



Sarcoma
Patient Advocacy
Global Network

13th SPAGN Annual Conference for Organizations Representing Patients with Sarcomas, GIST or Desmoid-Tumours May 11-13, 2023 in Dublin, Ireland

Crowne Plaza Dublin - Blanchardstown
Blanchardstown Town Centre, Dublin 15 | Ireland

PROGRAMME

DAY 1 – THURSDAY May 11, 2023	
10:00	Opening of the Registration Desk
12:30	OFFICIAL START OF THE CONFERENCE
12:30 (15)	Welcome to Dublin/Ireland on behalf of the SPAGN Board of Directors <i>Sorrel Bickley on behalf of the SPAGN Board of Directors</i>
S01 12:45 (45)	<i>Patient Host/Chair: Gerard van Oortmerssen, Netherlands</i> What are the main tasks of pathologists in sarcoma today? A job and task description - from finding the correct diagnosis (sarcoma subtype) to the molecular characterization of tumours Questions, comments from the audience <i>Bernadette Liegl Atzwanger, Austria</i>
S02 13:30 (60)	<i>Patient Host/Chair: Markus Wartenberg, Germany</i> We need more and better research in sarcomas. Get to know two examples of <u>systematic</u> programs: For basic research and research results coming directly from and for treatment reality <ul style="list-style-type: none"> The MASTER Program is a central platform for multidimensional characterization of patients with advanced rare cancers incl. Sarcomas. (20 Min.) Treatment resistance is a central problem in the treatment of cancer. Sarcomas in adolescents and young adults often stop responding to treatment too. The new national funded research project HEROES-AYA aims to discover how the molecular heterogeneity of sarcomas leads to treatment resistance. (20 Min.) Questions, comments from the audience (20 Min.) <i>Stefan Fröhling, Germany</i>
14:30 – 15:00	C O F F E E B R E A K (30 min.)
S03 15:00 (60)	<i>Patient Host/Chair: Markus Wartenberg, Germany</i> Adherence (Compliance) with oral therapies is a complex behaviour. Understanding the challenges and causes of non-adherence... <i>Rob Horne, Professor of Behavioural Medicine, UK</i>
S04 16:00 (75) Call for Abstracts!	<i>Session Chairs: Vandana Gupta, India</i> Sharing Best Practice in Patient Support or Patient Advocacy. Call for Abstracts: Completed, ongoing or planned projects 5 selected abstracts (ideally different countries/regions, type of projects) 10 minutes presentation time plus 5 minutes questions and discussions
17:15 – 17:30	S H O R T B R E A K (15 min.)

S05 17:30 (75) until max. 18:45	SPAGN AGM (ANNUAL GENERAL MEETING) 2023 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"> ▪ Report of the Board of Directors / Executive Director (2022) ▪ Financial report (2022) ▪ Outlook 2023 and beyond ▪ Applications/requests <i>SPAGN Board of Directors, Kathrin Schuster (Executive Director)</i>
19:30 (max. 120)	Networking Opportunity: Informal and voluntary “Get Together” (drinks & snacks) Including Award ceremony "Advocacy in Action Award 2022/23"

DAY 2 – FRIDAY May 12, 2023	
S06 07:30 (45)	Early Breakfast Session (...on a voluntary basis...) Patient Involvement in Cancer Research <ul style="list-style-type: none"> ▪ 2020+2021: Started on the European Level between Portugal, Germany and Slovenia >>> Process/Document: Principles of Successful Patient Involvement in Cancer Research. ▪ Practical Example: The concept of the “NCT National Center of Tumour Diseases”: “Patients as Research Partners” or how we are planning to establish a new cancer research culture in Germany <i>Markus Wartenberg, Germany</i> <i>(Chair of the “National NCT Patient Research Council”)</i>
08:30	Welcome to Day 2
S07 08:30 (60)	<i>Patient-Host-/Chair – Moderator: Roger Wilson, UK</i> Keynote: The patient in the room. Do we really listen? (20 Min.) <i>Winette van der Graaf, Netherlands</i> The patient / patient advocate perspective (10 Min.) <i>Roger Wilson, UK</i> Auditorium: Questions, Exchange of Experiences, Suggestions (30 Min.)
09:30 – 10:00	C O F F E E B R E A K (30 min.)
S08 10:00 (90)	<i>Patient-Host-/Chair: TBD</i> Bone Sarcomas: Focus on developments and special topics <ul style="list-style-type: none"> ▪ Important research updates for Osteosarcomas and Ewing Sarcomas (30 Min.) <i>Emanuela Palmerini, IT</i> ▪ FOSTER (Fight Osteosarcoma Through European Research) Project and early results of an osteosarcoma survey (15 Min) <i>Jazzmin Huber, UK</i> ▪ AYAs (Adolescents and Young Adults) with Sarcomas: An underserved community: Challenges and solutions... (30 Min.) <i>Winette van der Graaf, Netherlands</i>
11:30 – 13:00	L U N C H and NETWORKING (90 Min.)

S09 13:00 (75)	<p><i>Patient Host/Chair: Estelle Lecointe-Artzner, France</i></p> <p>HTA Health Technology Assessment: The systematic, evidence-based assessment of treatments, medical procedures and technologies with regard to their effects (incl. e.g. costs) on healthcare</p> <ul style="list-style-type: none"> Understanding the rationale and underlying factors behind HTA National vs. International: What is happening on the European level? <i>tbd</i> Let's see how different HTA-processes really are. Short "snapshots" from different countries (5 Min. each) UK: HTA via NICE <i>Jayne Bressington/Bradley Price</i> France <i>Estelle Artzner</i> Germany: HTA via G-BA / IQWiG <i>Markus Wartenberg/Christina Baumgarten</i> Canada: HTA as a provincial issue <i>David Josephy</i> Poland <i>Piotr Fonrobert</i>
S10 14:15 (60)	<p><i>Patient Host/Chair: TBD</i></p> <p>Diagnosis and therapy of cancer diseases by nuclear medicine. An area of impressive technological advances and impressive changes... Role of nuclear medicine in Sarcomas. <i>Wolfgang Fendler, Clinic for Nuclear Medicine, Germany</i></p>
15:15 – 15:45 COFFEE BREAK (30 min.)	
S11 15:45 (90)	<p>The SPAGN "Market Place Sessions": Choose your 3 favourite sessions from 5 offers (market booths)! (Each Sessions = 25 Min. >>> About half presentation and the other half exchange of experiences/discussion.) In between: 5 minutes break for changing the booth...</p> <p>Booth 1: Making materials for patients more patient-friendly and clear <i>Amy Bruno-Lindner, Austria</i></p> <p>Booth 2: The 101 of political lobbying: The UK-experience <i>Bradley Price, UK</i></p> <p>Booth 3: Basics of data protection and data security in patient organizations <i>Denise Reinke, USA</i></p> <p>Booth 4: How is a scientific publication (abstract) structured and how is it created <i>Bernd Kasper & Roger Wilson</i></p> <p>Booth 5: What to consider when working with pharmaceutical companies <i>N.N.</i></p>
17:15 BREAK BEFORE DINNER	
19:30	External Dinner

DAY 3 – SATURDAY May 13, 2023	
From 07:00	Breakfast: Meet Your Peers (...on a voluntary basis...) Breakfast tables - according to indication groups: Soft Tissue Sarcomas, Bone Cancer, GIST, Desmoids
08:30	Welcome to Day 3
S12 08:30 (120)	<i>Patient Host/Chair: Denise Reinke, USA & Sorrel Bickley, UK</i> The research forum for soft tissue sarcoma subtypes: Latest findings or promising studies that will or could change the standards of treatment of care... <i>Jon Trent, Peter Reichardt, Robin Jones, Bernd Kasper</i> <ul style="list-style-type: none"> • Leiomyosarcomas • Liposarcomas • Desmoids • Other selected subtypes (e.g., synovial, EHE, pecoma)
10:30 – 11:00	C O F F E E B R E A K (30 min.)
S13 11:00 (45)	<i>Patient Host/Chair: Kathrin Schuster, SPAGN</i> Tenosynovial giant cell tumor (TGCT) or Pigmented Villonodular Synovitis (PVNS): Brief introduction to the disease TGCT/PVNS (10 mins) <i>Sydney Stern, USA</i> The TGCT Consensus Paper: A joint patient-expert initiative (25 mins) <i>Silvia Stacchiotti, Italy</i>
S14 11:45 (60)	<i>Moderator: Roger Wilson, UK & Denise Reinke, USA</i> Working Session “Global Sarcoma Care Charter 2023”: Minimum global standards for diagnosis, treatment and care in Sarcomas. Underscoring the global need for equitable care and access to expertise and therapies Introduction and discussion
12:45	Closing Remarks – Farewell – End of Meeting- SPAGN Board of Directors
13:00 – 14:00	L U N C H and NETWORKING (60 min.)
14:00	Start of “New Horizons GIST-Meeting” (Separate conference with special agenda...)