

SPAGN Conference Participant Profile

Name: Giulia Personeni

Organisation: Desmoid Foundation Italy

Role / Stakeholder Type: Patient, Patient Advocate

Country: Italy

What is your connection to sarcoma or your sarcoma story?

I'm a desmoid tumor patient and I'm the founder and Vicepresident of Desmoid Foundation Italy

What's most important to know about your organization?

We work hard to support patients with desmoid tumours, offering free services to help them feel less alone during their journey through diagnosis and treatment. We have a community of over 800 active patients who support us and get involved.

What are you most interested in collaborating on?

Research, Awareness, Policy, Partnerships, Patient Support

Your role in the organisation and main areas of involvement:

Vicepresident: Research and Advocacy

How can others best connect with you after the conference?

desmoide.info@gmail.com

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

At our patient event this year, I received more hugs from strangers than I have in my entire life, but I'm so happy about it because it means we're making a difference to someone!

