

SPAGN Conference Participant Profile

Name: Jayne Bressington

Organisation: PAWS-GIST

Role / Stakeholder Type: Patient Advocate, Caregiver

Country: UK

What is your connection to sarcoma or your sarcoma story?

My 15 year old daughter Eve was diagnosed with a paediatric wild-type GIST in January 2010. We were told that there was no treatment, no cure and no research. This stimulated me to do everything in my power to change this outlook for my daughter and all others like her.

What's most important to know about your organization?

PAWS-GIST clinic is the only clinic in Europe focusing on rare PAWS-GIST patient and only the second clinic of its type in the world. We also have a tissue bank supplying researchers with the raw materials to undertake research for improved treatments and a cure.

What are you most interested in collaborating on?

Research, Innovation, Patient Support

Your role in the organisation and main areas of involvement:

I am involved in all aspects of PAWS-GIST: Patient, Support, Communications, Research & Advocacy. We run x3 clinics each year at Addenbrookes hospital in Cambridge.

How can others best connect with you after the conference?

Jayne@pawsgistclinic.org.uk

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

I love dancing and recently reached the semi-final of a dance with a stranger freestyle competition :)

