SPAGN Conference Participant Profile

Name: Markus Wartenberg

Organisation: German Sarcoma Foundation(Deu. Sarkom-Stiftung)

Role / Stakeholder Type: Patient Advocate

Country: Germany

What is your connection to sarcoma or your sarcoma story?

Co-founded the charity “Das Lebenshaus e.V.” in 2003 alongside GIST and sarcoma patients, and held various roles within the organisation until the end of 2019.My involvement as a patient advocate includes (excerpt):

- Co-initiator (2009) and, since 2013, elected Co-Chair of SPAGN
- 2009–2017: involved in the founding and management of the IKCC (International Kidney Cancer Coalition) – another intl. patient advocacy network
- From 01/2015 – 01/2017: Member of the ESMO Patient Advocates Working Group – the European patient committee of ESMO
- Since January 2020: Deputy Chair of the Board of the non-profit German Sarcoma Foundation
- Since 2020: Involved in the strategy and the development of the NCT National Center for Tumour Diseases and co-founder of PEAK, the Patient Expert Academy.
- Since June 2023: Spokesperson for the National NCT Patient Research Council and member of the NCT Steering Committee
- July 2024: Recipient of the German “Patient Expert Award” presented by the DKFZ (German Cancer Research Center) for exceptional commitment to cancer research and patient involvement

What's most important to know about your organization?

Our organisation now represents several thousand patients with sarcomas or GISTs, maintains close links with 30 specialist sarcoma centres in Germany, and is in contact with over 700 doctors with an interest in sarcomas.

The core objective is to bring about change for sarcoma/GIST patients and their families.

- Change for individual patients: through counselling, information and support services, as well as the tangible solidarity that ensures they do not face such rare diseases alone. In close collaboration with recognised sarcoma centres, the foundation strengthens patient empowerment and improves the patient experience.
- Change for many patients: Through active advocacy, the foundation acts as the ‘patient voice’ in sarcoma research and in health and care policy.

A key focus of our work is "patients as partners in cancer research". We are actively helping to shape this necessary cultural shift across the whole of Germany and across all types of cancer. In the field of sarcomas/GIST, we are now partners or even co-applicants in 10 major research projects...

What are you most interested in collaborating on?

Research, Awareness, Access, Policy, Partnerships, Innovation, Patient Support, Digital Oncology/AI

Your role in the organisation and main areas of involvement:

As a member of the Executive Board and Deputy Chair, I am currently primarily responsible for managing the staff team, networking within the oncology/sarcoma community, patient involvement in research, and development in digital oncology and AI. And I do all this in collaboration with a fantastic team of staff and volunteers...

How can others best connect with you after the conference?

markus.wartenberg@sarkome.de or markus.wartenberg@nct-patientenbeteiligung.de

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

My motto has always been: “If you can dream it, you can do it!” – Walt Disney.And I’m proud to be the “dad to girls” – two wonderful daughters and a granddaughter (almost 3 years old)...