

15th SPAGN Annual Conference

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

Co-hosted by the National Cancer Institute

The National Cancer Institute

National Institutes of Health, 9000 Rockville Pike
Bethesda, MD 20892

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	
<i>Campus of the National Institutes of Health</i>	
11:00	<i>Opening of the Registration Desk</i>
12:30 OFFICIAL START OF THE CONFERENCE (Room tbc)	
12:30 (30)	Welcome to Washington D.C., welcome to the USA! <i>Speakers: Denise Reinke, Brigitte Widemann, Douglas Lowy</i>
THE POWER OF COLLABORATION IN SARCOMA	
	<i>Session Chairs: Markus Wartenberg & co-chair TBD</i>
13:00 (30)	Key Note: Collaboration between HCPs and patient advocates: An opportunity for change and better outcomes <i>Speaker: Bill Tap, USA</i>
13:30 (30)	Precision oncology in sarcoma Future perspectives and benefits of collaboration <i>Speaker: TBC</i>
14:00 (15)	Discussion
14:15 – 14:45 COFFEE BREAK & NETWORKING (30 mins)	

	Session Chairs: Vandana Gupta & co-chair TBD
14:45 (75)	<p>Access to research and treatment in low and middle-income countries Can collaboration address challenges and drive impactful change?</p> <p>The expert perspective: Challenges in managing rare diseases and conducting clinical trials (20 min) <i>Speaker: Satish Gopal, USA</i></p> <p>The patient perspective: Challenges in South Africa – can the “Sarcoma Intelligent Specialist Network” proposal make an impact? (20 min) <i>Speaker: TBC</i></p> <p>The regulatory perspective: Challenges for regulators in advancing treatments for rare tumors globally (15 min) <i>Speaker: FDA & EMA-Speaker (TBC)</i></p>
16:00 (30)	Discussion
16:30	Short Break (15 mins)
	Session Chairs/Moderator: Denise Reinke & co-chair TBD
16:45 (75)	<p>Panel Discussion Patient-Partnered Research: Unpacking its power and how to make it happen <i>Panelists TBC</i></p>
18:00	END OF DAY 1

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

09:45	Group Photo			
09:45 – 10:15	C O F F E E B R E A K & NETWORKING (30 mins)			
CLINICAL TRIALS – CHANCES, CHALLENGES AND PITFALLS				
	<i>Session Chairs and moderation: Markus Wartenberg & Bernd Kasper</i>			
10:15 (45)	<p>Innovative approaches in clinical trials: Exploring challenges and solutions for rare and ultra-rare sarcomas <i>Impulse presentations from 3 perspectives</i></p> <p>From expert perspective <i>Speakers (10 mins each):</i> <i>Silvia Stacchiotti, IT & Mary Frances Wedekind Malone, USA</i></p> <ul style="list-style-type: none"> • 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? <p>From company perspective (10 min)</p> <ul style="list-style-type: none"> • Company challenges: How can research for rare cancers become more attractive? <p><i>Speaker :TBC</i></p> <p>From patient perspective (10 min) <i>Recording: Statement Roger Wilson</i> <i>Speakers: TBC</i></p>			
11:00 (40)	Panel discussion			
11:40	Short Break (20 mins)			
SARCOMA SUBTYPE GROUPS: RESEARCH, LATEST DEVELOPMENTS & MORE				
	Full program for tracks – please see below			
12:00 (60)	Soft Tissue Sarcomas (Room tbc)	GIST (Room tbc)	Bone Sarcomas (Room tbc)	Desmoid (Room tbc)
13:00 – 14:00	L U N C H and NETWORKING (60 min)			
	Full program for tracks – please see below			
14:00 (90)	Soft Tissue Sarcomas (Room tbc)	GIST (Room tbc)	Bone Sarcomas (Room tbc)	Desmoid (Room tbc)
15:30 – 16:00	C O F F E E B R E A K & NETWORKING (30 mins)			

CAPACITY BUILDING AND EMPOWERING – PART 1	
16:00 (120)	The SPAGN Market Place Sessions 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>
18:00	BREAK BEFORE DINNER
19:30	Dinner at Pizzeria da Marco, by kind invitation of the Sarcoma Foundation of America

DAY 3 – SUNDAY April 13, 2025	
The Bethesda Hotel	
8:30 (5)	Welcome to the day <i>Gerard van Oortmerssen</i>
IMPACT ON PATIENT OUTCOMES: TREATMENT & RESEARCH	
	<i>Session Chairs: Estelle Artzner & co-chair TBD</i>
08:35 (60)	Beyond systemic/medical therapies: What other disciplines have to offer for sarcoma patients <i>Key innovative developments from pathology, imaging, surgery and radiotherapy</i> <i>Speakers: TBC</i> <i>Pathology (15 min) / Imaging (15 min) / Surgery (15 min) / Radiotherapy: (15 min)</i>
9:35 (25)	Q&A and discussion
10:00 – 10:30	COFFEE BREAK & NETWORKING (30 mins)
CAPACITY BUILDING AND EMPOWERING – PART 2	
	<i>Session Chairs: Gabriele Ott & co-chair TBD</i>
10:30 (75)	Empowering patients: Lighthouse projects in patient advocacy <ul style="list-style-type: none"> - Presentations Advocacy in Action Award Winners/Submissions 2023/24 - Blog Voices of Sarcoma
11:45	Short Break (15 mins)
SPECIAL TOPIC: THE YOUNG SARCOMA POPULATION	
	<i>Session Chairs & moderators: Christina Baumgarten & co-chair TBD</i>
12:00 (60)	Workshop “Young people have cancer, too!” <i>Setting the stage:</i> Needs of children & AYA with sarcoma: Similarities and differences <i>Speakers: Brigitte Widemann, USA & TBC (15min)</i> <i>Group Discussion:</i> Unique challenges and how to address them
13:00	Closing Remarks – End of Meeting <i>Markus Wartenberg, Gerard van Oortmerssen and Denise Reinke on behalf of the SPAGN Board</i> <i>Brigitte Widemann on behalf of the NCI</i>

Soft Tissue Sarcoma Track – Agenda – Room TBC
Saturday, April 12, 2025

12:00 (5)	Welcome <i>Chairs: Sorrel Bickley & co-chair TBD</i>
12:05 (35)	Ultra-Rare Sarcomas: Challenges and profiles of selected subtypes <i>Speakers: Silvia Stacchiotti, IT</i>
12:40 (20)	Hereditary predispositions in sarcomas: Current insights and challenges <i>Speakers: Silvia Stacchiotti, IT</i>
13:00 – 14:00 L U N C H and NETWORKING (60 min)	
14:00 (60)	Research Updates: The role of immunooncology, T-cell therapy and other innovative approaches in sarcomas <i>Speaker: Jon Trent, USA</i>
15:00 (30)	Q&A and discussion

NEW HORIZONS GIST

Agenda – Room TBC
Saturday, April 12, 2025

12:00 (5)	Welcome <i>Chairs: Kai Pilgermann & LRG</i>
12:05 (55)	Navigating the current treatment and clinical trial landscape in GIST <i>Speaker: Jon Trent, USA</i>
13:00 – 14:00 L U N C H and NETWORKING (60 min)	
14:00 (45)	GIST – from one disease to many <i>Spotlight on the rare GIST subtypes non-KIT/PDGFR-mutated GIST</i> <i>Speakers: TBC</i>
14:45 (25)	The GISTT Summit: Learnings and findings <i>Speaker: TBC</i>
15:10 (20)	Q&A & Discussion

BONE SARCOMA ALLIANCE

Agenda – Room TBC

Saturday, April 12, 2025

12:00 (5)	Welcome <i>Chairs: Ornella Gonzato & Zoe Davison, Christina Ip-Toma</i>
12:05 (10)	Update from the BSA <i>Speaker: TBC</i>
12:15 (45)	Challenges after surgery <ul style="list-style-type: none">- How exercise can improve outcomes and quality of life- Addressing mental health (experiences from the chondrosarcoma community)- Infections <i>Speakers: TBC</i> Discussion
13:00 – 14:00 L U N C H and NETWORKING (60 min)	
14:00 (20)	Factors of poor prognosis in bone sarcoma adolescents and young adults <i>Speaker: TBC</i>
14:20 (20)	Managing shared decision-making in bone sarcoma surgery: Challenges and Benefits <i>Speaker: TBC</i>
14:40 (40)	Panel Discussion Are Multidisciplinary Teams (MDTs) focused on patients or diseases? How precision and personalized oncology, along with patient preferences, can improve patient-centered care <i>All speakers</i>

Desmoid Track – Agenda – Room TBC

Saturday, April 12, 2025 - WORK IN PROGRESS

12:05 (5)	Welcome <i>Chairs: Christina Baumgarten & Lynne Hernandez</i>
12:05 (55)	Research Updates <i>Speaker: Bernd Kasper, GER</i>
13:00 – 14:00 L U N C H and NETWORKING (60 min)	
14:00 (90)	Topic 2 <i>Speakers: TBC</i>
	Discussion, exchange, advocacy topics <i>Speaker: TBC</i>