

**12th SPAEN Annual Conference for Organizations
Representing Patients with Sarcomas, GIST or Desmoid-Tumours
24th – 26th of June 2022 in Frankfurt/Germany
SCANDIC FRANKFURT MUSEUMSUFER**



PROGRAMME

Hybrid event: Onsite sessions + live-streaming via Zoom
Recordings will be available after the meeting

Zoom-Link: <https://us06web.zoom.us/j/83945552092?pwd=a1NXQmdWY2IHWWU5aUVReUdIdVRLdz09>

Meeting ID: 839 4555 2092 - Passcode: 875478

DAY 1 – FRIDAY June 24, 2022	
11:00	Opening of the Registration Desk
12:30	Lunch (Restaurant Artrium)
13:30	OFFICIAL START OF THE CONFERENCE (Room Nr. 63)
13:30 (30)	Welcome to Frankfurt/Germany on behalf of the SPAEN Board <i>Markus Wartenberg (DE), Vandana Gupta (IND), Denise Reinke (US)</i>
14:00 (90)	Patient Involvement in (Rare) Cancer Research / Sarcoma Research <i>Chair: Markus Wartenberg</i> Introduction & Setting the Scene / <i>Markus Wartenberg (10 min)</i> Spotlight Session & Discussion (10 min each) <ul style="list-style-type: none"> • 20 Years of Patient Involvement in the UK: Key Learnings / <i>Roger Wilson (online)</i> • A New Journey: NCT Patients as Research Partners / <i>Markus Wartenberg</i> • Sarcomas: The Count-me-In Project / <i>Taylor Cusher (online)</i> • Chordoma Foundation: Patients driving Research / <i>Kimberley de Haseth, Chordoma Foundation US (online – pre-recorded)</i> • GIST Patient Registry USA / Latin America / <i>Piga Fernandez & Denisse Montoya, Life Raft Group US (online)</i> Exchange of experiences/ideas - discussion (20-30 min)
15:30	COFFEE BREAK (30 min.)
16:00 (120)	SPAEN AGM All Conference Participants are welcome! (Voting rights for SPAEN Members only) This session has an official invitation / agenda – important topics are: <ul style="list-style-type: none"> • Report of the Board of Directors (2021) • Financial Report (2021) • Outlook 2022 and beyond • Elections • Applications/requests <i>SPAEN Board</i>
18:00	BREAK BEFORE DINNER
19:00	Internal Dinner Scandic Hotel (Restaurant Artrium)

DAY 2 – SATURDAY June 25, 2022				
9:00 OFFICIAL START OF THE CONFERENCE (Room Nr. 63)				
09:00 (90)	Drug Repurposing <i>Moderator/Chairs: Denise Reinke (live), US & Ornella Gonzato (online), Italy</i> <i>Speaker: Pan Pantziarka, Anticancer Fund, UK (online) & Marco Schito, CURE Drug Repurposing Collaboratory (online), US</i> <i>Workshop / Roundtable</i>			
10:30 – 11:00 COFFEE BREAK (30 min.)				
11:00 (90)	Quality of Life, PROs and long-term survivorship <i>Chair: Roger Wilson (online)</i> <ul style="list-style-type: none">How PROs are changing and evolving as a valued tool in cancer research <i>Lee Aiyegbusi (online)</i>EORTC Item Library <i>Dagmara Kulis (online)</i>PROs - sarcoma specific issues <i>Olga Husson (online)</i>Living beyond cancer, quality of life and priorities for research <i>Richard Stephens (online)</i> Discussion			
12:30 – 14:00 LUNCH and NETWORKING (90 min.) - Restaurant Artrium Breakout rooms open in zoom from 13:45				
14:00 (90)	Soft Tissue Sarcomas (Room Nr. 63) <i>Chair: Denise Reinke, US</i> Medical & Research Update <i>Speaker: Robin Jones, UK (online)</i> Educational Spotlight: Liposarcomas <i>Speaker: Peter Reichardt, DE (live)</i>	GIST (Room Nr. 17) <i>Chair: Gerard v. Oortmerssen, NL</i> Medical & Research Update <i>Speaker: Jean Yves Blay, FR (online)</i> Avapritinib & Ripretinib in treatment algorithm – a status <i>Speaker: Jon Trent, US (online)</i>	Bone Sarcomas (Room Nr. 41) <i>Chair: Ornella Gonzato, IT</i> Medical Update & Research: Top 10 research projects in bone sarcoma <i>Speaker: A. Leithner, AT (live)</i> ctDNA in Bone Sarcoma <i>Speaker: Eleni Tomazou, AT (online)</i>	Desmoid (Room Nr. 25) <i>Chair: Christina Baumgarten, DE</i> Medical Update & Treatment Options <i>Speaker: B. Kasper (live)</i> Challenges of living with desmoids: Quality of Life, Support, Pain, Fertility/Pregnancy <i>Speaker: Chiara Colombo, IT (online)</i>
15:30 – 16:00 COFFEE BREAK (30 min.)				
16:00 (45)	Treatment decisions in elderly patients with metastatic disease <i>Speaker: Winette van der Graaf, NL (online)</i>	Role of surgery in all stages of disease <i>Speaker: Winan van Houdt, NL (online)</i>	Living with and beyond bone sarcoma (Physical Rehab Aspects, Mental Health, Body Image) <i>Speaker: Uta Dirksen, DE (online?)</i>	Networking

16:45 (60)	Chair: Annika Laakso, FIN Quality in sarcoma surgery: Image – board – biopsy <i>Jens Jakob, Germany (live)</i>
17:45	Announcement Advocacy in Action Award Winners 2021
18:15	BREAK BEFORE DINNER
19:30	External Dinner (Main-Nizza Restaurant in walking distance)

DAY 3 – SUNDAY June 26, 2022	
09:00 (120)	SPAEN Board & Working Group Meeting <i>Moderator: Denise Reinke, US (live)</i> <ul style="list-style-type: none"> • Sarcoma Centers/Networks of Excellence – access to treatment? • Minimal Requirements for Sarcoma Care & Management
11:00 – 11:30 COFFEE BREAK (30 min.)	
11:30 (90)	Cancer Care: Ensuring that digitalisation benefits rare cancer patients... <ul style="list-style-type: none"> • Digitalisation is changing healthcare systems (hcs) and the role of patients/patient advocates • Healthcare & (Rare) Cancers: Digitalisation will be a very important key: Digitalisation will (must) bring solutions (improvements) also for our Sarcoma-/GIST (Rare Cancer) Community <i>Markus Wartenberg, DE (live)</i> Examples from our global Sarcoma-/GIST patient community of how we are already involved in digitalisation or are even driving it forward: Prepared short presentations or spontaneous examples/ success stories from the audience – exchange/discussion...
13:00	Closing Remarks – End of Meeting <i>SPAEN Board</i>