

SPAGN Conference Participant Profile

Name: Inés Aulló Pérez

Organisation: AEAPAF

Role / Stakeholder Type: Patient / Patient Advocate

Country: Spain

What is your connection to sarcoma or your sarcoma story?

I'm a Desmoid tumor patient and patient advocate, besides living with the most known genetic disease that leads to them.

What's most important to know about your organization?

We welcome patients from Familial Adenomatous Polyposis and Desmoid Tumor, whether they are related or not to the FAP condition.

What are you most interested in collaborating on?

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

Your role in the organisation and main areas of involvement:

Delegate for Europe

How can others best connect with you after the conference?

diariodeunamutante@gmail.com

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

I'm proud of being able to create calm, supportive spaces where people feel heard and understood, holding space for people with care, clarity, and compassion 

