

SPAGN Conference Participant Profile

Name: Wilker Jordi Lopes Franco De Jesus

Organisation: Sarcomunicandonos Latin America /
Desmoid Brazil

Role / Stakeholder Type: Patient Advocate, Healthcare
Professional/Speaker, Oncology Pharmacist

Country: Brazil

What is your connection to sarcoma or your sarcoma story?

I am connected to the sarcoma community through my work in patient advocacy and support, particularly in Latin America. Through initiatives such as Sarcomunicádonos and the Desmoid Brazil Association, I work closely with patients and families, helping to reduce barriers to care and improve access to information. My motivation comes from witnessing the challenges faced by individuals with rare cancers and the need for more compassionate, patient-centered care. I am currently pursuing a master's degree in palliative care, focusing on compassion as a core element in healthcare. This work drives my commitment to strengthening awareness, support networks, and quality of care for people living with sarcoma.

What's most important to know about your organization?

Our organization is dedicated to supporting people affected by sarcomas and desmoid tumors through advocacy, education, and patient-centered care initiatives. We work to reduce barriers to diagnosis and treatment, strengthen support networks, and amplify patient voices across Latin America. Through projects like Sarcomunicádonos, we promote awareness, community engagement, and access to reliable information. In addition, we integrate compassionate care and compassion as core practices in our approach, aligned with my studies and work as a specialist in compassion and compassionate care. Our mission is grounded in compassionate care, aiming to improve quality of life and outcomes for patients and their families.

What are you most interested in collaborating on?

Research, Patient Support, I am particularly interested in positioning compassion as a measurable and scalable healthcare intervention, not only as a value, by actively engaging in research and advancing compassion studies at an international level with sarcoma patients.





Your role in the organisation and main areas of involvement:

Patient Advocate and Healthcare Professional , Clinical Oncology
Pharmacist



How can others best connect with you after the conference?

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

One thing I'm proud of is advancing compassionate care as a core practice in healthcare, grounded in compassion as an active approach to patient care. Through the Sarcomunicándonos project, in partnership with Desmoid Brazil and alongside Georgia, we were honored in 2025 as a leading oncology initiative at the largest oncology congress in Latin America. Our work in advocacy and patient navigation for sarcoma and desmoid tumors was nationally recognized, even among major institutions such as Instituto Ronald McDonald. The project gained strong visibility through TV programs, social media, and podcasts, reaching an audience of over 5,000 congress participants. It was an incredible achievement and an opportunity to bring a part of SPAGN to Latin America. WILKER FRANCO

