

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 | |
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| <i>Campus of the National Institutes of Health, The Masur Auditorium</i> | |
| 11:00 | Opening of the Registration Desk |
| 12:30 OFFICIAL START OF THE CONFERENCE (Masur Auditorium) | |
| 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</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: Alice Chen, USA</i> |
| 14:00 (15) | Discussion |
| 14:15 – 14:45 COFFEE BREAK & NETWORKING (30 mins) | |
| | <i>Session Chairs: Vandana Gupta & co-chair</i> |
| 14:45 (75) | Access to research and treatment in low and middle-income countries Can collaboration address challenges and drive impactful change? 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) |

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| | <p><i>Speaker: Lauren Pretorius, SA</i></p> <p>The regulatory perspective: Challenges for regulators in advancing treatments for rare tumors globally (15 min)</p> <p><i>Speaker: FDA & EMA-Speaker (TBD)</i></p> |
| 16:00 (30) | Discussion |
| 16:30 | Short Break (15 mins) |
| | Session Chairs/Moderator: Denise Reinke & co-chair |
| 16:45 (75) | <p>Patient-Partnered Research: Unpacking its power and how to make it happen</p> <p><i>Panelists</i></p> <ul style="list-style-type: none"> - <i>Jonathan Fletcher, USA</i> - <i>Douglas Lowy, USA</i> - <i>Markus Wartenberg, GER</i> - <i>Sorrel Bickley, UK</i> - <i>Bill Tap, USA</i> - <i>Winette van der Graaf, NL</i> |
| 18:00 | END OF DAY 1 |

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| DAY 2 – SATURDAY April 12, 2025 | |
| The Bethesda Hotel, room Bethesda ABC | |
| 08:15 | OFFICIAL START OF THE CONFERENCE (Room Bethesda ABC) |
| 8:30 (5) | <p>Welcome to the day</p> <p><i>Denise Reinke</i></p> |
| IMPORTANCE AND IMPACT OF PATIENT DATA | |
| | Session chairs: Gerard van Oortmerssen & co-chair |
| 8:35 (35) | <p>Educational Session: Patient Experience Data</p> <p>Understanding Patient Experience Data</p> <p><i>Speaker: Markus Wartenberg (10 min)</i></p> <p>Patient data as a contribution to research: Patient-reported outcomes (PRO)</p> <p><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</p> <p><i>Speaker: Verena Loidl, GER</i></p> |
| 09:35 (10) | Q&A / Discussion (15 min) |
| 09:45 | Group Photo |
| 09:45 – 10:15 | COFFEE BREAK & NETWORKING (30 mins) |

| CLINICAL TRIALS – CHANCES, CHALLENGES AND PITFALLS | | | | |
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| | Session Chairs and moderation: Markus Wartenberg & Bernd Kasper | | | |
| 10:15 (45) | <p>Innovative approaches in clinical trials: Exploring challenges and solutions for rare and ultra-rare sarcomas</p> <p><i>Impulse presentations from 3 perspectives</i></p> <p>From expert perspective</p> <p><i>Speakers (10 mins each):</i></p> <p><i>Silvia Stacchiotti, IT & Mary Frances Wedekind Malone, Center for Cancer Research NCI, 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: Uchenna Iloeje, Springworks</i></p> <p>From patient perspective (10 min)</p> <p><i>Recording: Statement Roger Wilson Speakers: Denise Robinson, USA</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 Bethesdan ABC) | GIST (Room Bethesdan D) | Bone Sarcomas (Room Cordell) | Desmoid (Room Wisconsin) |
| 13:00 – 14:00 | LUNCH and NETWORKING (60 min) | | | |
| | Full program for tracks – please see below | | | |
| 14:00 (90) | Soft Tissue Sarcomas | GIST | Bone Sarcomas | Desmoid |
| 15:30 – 16:00 | COFFEE BREAK & NETWORKING (30 mins) | | | |
| CAPACITY BUILDING AND EMPOWERING – PART 1 | | | | |
| Room Bethesdan ABC | | | | |
| 16:00 (120) | <p>The SPAGN Market Place Sessions</p> <p>Choose your 3 favourite sessions from 5 market booths! Each Session lasts 30 mins, 5 minutes break to change the booth</p> <p><i>Max. 10 mins presentation, 15-20 mins discussion</i></p> | | | |
| 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 | |
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| The Bethesda Hotel, room Bethesda ABC | |
| 8:30 (5) | Welcome to the day <i>Gerard van Oortmerssen</i> |
| IMPACT ON PATIENT OUTCOMES: TREATMENT & RESEARCH | |
| | Session Chairs: Estelle Artzner & co-chair |
| 08:35 (60) | Beyond systemic/medical therapies: What other disciplines have to offer for sarcoma patients Key innovative developments from pathology, imaging, surgery and radiotherapy Speakers: <ul style="list-style-type: none"> • Pathology: Jonathan Fletcher, USA (15 min) • Imaging: Eva Dombi, USA (15 min) • Surgery: Rebecca Gladdy, Canada (15 min) • Radiotherapy: Ashleigh Guadagnolo, USA (15 min) |
| 9:35 (25) | Q&A and discussion |
| 10:00 – 10:30 COFFEE BREAK & NETWORKING (30 mins) | |
| CAPACITY BUILDING AND EMPOWERING – PART 2 | |
| | Session Chairs: Gabriele Ott & co-chair |
| 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 | |
| | Session Chairs & moderators: Christina Baumgarten & co-chair |
| 12:00 (60) | Workshop “Young people have cancer, too!” Setting the stage: Needs of children & AYA with sarcoma: Similarities and differences Speakers: Brigitte Widemann & Brian Pennarola, NCI, US (15min) Group Discussion: Unique challenges and how to address them |
| 13:00 | Closing Remarks – End of Meeting Markus Wartenberg, Gerard van Oortmerssen and Denise Reinke on behalf of the SPAGN Board Brigitte Widemann on behalf of the NCI |

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

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| 12:00 (5) | Welcome <i>Chairs: Brandi Felser & co-chair</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: Margarita Raygada, USA</i> |
| 13:00 – 14:00 L U N C H and NETWORKING (60 min) | |
| 14:00 (60) | Research Updates: The role of immuno-oncology, 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 Bethesdan D
Saturday, April 12, 2025

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

BONE SARCOMA ALLIANCE

Agenda – Room Cordell Saturday, April 12, 2025

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| 12:00 (5) | Welcome <i>Chairs: Ornella Gonzato & co-chair</i> |
| 12:05 (10) | Update from the BSA <i>Speaker: Ornella Gonzato, IT</i> |
| 12:15 (45) | Advancing Knowledge: Latest Research and Clinical Trials in Bone Sarcomas <i>Speakers: Patrick Grohar, USA</i> |
| 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: Patrick Grohar, USA</i> |
| 14:20 (20) | Managing shared decision-making in bone sarcoma surgery: Challenges and Benefits <i>Speaker: TBD</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 Wisconsin
Saturday, April 12, 2025

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