people who have helped grow our patient organization into what it is today.



What's most important to know about your organization?

Cum Cura is the only Belgian patient organization dedicated exclusively to sarcoma. Our mission is to support patients and their families, raise awareness, and advocate for better care and research. We focus on connecting patients, connecting with healthcare specialists, providing reliable information, and ensuring their voices are heard at both national and international levels. Because sarcoma is rare and often unknown, we believe visibility and collaboration are essential. Above all, we aim to make sure no patient feels alone in their journey.



What are you most interested in collaborating on?

Research, Awareness, Policy, Partnerships, Innovation, Patient Support





Your role in the organisation and main areas of involvement:

As founder and active board member of Cum Cura, I am closely involved in the overall direction and development of the organization. My role focuses on patient advocacy, building partnerships with healthcare professionals and institutions, and representing the patient voice in policy and research initiatives. I also contribute to awareness campaigns and support activities for patients and families. Bringing people together and creating meaningful impact remains at the heart of everything I do.



How can others best connect with you after the conference?

email, open to partnerships



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

As a patient association, it can be quite a challenge to reach healthcare providers and specialists. With their busy schedules, it's not a given that we "stick" in their minds — let alone stand out among everything else that comes their way.

Last year, we decided to try something different: I sent all university hospitals a personalized post, including their own photos from their website, to highlight their sarcoma teams during Awareness Month. And suddenly... responses! Enthusiastic ones, even. 😊

Not long after, we noticed we were being contacted more often — even invited to workshops to help shape the new cancer plan in Belgium. Coincidence or not? Who knows.

But one thing is certain: sometimes you just have to get a little creative... and apparently, an unexpected "you're doing great" works better than politely knocking on the door once again 😊

