

# 14<sup>th</sup> SPAGN Annual Conference

April 19-21, 2024, Rome, Italy



## Precise House Mantegna Roma

Via Andrea Mantegna, 130 00147, Rome, Italy

<https://www.precisehotels.com/precise-house-mantegna-roma>

## PROGRAM

DAY 1 – FRIDAY April 19, 2024	
11:00	<b>Opening of the Registration Desk</b>
12:00	<b>Lunch</b>
<b>13:00 OFFICIAL START OF THE CONFERENCE (Room Space 3A +3B)</b>	
13:00 (30)	<b>Welcome to Rome, welcome to Italy!</b> <b>15 years of SPAEN/SPAGN: A travel in time</b> <i>Speakers: Markus Wartenberg, Roger Wilson, Ornella Gonzato</i>
13:30 (60)	<b>Real-world data &amp; evidence</b> <b>Chairs: Sorrel Bickley &amp; Mandy Basson/Carlos Koops, NL</b> <ul style="list-style-type: none"><li>• Why gathering real-world data is so important</li><li>• What sources do I have to collect real-world data?</li><li>• What impact can they have?</li><li>• How real-world data can influence decisions of regulators and reimbursement bodies?</li><li>• What's the role of real-world data in drug repurposing?</li></ul> <i>Speakers: Ana Amariutei, WECAN</i>
<b>14:30 – 15:00 COFFEE BREAK &amp; NETWORKING (30 mins)</b>	
15:00 (60)	<b>Molecular Diagnostics – an introduction</b> <b>Chairs: Ornella Gonzato</b> <ul style="list-style-type: none"><li>• What is it?</li><li>• How does it work?</li><li>• Why do we need it?</li><li>• What is a molecular tumor board?</li></ul> <i>Speakers: Eva Wardelmann, GER</i>
16:00	<b>Short Break (15 mins)</b>
16:15 (90)	<b>SPAGN AGM</b> 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"><li>• Report of the Board of Directors (2023)</li><li>• Financial Report (2023)</li><li>• Outlook 2024 and beyond</li><li>• Elections</li><li>• Applications/requests</li></ul> <b>SPAGN Board</b>
17:45	<b>BREAK BEFORE DINNER</b>
19:30	<b>Dinner</b>

## DAY 2 – SATURDAY April 20, 2024

08:30 <b>OFFICIAL START OF THE CONFERENCE (Room xxx)</b>					
08:30 (60)	<b>Surgery in Sarcomas</b> <i>Chairs: Gerard van Oortmerssen</i> <ul style="list-style-type: none"> <li>- Challenges and pitfalls when operating on sarcomas (30 min) <i>Speaker: Sylvie Bonvalot, FR</i></li> <li>- Clinical trials in surgery: Patient preference and its relevance for study design <i>Speaker: Jendrik Harges, GER</i></li> </ul>				
9:30 (75)	<b>Patient involvement in sarcoma clinical trials</b> <i>Chair: Markus Wartenberg, DE</i> <ul style="list-style-type: none"> <li>• Challenges of planning and conducting clinical trials in rare and ultra-rare cancers <i>Speakers: Robin Jones, UK</i></li> <li>• Case studies: Clinical trials - What questions do you need to ask? General and study-specific questions <i>Lead: Roger Wilson, UK &amp; Bernd Kasper, DE</i></li> </ul>				
10:45 – 11:30 <b>COFFEE BREAK &amp; NETWORKING (45 mins)</b>					
11:30 (60)	<b>Working Group &amp; Discussion Session:</b> <b>Clinical Trials:</b> <ul style="list-style-type: none"> <li>• Challenges and opportunities for patient organizations</li> <li>• Patient Experience Data (PED)</li> </ul> <i>Chairs: Denise Reinke, US &amp; Ornella Gonzato, IT</i>		<b>Working Group &amp; Discussion Session:</b> <b>Sarcoma Awareness</b> <i>Chair: Cory Archibald, DE</i>		
12:30 <b>Group Photo</b>					
12:40 – 14:00 <b>LUNCH and NETWORKING (90 min)</b>					
14:00 (90)	<b>Soft Tissue Sarcomas (Room x)</b> <i>Chair: Gerard v. Oortmerssen, NL &amp; Denise Reinke, USA</i>	<b>GIST (Room x)</b> <i>Chairs: Laura Occhiuzzi, USA &amp; Kai Pilgermann, DE</i>	<b>Bone Sarcomas (Room x)</b> <i>Chairs: Ornella Gonzato, IT &amp; Zoe Davison, UK</i>	<b>Desmoid (Room x)</b> <i>Chairs: Christina Baumgarten, DE</i>	<b>TGCT (Room x)</b> <i>Chair: Sydney Stern, USA</i>
<b>Full program for tracks – please see below</b>					
15:30 – 16:00 <b>COFFEE BREAK (30 min.)</b>					
<b>Full program for tracks – please see below</b>					
16:00 (60)					
17:00 (75)	<b>Sharing Best Practices</b> Presentations Advocacy in Action Award Winners/Submissions 2023/24 Selected projects <i>Chair: Gabriele Ott, DE/AUT</i>				
18:15 <b>BREAK BEFORE DINNER</b>					
19:30 <b>Dinner</b>					

## DAY 3 – SUNDAY April 21, 2024

08:30 (105)	<p><b>The SPAGN Market Place Sessions</b> Choose your 3 favourite sessions from 5 market booths! Each Session lasts 30 mins, 5 minutes break to change the booth <i>Max. 10 mins presentation, 15-20 mins discussion</i></p> <p><b>Booth 1:</b> Fundraising – the US example <i>Brandi Felser; USA</i></p> <p><b>Booth 2:</b> The 101 of political lobbying <i>tbc</i></p> <p><b>Booth 3:</b> Communications Doctor-Patient – the Australian example <i>tbc</i></p> <p><b>Booth 4:</b> Social Media <i>Cory Archibald, DE / Maria Brandt, DE</i></p> <p><b>Booth 5:</b> Peer-to-peer support <i>Zoe Davison / Kathleen Kane, UK</i></p> <p><b>Booth 6:</b> Storytelling <i>Roger Wilson, UK &amp; Gabi Ott, GER/AUT</i></p>
10:15– 10:45	<b>C O F F E E B R E A K (30 mins)</b>
10:45 (60)	<p><b>Working Group &amp; Discussion Session:</b> “Sarcoma Intelligent Specialist Networks” <i>Focus on Sarcoma Management and Care outside the US and -Europe</i> <b>Chairs: Roger Wilson, UK &amp; Vandana Gupta, IND</b></p>
11:45– 12:00	<b>Short Break (15 mins)</b>
12:00 (75)	<p><b>Artificial Intelligence in Sarcomas</b> <b>Chairs: Gerard van Oortmerssen, NL &amp; Gerry Feeney, UK</b></p> <ul style="list-style-type: none"><li>• Overview <i>Maria Brandt, DE</i></li><li>• A practical example <i>Sandro Pasquali, IT</i></li></ul>
13:15	<p><b>Closing Remarks – End of Meeting</b> <b>SPAGN Board</b></p>

## 5 Parallel Tracks (Soft Tissue Sarcoma/Bone Sarcoma/GIST/ TGCT/Desmoids)

### Soft Tissue Sarcoma Track – Agenda Saturday, 20<sup>th</sup> of April

14:00 (5)	<b>Welcome</b> <i>Chair: Gerard v. Oortmerssen, NL &amp; Denise Reinke, USA</i>
14:05 (60)	<b>Research &amp; Medical Update: What's new in Soft Tissue Sarcomas?</b> <i>Moderator: Denise Reinke</i>  <b>Report from the lab: About biomarkers and more (30 mins)</b> <i>Speaker: Sandro Pasquali, IT</i>  <b>Clinical trials and medical updates (30 mins)</b> <i>Speaker: Robin Jones, UK</i>
15:05 (25)	<b>Panel discussion and Q&amp;A session</b> <i>Moderator: Denise Reinke</i> <i>Panelists: Robin Jones, Roberta Sanfilippo</i>
15:30 – 16:00 <b>C O F F E E B R E A K (30 mins)</b>	
16:00 (60)	<b>Caught between disciplines: Organ-specific sarcomas</b> <i>Moderator: Gerard van Oortmerssen</i>  <b>Navigating the journey of being a patient between disciplines (10 mins)</b> <i>Speaker: Marloes van Esterik, NL</i>  <b>Spotlights:</b> <ul style="list-style-type: none"><li>• <b>Uterine LMS (20 mins)</b> <i>Roberta Sanfilippo, Italy</i></li><li>• <b>Phyllodes (20 mins)</b> <i>Speaker: Frederieke van Duijnhoven, NL</i></li></ul>

**GIST Track – Agenda**  
**Saturday, 20<sup>th</sup> of April**

14:00 (5)	<b>Welcome</b> <i>Chairs: Laura Occhiuzzi, USA &amp; Kai Pilgermann, GER</i>
14:05 (30)	<b>Molecular and Genomic Drivers of GIST</b> <i>Moderator: Laura Occhiuzzi, USA</i> <i>Speaker: Eva Wardelmann</i>
14:35 (55)	<b>Current developments in GIST research: From research to clinical trials</b> <i>Moderator: Laura Occhiuzzi, USA</i> <i>Speaker: Mehdi Brahmi, France</i>
15:30 – 16:00	<b>C O F F E E B R E A K (30 mins)</b>
16:00 (60)	<b>Navigating GIST in 2024:</b> <b>Implications of new findings and treatment options for patients</b> <i>Moderators: Kai Pilgermann &amp; Laura Occhiuzzi</i> <i>Speaker: Peter Reichardt, GER (15 mins)</i>  <i>Panel discussion and Q&amp;A session (45 mins)</i> <i>Panelists: Peter Reichardt, Eva Wardelmann and Mehdi Brahmi</i>

**Bone Sarcoma Track – Agenda**  
**Saturday, 20<sup>th</sup> of April**

14:00 (5)	<p><b>Welcome</b></p> <p><i>Chairs: Ornella Gonzato, IT &amp; Zoe Davison, UK</i></p>
14:05 (15)	<p><b>Bone Sarcoma Survey Results &amp; Bone Sarcoma Alliance</b></p> <p><i>Speakers: Ornella Gonzato, IT &amp; Zoe Davison, UK</i></p>
14:20 (25)	<p><b>Precision surgery in Bone Sarcomas:</b>  <b>Technological advances for more tailored approaches and better functional outcomes</b></p> <p><i>Moderator: Ornella Gonzato, IT</i>  <i>Speaker: Domenico Andrea Campanacci, IT</i></p>
14:45 (20)	<p><b>The role of proton therapy and carbon Ion radiotherapy in Bone Sarcomas</b></p> <p><i>Moderator: Ornella Gonzato, IT</i>  <i>Speaker: Maria Rosaria Fiore, IT</i></p>
15:05 (25)	<p><b>Immunotherapy and target therapies in bone sarcomas: What's new?</b></p> <p><i>Moderator: Ornella Gonzato, IT</i>  <i>Speaker: Uta Dirksen, GER</i></p>
15:30 – 16:00	<b>C O F F E E B R E A K (30 mins)</b>
16:00 (30)	<p><b>Biomarkers in Bone Sarcomas from early diagnosis to prognosis, clinical decision-making and response monitoring. Where are we now?</b></p> <p><i>Moderator: Zoe Davison, UK</i>  <i>Speaker: Sue Burchill, UK</i></p>
16:30 (30)	<p><b>Survivorship and Quality of Life: managing long-term side effects and addressing the psychosocial aspects of survivorship (in different age groups?)</b></p> <p><i>Moderator: Zoe Davison, UK</i>  <i>Speaker: Uta Dirksen, GER</i></p>

**Desmoid Track – Agenda**  
**Saturday, 20<sup>th</sup> of April**

14:00 (5)	<b>Welcome</b> <i>Chair: Christina Baumgarten</i>
14:05 (55)	<b>New and innovative projects in several countries</b> <i>Speakers: Patient representatives from different countries</i>
15:00 (30)	<b>Challenges with research grants for Desmoid tumors (borderline/benign tumors)</b> <i>Discussion Session</i>
<b>15:30 – 16:00 COFFEE BREAK (30 mins)</b>	
16:00 (30)	<b>FAP &amp; Desmoids</b> <i>Speaker: Marco Vitellaro, IT</i>
16:30 (30)	<b>Latest Edition on the Desmoid Consensus Paper</b> <i>Speaker: Bernd Kasper, GER</i>

**TGCT Track – Agenda**  
**Saturday, 20<sup>th</sup> of April**

14:00 (5)	<b>Welcome</b> <i>Chair: Sydney Stern</i>
14:05 (25)	<b>Diagnosis Discourse: Differentiating between localized and diffuse TGCT</b> <i>Speaker: Emanuela Palmerini, Italy</i>
14:30 (30)	<b>Surgical Management of TGCT</b> <i>Speaker: Jendrik Hardes, GER</i>
15:00 (30)	<b>The Do's and Don't of Systemic Therapy in TGCT</b> <i>Speaker: Giacomo Baldi, Italy</i>
15:30 – 16:00	<b>C O F F E E B R E A K (30 mins)</b>
16:00 (30)	<b>Navigating Clinical Trials in TGCT</b> <i>Speaker: Mehdi Brahmi, France</i>
16:30 (30)	<b>Q&amp;A Panel Discussion</b> <i>Moderator: Sydney Stern</i> <i>Speakers: Emanuela Palmerini, Giacomo Baldi, Jendrik Hardes</i>