



2024 SPAGN ANNUAL CONFERENCE

Celebrating 15 years!



**Sarcoma
Patient Advocacy
Global Network**

April 19-21 | Rome
Precise House Mantegna



Dear patient representatives, sarcoma experts, and pharmaceutical partners:

We would like to welcome you to Rome for our 14th SPAGN Annual Conference and Annual General Meeting.

It is now 15 years ago, when 11 European GIST and sarcoma patient groups found their way together and brought Sarcoma Patients EuroNet to life in April 2009.

What was true back then is still true today: We strive to ensure that sarcoma patients live longer, and with a better quality of life.

In the beginning, we focused our work on Europe. However, it soon became clear that the challenges of the sarcoma community are global, and it became a priority for us to expand our network and work together to improve the situation for sarcoma patients.

In 2016, SPAEN opened our membership to groups outside Europe. And in 2022, we changed our name to reflect our growing global footprint.

Today, Sarcoma Patient Advocacy Global Network unites more than 65 patient organizations from every continent. **Now, as then, we have a common vision: One day sarcomas will be preventable or curable.**

Until then, patients, experts and other stakeholders work together globally to:

- drive sarcoma research
- improve early and correct diagnosis
- secure timely access to interdisciplinary expert care
- provide patient-oriented information and support

After 15 years, our community has achieved a great deal – truly living up to our motto of “Working together, making a difference!”

And we know we can do more.

We will continue uniting the forces of patients, relatives and patient representatives, healthcare professionals and partners from the industry to change the lives of people affected by sarcoma.

Until there is a cure!

Your SPAGN Board of Directors & Team





11:00	60 min	<i>Opening of Registration Desk</i>	
12:00	60 min	<i>LUNCH</i>	
13:00		OFFICIAL START OF CONFERENCE	ROOM 3A-3B
13:00	30 min	Welcome to Italy! 15 years of SPAEN/SPAGN: A Travel in Time <i>SPEAKERS: Markus Wartenberg, Roger Wilson, Ornella Gonzato</i>	
13:30	60 min	Real-World Data & Evidence <i>CHAIRS Sorrel Bickley, UK & Christina Ip-Toma, US</i> <ul style="list-style-type: none">• Why gathering real-world data is so important• What sources do I have to collect real-world data?• What impact can they have?• How real-world data influences decisions of regulators and reimbursement bodies?• What's the role of real-world data in drug repurposing? <i>SPEAKERS Ana Amariutei, WECAN</i>	
14:30	30 min	<i>COFFEE BREAK & NETWORKING</i>	
15:00	60 min	Molecular Diagnostics: An Introduction <i>CHAIRS: Ornella Gonzato, IT & Jayne Bressington, UK</i> <ul style="list-style-type: none">• What is it?• How does it work?• Why do we need it?• What is a molecular tumor board? <i>SPEAKER: Eva Wardelmann, DE</i>	
16:00	15 min	<i>BREAK</i>	
16:15	90 min	SPAGN AGM All Conference Participants welcome! (Voting for SPAGN Members only) <ul style="list-style-type: none">• Report of the Board of Directors (2023)• Financial Report (2023)• Outlook 2024 and beyond• Elections• Applications/requests <i>CHAIRS: SPAGN Board</i>	
17:45		<i>BREAK BEFORE DINNER</i>	
19:30		<i>DINNER</i>	





08:30		START OF DAY 2					ROOM 3A-3B	
08:30	60 min	Surgery in Sarcomas <i>CHAIRS: Gerard van Oortmerssen, NL & Angelika Sandakly, FR</i>		Challenges and pitfalls when operating on sarcomas		Clinical trials in surgery: Relevance of patient preference for study design		
		<i>SPEAKER: Sylvie Bonvalot, FR</i>		<i>SPEAKER: Jendrik Harges, DE</i>				
09:30	75 min	Patient Involvement in Sarcoma Clinical Trials <i>CHAIRS: Markus Wartenberg, DE & Roger Wilson, UK</i>		Challenges of planning and conducting clinical trials in rare and ultra-rare cancers		Case studies: Clinical trials - What questions do you need to ask? General and study-specific questions		
		<i>SPEAKER: Robin Jones, UK</i>		<i>LEAD: Roger Wilson, UK & Bernd Kasper, DE</i>				
10:45	45 min	COFFEE BREAK & NETWORKING						
11:30	60 min	Working Group & Discussion Sessions						
		Clinical Trials: Challenges/opportunities for patient organizations & Patient Experience Data (PED) <i>CHAIRS: Denise Reinke, US & Ornella Gonzato, IT</i>			Sarcoma Awareness: Opportunities for coordinated messaging to raise global awareness <i>CHAIRS: Cory Archibald, DE & Kathrin Schuster, DE</i>			
12:30	10 min	GROUP PHOTO						
12:40	80 min	LUNCH & NETWORKING						
14:00	90 min	Choose Your Track (see insert for full program)						
		TRACK 1	TRACK 2	TRACK 3	TRACK 4	TRACK 5		
		Soft Tissue Sarcomas	GIST	Bone Sarcomas	Desmoid	TGCT		
15:30	30 min	COFFEE BREAK						
16:00	60 min	Choose Your Track (see insert for full program)						
17:00	75 min	Sharing Best Practices <i>CHAIR: Gabriele Ott, DE/AT</i>		Advocacy in Action: Presentations of selected projects and awards				
18:15	BREAK BEFORE DINNER							
19:30	DINNER							





08:30		START OF DAY 3	ROOM 3A-3B
08:30	105 min	The SPAGN Marketplace Sessions Choose your 3 favourite sessions from 5 market booths! Each session lasts 30 minutes, with a 5-minute break in between to change booths <i>(10 minutes presentation / 15-20 minutes discussion)</i> BOOTH 1: Fundraising – The US Example <i>SPEAKER: Brandi Felser, US</i> BOOTH 2: Standards of Excellence for Patient Organizations <i>SPEAKER: Lauren Pretorius, ZA</i> BOOTH 3: Social Media <i>SPEAKERS: Cory Archibald, DE / Maria Brandt, DE</i> BOOTH 4: Peer-to-Peer Support <i>SPEAKERS: Zoe Davison, UK / Kathleen Kane, UK</i> BOOTH 5: Storytelling <i>SPEAKERS: Roger Wilson, UK / Gabi Ott, DE/AT</i>	
10:15	30 min	COFFEE BREAK & NETWORKING	
10:45	60 min	Working Group & Discussion Session: Sarcoma Intelligent Specialist Networks Focus on Sarcoma Management & Care outside the US and Europe <i>CHAIRS: Roger Wilson, UK & Vandana Gupta, IN</i>	
11:45	15 min	SHORT BREAK	
12:00	75 min	Artificial Intelligence in Sarcomas <i>CHAIR: Gerard van Oortmerssen, NL</i> <ul style="list-style-type: none">• Overview <i>SPEAKER: Maria Brandt, DE</i>• A practical example <i>SPEAKER: Sandro Pasquali, IT</i>	
13:15		Closing Remarks – End of Meeting <i>CHAIRS: SPAGN Board</i>	



15 years of working together, making a difference



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Thank you to our Sustaining Partners & Corporate Members



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