

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

April 11-13, 2024, Washington D.C., USA

Co-hosted by the National Cancer Institute



## The Bethesda Hotel

8120 Wisconsin Ave | Bethesda | Maryland | 20814

<https://www.hilton.com/en/hotels/wasbaup-the-bethesdan-hotel/>

## PROGRAM

DAY 1 – FRIDAY April 11, 2025	
<b>Room Bethesdan DC</b>	
11:00	<b>Opening of the Registration Desk</b>
<b>12:30 OFFICIAL START OF THE CONFERENCE</b>	
12:30 (30)	<b>Welcome to Washington D.C., welcome to the USA!</b> <i>Speakers: Denise Reinke, Brigitte Widemann, Douglas Lowy</i>
<b>THE POWER OF COLLABORATION IN SARCOMA</b>	
	<b>Session Chairs: Markus Wartenberg &amp; Bernd Kasper</b>
13:00 (30)	<b>Key Note:</b> <b>Collaboration between HCPs and patient advocates:</b> <b>An opportunity for change and better outcomes</b> <i>Speaker: Bill Tap, USA</i>
13:30 (30)	<b>Precision oncology in sarcoma</b> <b>Future perspectives and benefits of collaboration</b> <i>Speaker: Alice Chen, USA</i>
14:00 (15)	<b>Discussion</b>
<b>14:15 – 14:45 COFFEE BREAK &amp; NETWORKING (30 mins)</b>	
	<b>Session Chairs: Vandana Gupta &amp; Gabriele Ott</b>
14:45 (75)	<b>Access to research and treatment in low and middle-income countries</b> <b>Can collaboration address challenges and drive impactful change?</b>  The expert perspective: Challenges in managing rare diseases and conducting clinical trials (20 min) <i>Speaker: Satish Gopal, Director Center for Global Health (CGH), NCI, USA</i>  The patient perspective: Challenges in South Africa – can the “Sarcoma Intelligent Specialist Network” proposal make an impact? (20 min) <i>Speaker: Lauren Pretorius, SA</i>  The regulatory perspective: Challenges for regulators in advancing treatments for rare tumors globally (15 min) <i>Speaker: FDA &amp; EMA-Speaker (TBD)</i>

16:00 (30)	<b>Discussion</b>
16:30	<b>Short Break (15 mins)</b>
	<i>Session Chairs/Moderator: Denise Reinke &amp; Brigitte Widemann</i>
16:45 (75)	<b>Patient-Partnered Research: Unpacking its power and how to make it happen</b> <i>Panelists</i> <ul style="list-style-type: none"> <li>- Jonathan Fletcher, USA</li> <li>- Douglas Lowy, USA</li> <li>- Markus Wartenberg, GER</li> <li>- Bill Tap, USA</li> <li>- Winette van der Graaf, NL</li> </ul>
18:00	<b>END OF DAY 1</b>

<b>DAY 2 – SATURDAY April 12, 2025</b>	
<i>Room Bethesdan ABC &amp; breakout rooms</i>	
08:15	<b>OFFICIAL START OF THE CONFERENCE (Room Bethesdan ABC)</b>
8:30 (5)	<b>Welcome to the day</b> <i>Denise Reinke</i>
<b>IMPORTANCE AND IMPACT OF PATIENT DATA</b>	
	<i>Session chair: Gerard van Oortmerssen</i>
8:35 (35)	<b>Educational Session: Patient Experience Data</b> <b>Understanding Patient Experience Data</b> <i>Speaker: Markus Wartenberg (10 min)</i> <b>Patient data as a contribution to research: Patient-reported outcomes (PRO)</b> <i>Speaker: Winette van der Graaf, NL (25 min)</i>
9:10 (25)	<b>The global reality of sarcoma diagnosis:</b> <b>Findings of the Global Sarcoma Patient Diagnosis Survey</b> <i>Speaker: Verena Loidl, GER</i>
09:35 (10)	<b>Q&amp;A / Discussion (15 min)</b>
09:45	<b>Group Photo</b>
09:45 – 10:15	<b>COFFEE BREAK &amp; NETWORKING (30 mins)</b>

**CLINICAL TRIALS – CHANCES, CHALLENGES AND PITFALLS**

*Session Chairs and moderation: Markus Wartenberg & Bernd Kasper*

10:15  
(45)

**Innovative approaches in clinical trials:  
Exploring challenges and solutions for rare and ultra-rare sarcomas**  
*Impulse presentations from 3 perspectives*

**From expert perspective**  
*Speakers (10 mins each):*  
*Silvia Stacchiotti, IT &*  
*Mary Frances Wedekind Malone, Center for Cancer Research NCI, USA*

- **Current status of clinical trials:** What is the current approach to clinical trials, balancing patient numbers and statistical uncertainties?
- **Experts' vision:** How can we make clinical trials for rare cancers more efficient and targeted?

**From company perspective (10 min)**

- **Company challenges:** How can research for rare cancers become more attractive?

*Speaker: Uchenna Iloeje, Springworks*

**From patient perspective (10 min)**  
*Recording: Statement Roger Wilson*  
*Speakers: Denise Robinson, USA*

11:00  
(40)

**Panel discussion**

11:40

**Short Break (20 mins)**

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

	<b>Full program for tracks – please see below</b>			
12:00 (60)	<b>Soft Tissue Sarcomas (Room Bethesdan ABC)</b>	<b>GIST (Room Bethesdan D)</b>	<b>Bone Sarcomas (Room Cordell)</b>	<b>Desmoid (Room Wisconsin)</b>

13:00 – 14:00 **LUNCH and NETWORKING (60 min)**

	<b>Full program for tracks – please see below</b>			
14:00 (90)	<b>Soft Tissue Sarcomas</b>	<b>GIST</b>	<b>Bone Sarcomas</b>	<b>Desmoid</b>

15:30 – 16:00 **COFFEE BREAK & NETWORKING (30 mins)**

**CAPACITY BUILDING AND EMPOWERING – PART 1**

**Room Bethesdan ABC**

16:00 (120)	<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>Storytelling</b> – hosted by <i>Katja Winter, German Sarcoma Foundation</i></p> <p><b>Running a Sarcoma Patient Helpline</b> – by <i>Carly McDonald, Sarcoma UK</i></p> <p><b>Health Technology Assessment (HTA): What is it and what's new with the HTAR?</b> – hosted by <i>Adela Maghear, Genç Birikim Derneği, Turkey</i></p> <p style="text-align: center;"><b>More to be determined!</b></p>
18:00	<b>BREAK BEFORE DINNER</b>
19:30	<b>Dinner at <i>Pizzeria da Marco</i>, by kind invitation of the Sarcoma Foundation of America</b>

<b>DAY 3 – SUNDAY April 13, 2025</b>	
<b>Room Bethesdan ABC</b>	
8:30 (5)	<p><b>Welcome to the day</b> <i>Gerard van Oortmerssen</i></p>
<b>IMPACT ON PATIENT OUTCOMES: TREATMENT &amp; RESEARCH</b>	
	<b>Session Chairs: <i>Estelle Artzner</i></b>
08:35 (60)	<p><b>Beyond systemic/medical therapies: What other disciplines have to offer for sarcoma patients</b> <b>Key innovative developments from pathology, imaging, surgery and radiotherapy</b></p> <p><b>Speakers:</b></p> <ul style="list-style-type: none"> <li>• <i>Pathology: Jonathan Fletcher, USA (15 min)</i></li> <li>• <i>Imaging: Eva Dombi, USA (15 min)</i></li> <li>• <i>Surgery: Rebecca Gladdy, Canada (15 min)</i></li> <li>• <i>Radiotherapy: Ashleigh Guadagnolo, USA (15 min)</i></li> </ul>
9:35 (25)	<b>Q&amp;A and discussion</b>
10:00 – 10:30 <b>COFFEE BREAK &amp; NETWORKING (30 mins)</b>	
<b>CAPACITY BUILDING AND EMPOWERING – PART 2</b>	
	<b>Session Chairs: <i>Gabriele Ott</i></b>
10:30 (75)	<p><b>Empowering patients: Lighthouse projects in patient advocacy</b></p> <ul style="list-style-type: none"> <li>- Presentations Advocacy in Action Award Winners/Submissions 2023/24</li> <li>- Blog Voices of Sarcoma</li> </ul>
11:45	<b>Short Break (15 mins)</b>
<b>SPECIAL TOPIC: THE YOUNG SARCOMA POPULATION</b>	

	<b><i>Session Chairs &amp; moderators: TBD</i></b>
12:00 (60)	<p><b>Workshop “Young people have cancer, too!”</b></p> <p><b><i>Setting the stage:</i></b>  <b>Needs of children &amp; AYA with sarcoma: Similarities and differences</b>  <i>Speakers: Brigitte Widemann &amp; Brian Pennarola, NCI, US (15min)</i></p> <p><b><i>Group Discussion:</i></b>  <b>Unique challenges and how to address them</b></p>
13:00	<p><b><i>Closing Remarks – End of Meeting</i></b></p> <p><i>Markus Wartenberg, Gerard van Oortmerssen and Denise Reinke on behalf of the SPAGN Board</i></p> <p><i>Brigitte Widemann on behalf of the NCI</i></p>

**Soft Tissue Sarcoma Track – Agenda – Room Bethesdan ABC**  
**Saturday, April 12, 2025**

12:00 (5)	<b>Welcome</b> <i>Chairs: Estelle Lecointe-Artzner &amp; Brandi Felser</i>
12:05 (35)	<b>Ultra-Rare Sarcomas: Challenges and profiles of selected subtypes</b> <i>Speakers: Silvia Stacchiotti, IT</i>
12:40 (20)	<b>Hereditary predispositions in sarcomas: Current insights and challenges</b> <i>Speakers: Margarita Raygada, USA</i>
<b>13:00 – 14:00 L U N C H and NETWORKING (60 min)</b>	
14:00 (60)	<b>Research Updates: The role of immuno-oncology, T-cell therapy and other innovative approaches in sarcomas</b> <i>Speaker: Jon Trent, USA</i>
15:00 (30)	<b>Q&amp;A and discussion</b>

## NEW HORIZONS GIST

Agenda – Room Bethesdan D  
Saturday, April 12, 2025

12:00 (5))	<b>Welcome</b> <i>Chairs: Kai Pilgermann &amp; Carol Tordella</i>
12:05 (45)	<b>Navigating the current treatment and clinical trial landscape in GIST</b> <i>Speaker: Jon Trent , USA</i>
12:50 (10)	<b>Q&amp;A</b>
<b>13:00 – 14:00 L U N C H and NETWORKING (60 min)</b>	
14:00 (30)	<b>GIST – from one disease to many</b> <i>Spotlight on the rare GIST subtypes non-KIT/PDGFR-mutated GIST</i> <i>Speakers: John Glod, USA &amp; Andrew Blakely, USA</i>
14:30 (30)	<b>The GISTT Summit: Learnings and findings</b> <i>Speaker: Jonathan Fletcher, USA</i>
15:10 (30)	<b>Q&amp;A &amp; Discussion</b>

## BONE SARCOMA ALLIANCE

### Agenda – Room Cordell Saturday, April 12, 2025

12:00 (5)	<b>Welcome</b> <i>Chairs: TBD</i>
12:05 (55)	<b>Advancing Knowledge: Latest Research and Clinical Trials in Bone Sarcomas</b> <i>Speakers: Patrick Grohar, USA</i>
13:00 – 14:00	<b>L U N C H and NETWORKING (60 min)</b>
14:00 (20)	<b>Factors of poor prognosis in bone sarcoma adolescents and young adults</b> <i>Speaker: Patrick Grohar, USA</i>
14:20 (20)	<b>Managing shared decision-making in bone sarcoma surgery: Challenges and Benefits</b> <i>Speaker: Kurt Weiss, USA</i>
14:40 (40)	<b>Panel Discussion</b> <b>Are Multidisciplinary Teams (MDTs) focused on patients or diseases?</b> How precision and personalized oncology, along with patient preferences, can improve patient-centered care <i>All speakers</i>



**Desmoid Track – Agenda – Room Wisconsin**  
**Saturday, April 12, 2025**

12:05 (5)	<b>Welcome</b> <i>Chairs: Christina Baumgarten &amp; Lynne Hernandez</i>
12:05 (55)	<b>Research Updates</b> <i>Speaker: Bernd Kasper, GER &amp;</i>
13:00 – 14:00	<b>L U N C H and NETWORKING (60 min)</b>
14:00 (90)	<b>Challenges in the management of Desmoid tumors in Brazil</b> <i>Speakers: Fernando Campos, Brazil</i>
	<b>Discussion, exchange, advocacy topics</b> <i>Speakers from different Desmoid patient groups</i>