

SPAGN Conference Participant Profile

Name: Piotr Fonrobert

Organisation: Stowarzyszenie Pomocy Chorym na GIST

Role / Stakeholder Type: Patient, Patient Advocate

Country: Poland



What is your connection to sarcoma or your sarcoma story?

GIST is my type of sarcoma. It appeared unexpectedly, without any symptoms, and was surgically removed in 2008. Since then, I have dedicated myself to supporting others who are now facing this disease. My personal experience has shaped my commitment to ensuring that no patient feels alone or uninformed on their journey."



What's most important to know about your organization?

We are a highly active and - for such a rare cancer - remarkably large patient organization. We work to break down the barriers that people with GIST encounter, not only in treatment but also in navigating the broader healthcare system. A key part of our mission is ensuring that all modern therapies are accessible within Poland's reimbursement framework.



What are you most interested in collaborating on?

Research, Awareness, Policy, Innovation, Patient Support



Your role in the organisation and main areas of involvement:

In my Association, we devote much of our work to helping patients understand GIST - not only what the disease is, but also what treatment options and therapeutic pathways are available to them. Over the years, this mission has naturally led us to engage more deeply in broader, systemic health-care issues. As a result, we regularly take part in discussions held by the Health Committees of the Polish Parliament, bringing the patient perspective into national decision-making. Personally, I also serve as a member of the Patient Organizations Council advising the Minister of Health, where I work alongside other leaders to strengthen the voice of patients in shaping health policy.





How can others best connect with you after the conference?

email - stowarzyszenie@gist.pl



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

A fun fact I'm proud of: partly thanks to our efforts, GIST is no longer a little-known disease among general practitioners in Poland - which was still very common when I was diagnosed

