

# 16<sup>th</sup> 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	<b>Opening of the Registration Desk</b>
11:30	<b>Lunch</b>
<b>12:30 OFFICIAL START OF THE CONFERENCE (Sune Bergström Aula)</b>	
12:30 (30)	<b>Welcome to Stockholm, welcome to Sweden!</b> <i>Markus Wartenberg &amp; Denise Reinke, SPAGN Board Co-chairs</i> <i>Per Alvers, Olivia Hammar, Sarkomföreningen</i> <i>Andri Papakonstantinou, Karolinska University Hospital</i>
<b>PROGRESS THAT MATTERS: INNOVATIONS IN SARCOMAS</b>	
13:00 (60)	<b>The power of the patient's contribution to research: Why we can't advance treatments without it</b> <ul style="list-style-type: none"><li>• <b>Patient Reported Outcomes and Quality of Life (30 min)</b> <i>Speaker: TBD</i></li><li>• <b>Critical value of research biospecimens (20 min)</b> <i>Speakers/Discussants: Christina Ip-Toma, US &amp; TBD</i></li></ul> <b>Chair: Roger Wilson &amp; Denise Reinke</b>
14:00 (15)	<b>Discussion</b>
<b>14:15 – 14:45 COFFEE BREAK &amp; NETWORKING (30 mins)</b>	

<p>14:45 (60)</p>	<p><b>From sequencing to personalized therapy: Understanding genetic/genomic data and implications for sarcoma treatment</b></p> <p><b>Setting the stage – what we need to know (10 mins)</b> <i>Felix Haglund, SWE</i></p> <p><i>Panelists: Roger Wilson, UK; Felix Haglund, SWE; Bernd Kasper, GER</i> <b>Moderator: Magnus Carlsson</b></p>
<p>15:45 – 16:00 <b>SHORT BREAK (15 min)</b></p>	
<p><b>CELEBRATING AND HONORING ACHIEVEMENTS</b></p>	
<p>16:00 (15)</p>	<p><b>Lifetime Achievement Awards 2026</b> <i>Chair: Estelle Lecointe-Artzner &amp; Roger Wilson</i></p>
<p>16:15 (75)</p>	<p><b>Sharing Best Practices &amp; Advocacy in Action Awards</b></p> <ul style="list-style-type: none"> <li>- Presentations Advocacy in Action Award Winners/Submissions 2026</li> <li>- 10 years of listening, learning, and impact: The Sarcoma UK support line <i>Carly McDonald &amp; Sam Hackett</i></li> </ul> <p><i>Chair: Gabi Ott &amp; Ornella Gonzato</i></p>
<p>17:30 <b>Change of Location</b></p>	
<p>18:00 <b>SPAGN Board of Directors: Speed-Dating (Carolina Tower Hotel)</b></p>	
<p>18:30 <b>MIX AND MINGLE: INFORMAL GET-TOGETHER (Conference Lobby, Carolina Tower Hotel)</b></p>	

# DAY 2 – SATURDAY May 2, 2026

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

8:30 (5)	<b>Welcome to the day</b> <i>Kai Pilgermann</i>
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8:35 (70)	<p><b>SPAGN Annual General Meeting (AGM)</b></p> <p>All Conference Participants are welcome! (Voting rights for SPAGN Members only)</p> <p>This session has an official invitation / agenda – important topics are:</p> <ul style="list-style-type: none"> <li>• Report of the Board of Directors (2025)</li> <li>• Financial Report (2025)</li> <li>• Review 2025 &amp; Outlook 2026</li> <li>• SPAGN Strategy 2031</li> <li>• Elections</li> <li>• Applications/requests</li> </ul> <p><i>SPAGN Board</i></p>
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9:45 – 10:15 **COFFEE BREAK & NETWORKING (30 min)**

## EMPOWERING THROUGH PATIENT INSIGHT

10:15 (60)	<p><b>Sarcoma treatment in motion: New therapies, trials, and approvals</b></p> <p><i>Excursion: When no treatment options exist: How patients and experts can drive change together</i></p> <p><i>Speaker: Robin Jones, UK</i></p> <p><i>Chair: Brandi Felser</i></p>
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11:15 (15)	<b>Q&amp;A</b>
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11:30 **Group Photo**

11:40 **Change of Location to Carolina Tower Hotel**

11:45 – 13:00 **LUNCH and NETWORKING (75 min)**

## BREAKOUT SESSIONS

## SARCOMA SUBTYPE GROUPS: RESEARCH, LATEST DEVELOPMENTS & MORE

	<b>Full program for tracks – please see below</b>			
13:00 (120)	<p><b>Soft Tissue Sarcomas (Room Röntgen)</b></p> <p><i>Chair: Estelle Lecoinge-Artzner, Natalia Fernandez</i></p>	<p><b>GIST (Room Fleming)</b></p> <p><i>Chairs: Kai Pilgermann, &amp; Tara Ruggiero</i></p>	<p><b>Bone Sarcomas (Room Pavlov)</b></p> <p><i>Chairs: Ornella Gonzato &amp; TBD</i></p>	<p><b>Desmoid (Room Pasteur)</b></p> <p><i>Chairs: Christina Baumgarten &amp; TBD</i></p>

15:00 – 15:30 **COFFEE BREAK (30 min.)**

15:30 (45)	<p><i>Working Group &amp; Discussion Session:</i></p> <p><b><i>For Beginners: From Experience to Impact: First Steps in Research Advocacy</i></b></p> <p>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.</p> <p><b><i>Chairs/Speakers: Andy Westwood &amp; Markus Wartenberg</i></b></p>	<p><i>Working Group &amp; Discussion Session:</i></p> <p><b><i>Advanced Research Advocacy: Influencing Design, Decisions &amp; Direction</i></b></p> <p>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</p> <p><b><i>Chairs/Speakers: Roger Wilson &amp; Bernd Kasper</i></b></p>
<b>16:15 – 16:30 SHORT BREAK (15 min)</b>		
<b>IMPACT SESSIONS: BUILDING STRONGER SARCOMA COMMUNITIES</b>		
16:30 (105)	<p><b>Market Place Sessions</b></p> <ul style="list-style-type: none"> <li>• <b><i>Table 1 –What makes a great patient advocate?</i></b> <i>TBD</i></li> <li>• <b><i>Table 2 - Collaboration with pharma / commercial companies: Opportunities and pitfalls</i></b> <i>TBD</i></li> <li>• <b><i>Table 3 – From Advocacy to policy change: Lobbying as patient organisation</i></b> <i>TBD</i></li> <li>• <b><i>Table 4 – How to work towards financial sustainability in patient organizations</i></b> <i>TBD</i></li> <li>• <b><i>Table 5 – Volunteer Engagement: Exchanging ideas, tackling challenges</i></b> <i>Katja Winter, GER</i></li> </ul>	
<b>18:15 BREAK BEFORE DINNER</b>		
19:30	<i>Dinner at Macelleria</i>	

<b>DAY 3 – SUNDAY May 3, 2026</b>	
08:30 <b>OFFICIAL START OF THE CONFERENCE (Sune Bergström Aula)</b>	
8:30 (5)	<b>Welcome to the day</b> <i>Denise Reinke</i>
<b>COLLABORATING FOR PROGRESS</b>	
08:35 (55)	Working Group & Discussion Session: <b>Understanding AYA and children – opportunities and challenges</b> <i>Speakers:</i> <i>Sandra Strauss, UK, Nikolas Herold, SWE,</i> <i>Olivia Hammar, SWE, Julie Kramer, USA, Sami Sandakly, FR</i> <b>Chair: Denise Reinke &amp; Angelika Mayer</b>
9:30 (60)	<b>Collaborating for Impact: Building effective research partnerships</b> <ul style="list-style-type: none"> <li><i>Example 1:</i> Euro Ewing Consortium – a lighthouse example for researcher-patient collaboration (5-10 min) <i>Speaker: Sandra Strauss &amp; Andy Westwood, UK</i></li> <li><i>Example 2:</i> Clear Cell Sarcoma – a collaboration coming together (5-10 min) <i>John &amp; Ellie Showler, UK and Lennie Woods, USA, Sandra Strauss</i></li> </ul> <b>Panel Discussion</b>  <i>Panelists: Sandra Strauss, UK, Andy Westwood, UK,</i> <i>John &amp; Ellie Showler, UK and Lennie Woods, USA</i>  <b>Chair: Denise Reinke &amp; Ornella Gonzato</b>
10:30– 11:00 <b>COFFEE BREAK (30 mins)</b>	
<b>FROM CLINICAL INSIGHT TO COLLECTIVE ACTION</b>	
11:00 (60)	<b>In the doctor's shoes: Case discussions</b> <i>Speaker: Peter Reichardt, GER</i> <b>Chair: Markus Wartenberg</b>
12:00 (20)	<b>Unique Among Cancers: What Makes Sarcoma Different—and Why It Matters.</b> <b>Findings from a Sarcoma UK initiative (15 min)</b> <i>Speaker: Andy French, Sarcoma UK</i>
12:20 (25)	<b>Working Group &amp; Discussion Session: Education &amp; Capacity Building Needs</b> <b>Chair: Markus Wartenberg &amp; Brandi Felser</b>
12:45 (15)	<b>Closing Remarks – End of Meeting</b> <b>SPAGN Board</b>

## 3-4 Parallel Tracks

### Saturday, May 2

#### Soft Tissue Sarcoma – Agenda

Room Wilhelm Röntgen

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

#### Bone Sarcoma – Agenda

Room Ivan Pavlov

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

# NEW HORIZONS GIST 2026

## GIST – Agenda

### NEW HORIZONS GIST

Room Alexander Fleming

13:00 (5)	<b>Welcome</b> <i>Chairs: Kai Pilgermann &amp; Tara Ruggiero</i>
13:05 (10)	<b>Building Global Advocacy Capacity for GIST: The Global Advocate Academy Course</b> <i>Speaker: Tara Ruggiero</i>
13:15 (20)	<b>25 Years of GIST: Reflections on the Journey that Changed Everything</b> <i>Speaker: Heikki Joensuu, FIN &amp; Peter Reichardt, GER</i>
13:50 (50)	<b>The Changing Landscape of GIST Treatment and Clinical Trials</b> <ul style="list-style-type: none"><li>• Overview</li><li>• Emerging therapies and options</li><li>• Deep dive second-line therapy: sunitinib, alternatives, and secondary mutations (evidence and clinical approaches)</li></ul> <i>Speaker: Peter Reichardt, GER</i>
14:40 (20)	<b>Discussion</b>

## Desmoid Track – Agenda

Saturday, May 2

Room Louis Pasteur

13:00 (5)	<b>Welcome</b> <i>Chairs: Christina Baumgarten &amp; TBD</i>
13:05 (115)	<b>Managing Challenges and Driving Change</b> <i>To be determined further</i>