

A Conversation with Mimma Spagnolo

CSPA Committee Member: Affiliate Members, Breaking Barriers



Mimma Spagnolo

Chairperson of the Board

Why did you get involved with CSPA?

Living with Gorlin Syndrome—a rare genetic condition that can cause multiple basal cell carcinomas and other health issues—has given me firsthand experience with the physical, emotional, and practical challenges of managing a chronic skin condition. I've spent much of my life navigating the healthcare system, advocating for myself, and learning how important it is to have a community that truly understands your journey. When I learned about the work CSPA was doing, I immediately felt aligned with its mission to amplify the voice of skin patients. My background in advocacy and leadership made me feel like I could contribute in a meaningful way.

What do you perceive as outcomes of your involvement?

Serving on the board—and now as Chairperson—has allowed me to help shape strategic initiatives that directly impact patients across Canada. I want to see the CSPA grow in reach and influence, strengthening our voice in conversations about equitable care, research funding, and public awareness. Personally, it's incredibly rewarding to know that our work is creating real support systems for people living with conditions like Gorlin syndrome, psoriasis, eczema, and other skin, hair and nail diseases. I believe our collective efforts are empowering patients to speak up and feel seen.

Why do you like volunteering with CSPA?

Volunteering with CSPA gives me purpose and a strong sense of connection. It's fulfilling to work alongside others who are just as passionate about improving the lives of skin patients. It's also been an opportunity for personal growth—learning from other patient experiences and being part of something bigger than myself. For someone with a lifelong condition, it's healing to be able to turn lived experience into meaningful change.

Why would you tell others that they should get involved with CSPA?

If you've ever felt isolated or misunderstood because of your skin condition, getting involved with CSPA can change that. Whether you're a patient, caregiver, healthcare provider, or advocate, your voice matters. CSPA offers a platform to connect, influence policy, raise awareness, and help others who might be earlier in their journey. It's a chance to be part of a compassionate, driven community that's truly making a difference in people's lives.

Has a personal connection with the skin patient community inspired your participation?

Absolutely. Living with Gorlin Syndrome means I've met so many others who feel like their experiences are invisible or minimized. That sense of solidarity and shared struggle has been a major driving force behind my involvement. I know what it feels like to face medical appointments, surgeries, and stigma—and I want others to know they're not alone. My participation is deeply rooted in that personal connection and a desire to use my story to uplift others.