

SPAGN Conference Participant Profile

Name: Irene Badura

Organisation: Chordoma Foundation

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

Country: Germany

What is your connection to sarcoma or your sarcoma story?

My grandson, who was 6 at the time, was diagnosed with chordoma in 2020. It was very difficult for us to find the best treatment option. Now I don't want other patients to be treated by "non-experts"

What's most important to know about your organization?

The Chordoma Foundation is led by patients. Patients from all over the world seek and receive help here. It has its own laboratory and conducts extensive research.

What are you most interested in collaborating on?

Research, Awareness, Patient Support

Your role in the organisation and main areas of involvement:

I am helping other patients to get information and find experts in German speaking countries. I'm also running an online self- help group for chordoma patients and caregivers.

How can others best connect with you after the conference?

Deutschland@chordomafoundation.org

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

Last year, we held our first in-person meeting with 50 participants from Germany, Austria, Switzerland, and Luxembourg.

