

16th SPAGN Annual Conference

May 1-3, 2026, Stockholm, Sweden

Karolinska University Hospital, Sune Bergström Aula

Eugenivägen 3, Solna/Stockholm, Sweden

&

Elite Hotel Carolina Tower

Eugenivägen 6, 171 64 Solna/Stockholm, Sweden



PROGRAM

DAY 1 – FRIDAY May 1, 2026	
11:00	Opening of the Registration Desk
11:30	Lunch
12:30	OFFICIAL START OF THE CONFERENCE (Sune Bergström Aula)
12:30 (30)	Welcome to Stockholm, welcome to Sweden! <i>Markus Wartenberg & Denise Reinke, SPAGN Board Co-chairs</i> <i>Per Alvers, Olivia Hammar, Sarkomföreningen</i> <i>Andri Papakonstantinou, Karolinska University Hospital</i>
13:00 (60)	The power of the patient's contribution to research: Why we can't advance treatments without it <ul style="list-style-type: none">• Patient Reported Outcomes and Quality of Life (30 min) <i>Speaker: Tessa van Amerongen, NL</i>• Critical value of research biospecimens (30 min) <i>Speakers/Discussants: Christina Ip-Toma, US & Nikolas Herold, SWE</i> Chair: Roger Wilson & Denise Reinke
14:00 (15)	Discussion
14:15 – 14:45	COFFEE BREAK & NETWORKING (30 mins)
14:45 (60)	From sequencing to personalized therapy: Understanding genetic/genomic data and implications for sarcoma treatment Setting the stage – what we need to know (10 mins) <i>Felix Haglund, SWE</i> <i>Panelists: Roger Wilson, UK; Felix Haglund, SWE; Bernd Kasper, GER</i> Moderator: Magnus Carlsson
15:45 – 16:00	SHORT BREAK (15 min)

16:00 (75)	Sharing Best Practices & Advocacy in Action Awards <ul style="list-style-type: none"> - Presentations Advocacy in Action Award Winners/Submissions 2026 - 10 years of listening, learning, and impact: The Sarcoma UK support line <i>Carly McDonald & Sam Hackett</i> Chair: Gabi Ott & Ornella Gonzato
17:15	Change of Location
18:00	SPAGN Board of Directors: Speed-Dating (Conference Lobby, 1st floor Carolina Tower Hotel)
18:30	MIX AND MINGLE: INFORMAL GET-TOGETHER (Conference Lobby 1st floor)

DAY 2 – SATURDAY May 2, 2026	
08:30 OFFICIAL START OF THE CONFERENCE (Sune Bergström Aula)	
8:30 (5)	Welcome to the day <i>Kai Pilgermann</i>
8:35 (70)	SPAGN Annual General Meeting (AGM) All Conference Participants are welcome! (Voting rights for SPAGN Members only) This session has an official invitation / agenda – important topics are: <ul style="list-style-type: none"> • Report of the Board of Directors (2025) • Financial Report (2025) • Review 2025 & Outlook 2026 • SPAGN Strategy 2031 • Elections • Applications/requests SPAGN Board
9:45 – 10:15 C O F F E E B R E A K & NETWORKING (30 min)	
10:15 (60)	Sarcoma treatment in motion: New therapies, trials, and approvals Excursion: When no treatment options exist: How patients and experts can drive change together <i>Speaker: Robin Jones, UK</i> Chair: Brandi Felser
11:15 (15)	Q&A
11:30 (15)	Lifetime Achievement Awards 2026 Chair: Estelle Lecointe-Artzner & Roger Wilson
11:45 Group Photo & Change of Location to Carolina Tower Hotel	
12:00 – 13:00 L U N C H and NETWORKING (60 min)	

BREAKOUT SESSIONS				
	Full program for tracks – please see below			
13:00 (120)	Soft Tissue Sarcomas (Room Röntgen) <i>Chair: Brandi Felser & Natalia Fernandez</i>	GIST (Room Fleming) <i>Chairs: Kai Pilgermann & Tara Ruggiero</i>	Bone Sarcomas (Room Pavlov) <i>Chairs: Ornella Gonzato & Christina Ip-Toma</i>	Desmoid (Room Pasteur) <i>Chairs: Desmoid Working Group</i>
15:00 – 15:30 COFFEE BREAK (30 min.)				
15:30 (45)	Working Group & Discussion Session: (Room Röntgen) <i>For Beginners: From Experience to Impact: First Steps in Research Advocacy</i> Highlight the importance and benefits of early patient involvement in research, clarify the roles patients can play, and explore how engagement can be meaningfully and effectively designed. Define potential next steps for research advocacy training and education of SPAGN members. <i>Chairs/Speakers: Andy Westwood & Markus Wartenberg</i>		Working Group & Discussion Session: (Room Fleming) <i>Advanced Research Advocacy: Influencing Design, Decisions & Direction</i> Bringing the patient perspective to drug development studies - Phase I/II trials: Benefit-risk assessment, information needs, burden and ethical questions from the patient perspective <i>Chairs/Speakers: Roger Wilson & Bernd Kasper</i>	
16:15 – 16:30 SHORT BREAK (15 min)				
16:30 (105)	Market Place Sessions (in all four rooms) <ul style="list-style-type: none"> • <i>Table 1 –What makes a great patient advocate?</i> <i>Estelle Lecointe-Artzner & Natalia Fernandez</i> • <i>Table 2 - Collaboration with pharma / commercial companies: Opportunities and pitfalls</i> <i>Markus Wartenberg</i> • <i>Table 3 – From advocacy to policy change: Influencing government and the health service on behalf of people affected by sarcoma</i> <i>Andy French</i> • <i>Table 4 – How to work towards financial sustainability in patient organizations</i> <i>Alberto Martinez Gutierrez</i> • <i>Table 5 – How can volunteer engagement be encouraged? Clarity, responsibility, communication</i> <i>Katja Winter</i> 			
18:15	BREAK BEFORE DINNER			
19:30	<i>Dinner at Macelleria</i>			

DAY 3 – SUNDAY May 3, 2026

08:30 **OFFICIAL START OF THE CONFERENCE (Sune Bergström Aula)**

8:30 (5) **Welcome to the day**
Denise Reinke

COLLABORATING FOR PROGRESS

08:35 (55) Working Group & Discussion Session:
Understanding AYA and children – opportunities and challenges

Speakers: Sandra Strauss, UK, Nikolas Herold, SWE, Olivia Hammar, SWE, Julie Kramer, USA, Sami Sandakly, FR

Chair: Denise Reinke & Angelika Mayer

9:30 (60) **Collaborating for Impact: Building effective research partnerships**

- *Example 1: Euro Ewing Consortium – a lighthouse example for researcher-patient collaboration*
Speaker: Sandra Strauss & Andy Westwood, UK
- *Example 2: Clear Cell Sarcoma – a collaboration coming together*
John & Ellie Showler, UK and Lennie Woods, USA, Sandra Strauss, UK

Panel Discussion

Panelists: Sandra Strauss, UK, Andy Westwood, UK, John & Ellie Showler, UK and Lennie Woods, USA

Chair: Denise Reinke & Ornella Gonzato

10:30– 11:00 **COFFEE BREAK (30 mins)**

11:00 (60) **In the doctor's shoes: Case discussions**
Speaker: Peter Reichardt, GER
Chair: Markus Wartenberg

12:00 (20) **Unique Among Cancers: What Makes Sarcoma Different—and Why It Matters. Findings from a Sarcoma UK initiative (15 min)**
Speaker: Andy French, Sarcoma UK

12:20 (25) **Working Group & Discussion Session: Education & Capacity Building Needs**
Chair: Markus Wartenberg & Brandi Felser

12:45 (15) **Closing Remarks – End of Meeting**
SPAGN Board

4 Parallel Tracks

Saturday, May 2

Soft Tissue Sarcoma

Room Wilhelm Röntgen

13:00 (5)	Welcome <i>Chairs: Brandi Felser & Natalia Fernandez</i>
13:05 (40)	Advances in Soft Tissue Sarcoma: Research and Treatment Updates <i>Speaker: Andri Papakonstantinou, SWE</i>
13:45 (25)	Role of ctDNA in STS: Hope or hype? <i>Speaker: Judith Bovee, NL</i>
14:10 (25)	The LMS Consensus Roundtable: Controversies and alignments <i>Speaker: Bernd Kasper, GER</i>
14:35 (25)	Discussion

Bone Sarcoma

Room Ivan Pavlov

13:00 (5)	Welcome <i>Chairs: Ornella Gonzato & Christina Ip-Toma</i>
13:05 (45)	Medical Update & Research: Top 10 research projects in bone sarcoma <i>Speaker: Sandra Strauss, UK</i>
13:50 (40)	Bone surgery of the upper and lower extremities <i>Speaker: Jendrik Hardes, GER</i>
14:30 (30)	Q & A

NEW HORIZONS GIST 2026

NEW HORIZONS GIST

Room Alexander Fleming

13:00 (5)	<p>Welcome</p> <p><i>Chairs: Kai Pilgermann & Tara Ruggiero</i></p>
13:05 (10)	<p>Building Global Advocacy Capacity for GIST: The Global Advocate Academy Course</p> <p><i>Speaker: Tara Ruggiero</i></p>
13:15 (10)	<p>Update on the PAWS GIST clinic</p> <p><i>Speaker: Ramesh Bulusu, UK</i></p>
13:25 (25)	<p>25 Years of GIST: Reflections on the Journey that Changed Everything</p> <p>A reflection on how GIST evolved over 25 years, exploring early challenges, major breakthroughs, and lasting lessons for the future.</p> <p><i>Speaker: Heikki Joensuu, FIN</i></p>
13:50 (50)	<p>The Changing Landscape of GIST Treatment and Clinical Trials</p> <p><i>Help understand the current and emerging treatment options and clinical trials in GIST, and to provide practical guidance for navigating this evolving landscape</i></p> <ul style="list-style-type: none"> • Overview • Emerging therapies and options • Deep dive second-line therapy: sunitinib, alternatives, and secondary mutations (evidence and clinical approaches) <p><i>Speaker: Peter Reichardt, GER</i></p>
14:40 (20)	<p>Discussion</p>

Desmoid Track

Room Louis Pasteur

13:00 (5)	<p>Welcome</p> <p><i>Chairs: Christina Baumgarten & Desmoid Working Group</i></p>
13:05 (115)	<p>Managing Challenges and Driving Change</p> <p><i>From adverse event management and awareness/education to scientific updates and real-life patient living situations</i></p>