

SPAGN Conference Participant Profile

Name: Carly McDonald

Organisation: Sarcoma UK

Role / Stakeholder Type: Healthcare Professional/Speaker

Country: UK



What is your connection to sarcoma or your sarcoma story?

I joined Sarcoma UK 5 1/2 years ago as a Support Line Advisor, having previously worked as a healthcare professional within the NHS. I have a passion for ensuring personalised care and empowering individuals with accurate and thorough information, whilst supporting informed choices and acting as an advocate for people.



What's most important to know about your organization?

Sarcoma UK is the only UK-based charity focusing on all types of sarcoma, desmoid tumours and TGCT. We fund vital research, offer support to anyone affected and campaign for better treatments, enabling individuals to live longer and better lives.



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:

I am part of a team who facilitate Sarcoma UK's Support Line, which is available to anybody affected by sarcoma, desmoid tumours and TGCT. I guide Sarcoma Support Group Leaders across the UK and lead on our direct referral service, where clinical teams refer individuals affected by sarcoma, desmoid tumours and TGCT to our team, for additional support and signposting. I work alongside Sarcoma UK's policy team to advocate for families affected by sarcoma, the communications team to promote our work and spread awareness, and the research team to ensure individuals are provided with current information about research studies and clinical trials. I help to recruit those affected by sarcoma to Sarcoma UK's involvement network, who shape the work of the charity.



How can others best connect with you after the conference?

carly.mcdonald@sarcoma.org.uk



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

Fun fact: I met Desmond Tutu at a Florence Nightingale Commemoration Service, where I carried a lamp through Westminster Abbey! Proud moment: In 2025, I led two Community Days for those affected by sarcoma, desmoid tumours and TGCT, enabling people to connect, learn and share. I'm also proud of my children, particularly their sporting achievements!!

