

SPAGN Conference Participant Profile

Name: Joost Groen

Organisation: Patiëntenplatform Sarcomen

Role / Stakeholder Type: Patient, Patient Advocate

Country: The Netherlands

What is your connection to sarcoma or your sarcoma story?

In 2020 I was diagnosed with GIST. After emergency surgery and three years of adjuvant medication the disease seemed to have left my body. I became a patient advocate pretty much right away, taking care of peer contact, writing understandable information and advocacy work. Unfortunately this year recurrence was discovered so I'm back on medication. It's fingers crossed I will be around for much longer as I'm not done yet.

What's most important to know about your organization?

We take care of sarcoma patient advocacy in the broadest sense of the word, from organizing peer contact sessions to speaking up about medication shortages and reviewing expert hospitals.

What are you most interested in collaborating on?

Research, Innovation

Your role in the organisation and main areas of involvement:

Research and advocacy work

How can others best connect with you after the conference?

Check me on LinkedIn: [linkedin.com/in/joost-groen](https://www.linkedin.com/in/joost-groen)

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

As a patient advocate I took part in several opposition committees to PhD defenses. I am proud to represent the patient perspective in these occasions.

