

11:00	60 min	<i>Opening of Registration Desk</i>
12:30		<b>OFFICIAL START OF CONFERENCE</b> <span style="float: right;">Bethesdan DC</span>
12:30	30 min	<b>Welcome to Washington, D.C.!</b> <i>SPEAKERS: Denise Reinke, Brigitte Widemann, John Glod &amp; Douglas Lowy (USA)</i>
<b>THE POWER OF COLLABORATION IN SARCOMA</b>		
		<i>SESSION CHAIRS: Markus Wartenberg &amp; Bernd Kasper (Germany)</i>
13:00	30 min	<b>Keynote: Collaboration between HCPs and patient advocates – An opportunity for change and better outcomes</b> <i>SPEAKER: Bill Tap (USA)</i>
13:30	30 min	<b>Precision oncology in sarcoma – Future perspectives and benefits of collaboration</b> <i>SPEAKER: Alice Chen (USA)</i>
14:00	15 min	Discussion
14:15	30 min	<b>COFFEE BREAK &amp; NETWORKING</b>
		<i>SESSION CHAIRS: Vandana Gupta (India) &amp; Gabi Ott (Germany)</i>
14:45	75 min	<b>Access to research &amp; treatment in low and middle-income countries. Can collaboration address challenges and drive impactful change?</b>
	20 min	The expert perspective: Challenges in managing rare diseases and conducting clinical trials <i>SPEAKER: Satish Gopal (USA)</i>
	20 min	The patient perspective: Challenges in South Africa – can the “Sarcoma Intelligent Specialist Network” proposal make an impact? <i>SPEAKER: Lauren Pretorius (South Africa)</i>
	15 min	The local reality of sarcoma care: Lessons from Brazil’s experience <i>SPEAKER: Fernando Campos (Brazil)</i>
16:00	30 min	Discussion
16:30	15 min	<b>BREAK</b>
		<i>SESSION CHAIRS: Denise Reinke &amp; Brigitte Widemann (USA)</i>
16:45	75 min	<b>Patient-Partnered Research: Unpacking its power and how to make it happen</b> <i>PANELISTS: Winette van der Graaf (Netherlands), Gabi Ott (Germany), Jonathan Fletcher (USA), Bill Tap (USA), and Markus Wartenberg (Germany)</i>
18:00		<b>END OF DAY 1</b>

**08:15** **START OF DAY 2** **Bethesdan ABC**

**08:15** 15 min **SPAGN Lifetime Achievement Awards**  
*PRESENTED BY: Markus Wartenberg, Gerard van Oortmerssen & Denise Reinke*

**08:30** 5 min **Welcome to the day**  
*SPEAKER: Denise Reinke (USA)*

**IMPORTANCE AND IMPACT OF PATIENT DATA**

*SESSION CHAIR: Gerard van Oortmerssen (Netherlands)*

**08:35** 35 min **Educational Session: Patient Experience Data**

10 min **Understanding Patient Experience Data**

*SPEAKER: Markus Wartenberg (Germany)*

25 min **Patient data as a contribution to research: Patient-reported outcomes**

*SPEAKER: Winette van der Graaf (Netherlands)*

**09:10** 25 min **The global reality of sarcoma diagnosis – Findings of the Global Sarcoma Diagnosis Pathway Survey**

*SPEAKER: Verena Loidl (Germany)*

**09:35** 10 min **Q&A / Discussion**

**09:45** 30 min **GROUP PHOTO – FOLLOWED BY COFFEE BREAK & NETWORKING**

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

*SESSION CHAIRS: Markus Wartenberg & Bernd Kasper (Germany)*

**10:15** 45 min **Innovative approaches in clinical trials: Exploring challenges and solutions for rare and ultra-rare cancers**

20 min **The Expert Perspective**

*SPEAKERS: Silvia Stacchiotti (Italy) & Mary Frances Wedekind Malone (USA)*

10 min **The Company Perspective & Challenges: How can research for rare cancers become more attractive?**

*SPEAKER: Uchenna Iloeje, Springworks (USA)*

10 min **The Patient Perspective**

*SPEAKERS: Roger Wilson – Recorded Statement (UK) & Denise Robinson (USA)*

**11:00** 40 min **Panel Discussion – *SPEAKERS: All presenters & Martha Donoghue, FDA (USA)***

**11:40** 20 min **BREAK**

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

**12:00** 60 min **See full program tracks on next page**

**13:00** 60 min **LUNCH & NETWORKING**

**14:00** 90 min **See full program tracks on next page**

**15:30** 30 min **COFFEE BREAK & NETWORKING**

TRACKS		SOFT TISSUE SARCOMAS	NEW HORIZONS GIST	BONE SARCOMAS	DESMOIDS
ROOM		BETHESDAN ABC	BETHESDAN D	CORDELL	WISCONSIN
TIME	LENGTH	<i>CHAIRS: Brandi Felser (USA) &amp; Estelle Lecointe-Artzner (FRA)</i>	<i>CHAIRS: Kai Pilgermann (GER) &amp; Carol Tordella (USA)</i>	<i>CHAIRS: Christina Ip-Toma (USA) &amp; Denise Reinke (USA)</i>	<i>CHAIR: Lynne Hernandez (USA)</i>
12:00	5 min	Welcome	Welcome	Welcome	Welcome
12:05	55 min	<p>Ultra Rare Sarcomas: Challenges and profiles of selected subtypes (35 min)</p> <p><i>SPEAKER: Silvia Stacchiotti (Italy)</i></p> <p>Hereditary predispositions in Sarcomas: Current Insights &amp; Challenges (20 min)</p> <p><i>SPEAKER: Margarita Raygada (USA)</i></p>	<p>Navigating the current treatment and clinical trial landscape in GIST (45 min)</p> <p><i>SPEAKER: Jon Trent (USA)</i></p> <p>Q&amp;A Discussion (10 min)</p>	<p>Prospects and challenges towards improved outcomes for bone sarcomas (55 min)</p> <p><i>SPEAKER: Patrick Grohar (USA)</i></p>	<p>Research Updates (55 min)</p> <p><i>SPEAKER: Bernd Kasper (GER)</i></p>
13:00	60 MIN	<b>LUNCH &amp; NETWORKING</b>			
14:00	90 min	<p>Research Updates: The role of immuno-oncology, T-cell therapy &amp; other innovations in sarcoma (60 min)</p> <p><i>SPEAKER: Jon Trent (USA)</i></p> <p>Q&amp;A Discussion (30 min)</p>	<p>Spotlight on the rare GIST subtypes non-KIT/PDGFR-mutated GIST (30 min)</p> <p><i>SPEAKERS: John Glod (USA) &amp; Andrew Blakely (USA)</i></p> <p>GIST Summit: Learnings &amp; Findings (30 min)</p> <p><i>SPEAKER: Jon Fletcher (USA)</i></p> <p>Q&amp;A Discussion (30 min)</p>	<p>Update from the Bone Sarcoma Alliance (10 min)</p> <p><i>SPEAKER: Kathrin Schuster (GER)</i></p> <p>Managing Shared Decision-Making in Bone Sarcoma Surgery (30 min)</p> <p><i>SPEAKER: Kurt Weiss (USA)</i></p> <p>Discussion: Are MDTs focused on patients or diseases? (50 min)</p>	<p>Challenges in the management of Desmoid tumors in Brazil (30 mins)</p> <p><i>SPEAKER: Fernando Campos (Brazil)</i></p> <p>Discussion, Exchange, Advocacy Topics (60 min)</p> <p><i>SPEAKERS FROM DIFFERENT DESMOID PATIENT GROUPS</i></p>
15:30	30 MIN	<b>COFFEE BREAK &amp; NETWORKING</b>			

## DAY 2 - PROGRAM CONCLUSION

### CAPACITY BUILDING & EMPOWERING – PART 1

#### 16:00 120 min The SPAGN Marketplace Sessions

Choose your 3 favorite sessions from 5 market booths! Each session lasts 30 minutes, with a 5-minute break in between to change booths

*(10 minutes presentation / 15-20 minutes discussion)*

#### **BOOTH 1: STORYTELLING**

***SPEAKER:*** *Katja Winter (Germany)*

#### **BOOTH 2: RUNNING A SARCOMA SUPPORT LINE**

***SPEAKER:*** *Carly McDonald (UK)*

#### **BOOTH 3: THE POWER OF LOBBYING**

***SPEAKER:*** *Brandi Felser (USA)*

#### **BOOTH 4: STARTING YOUR OWN RESEARCH: WHAT TO CONSIDER**

***SPEAKERS:*** *Verena Loidl (Germany) & Denise Robinson (USA)*

#### **BOOTH 5: HEALTH TECHNOLOGY ASSESSMENT (HTA): WHAT IS IT?**

***SPEAKER:*** *Adela Maghear (Turkey)*

**18:00**

***BREAK BEFORE DINNER***

**19:30**

***DINNER AT PIZZERIA DA MARCO***

**08:15**      **START OF DAY 3**      **Bethesdan ABC**

**08:30**    **5 min**    **Welcome to the day**  
***SPEAKER:** Gerard van Oortmerssen (Netherlands)*

**IMPACT ON PATIENT OUTCOMES: TREATMENT & RESEARCH**

***SESSION CHAIR:** Estelle Artzner (France)*

**08:35**    **60 min**    **Beyond systemic / medical therapies: What other disciplines have to offer sarcoma patients**

*Key innovative developments from pathology, imaging, surgery & radiotherapy*

***SPEAKERS:***

*Jonathan Fletcher (USA) - Pathology*

*Eva Dombi (USA) - Imaging*

*Kurt Weiss (USA) - Surgery*

*Ashleigh Guadagnolo (USA) - Radiotherapy*

**09:35**    **25 min**    **Q&A / Discussion**

**10:00**    **30 min**    **COFFEE BREAK & NETWORKING**

**CAPACITY BUILDING & EMPOWER – PART 2**

***SESSION CHAIR:** Gabi Ott (Germany)*

**10:30**    **75 min**    **Empowering Patients: Lighthouse projects in patient advocacy**

Presentations by Advocacy in Action Award Winners / Submissions

Blog "Voices of Sarcoma"

**11:40**    **15 min**    **BREAK**

**SPECIAL TOPIC: THE YOUNG SARCOMA POPULATION**

***SESSION CHAIRS:** Lennie Woods (USA) & Matt Sha (Canada)*

**12:00**    **60 min**    **Workshop: "Young people have cancer, too!"**

Needs of children and AYA with sarcoma

***SPEAKERS:** Brigitte Widemann (USA) & Brian Pennarola (USA)*

Group Discussion: Unique challenges & How to address them

**13:00**      **Closing Remarks & End of Conference**

*Markus Wartenberg (Germany), Gerard van Oortmerssen (Netherlands) & Denise Reinke (USA) on behalf of the SPAGN Board*

*Brigitte Widemann (USA) on behalf of the NCI*