

# SPAGN Conference Participant Profile

**Name:** Lennie Woods

**Organisation:** Clear Cell Sarcoma Foundation

**Role / Stakeholder Type:** Patient Advocate

**Country:** USA

## What is your connection to sarcoma or your sarcoma story?

My daughter Sara Was diagnosed with CCS in 2016 and it returned in 2018. We realized quickly that the need for research and CCS specific data was critical to be able to make the best treatment decisions. The day after her second surgery my husband and I made a promise to do everything in our power to give CCS patients a place to be heard and create positive changes in research and find better effective treatments.

## What's most important to know about your organization?

We work everyday like a life depends on it because many do. We also are commtted to making sure each CCS patient voice is heard even when they are not able to speak. The lived experiences of the CCS patient community is what drives us and what we believe is also required for discovering an effective CCS treatment. We did not start the movement created in 2010 by several CCS patients that found each other and began to document treatment patterns however we stand on their shoulders and continue the fight to cure CCS.

## What are you most interested in collaborating on?

Research, Partnerships, Innovation, Patient Support, data collection on treatments so we progress toward effective ones

## Your role in the organisation and main areas of involvement:

Patient support, patient advocacy and research

## How can others best connect with you after the conference?

[lennie@clearcellsarcoma.org](mailto:lennie@clearcellsarcoma.org)

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

I have an impressive collection of Dewalt power tools that I know how to use:) and I have designer chickens

