2025 SPAGN ANNUAL CONFERENCE
Washington, D.C.
WASHINGTON, D.C.
April 11-13 | The Bethesdan Hotel

15th SPAGN Annual Conference

Gathering in Washington, D.C., USA, from April 11–13, 2025, the SPAGN community convened for its 15th Annual Conference.

This event marked the first SPAGN Annual Conference held in North America, strengthening global connections in sarcoma advocacy. The conference brought together 130 sarcoma patient advocates, experts, and partners from more than 30 countries.

The three days featured a variety of sessions and activities:

➡️ Five technical plenary sessions
➡️ Specialized tracks organized by sarcoma type and patient populations
➡️ Working groups and discussions
➡️ Presentation of award winners for the SPAGN Advocacy in Action Awards, the inaugural Paola Gonzato Memory Award, and the Lifetime Achievement Awards

You can access the full session recordings [here.](#) Individual session links are included below in the report.

I. Welcome and Opening Session

Denise Reinke, SPAGN Board Member, opened the conference by welcoming participants and highlighting the vital role of global collaboration, patient empowerment, and advocacy in advancing sarcoma care. She offered special thanks to Brigitte Widemann of the National Cancer Institute (NCI) for her partnership and support in making the conference possible. Douglas Lowy, Principal Deputy Director of the NCI, and John Glod from the NCI's Pediatric Oncology Branch, extended a warm welcome on behalf of the Institute, which is located nearby the conference venue and played a key role in co-organizing the event. Their remarks helped set the stage for three days of learning, exchanging experiences, and strengthening the international network of sarcoma advocates.

II. Main Sessions

1. The Power of Collaboration in Sarcoma (Parts I–III)

In Part I Alice Chen highlighted successful collaborations between patient advocates and medical experts that have advanced sarcoma research, improved trial design, and strengthened advocacy outcomes.

In Part II Satish Gopal, Lauren Pretorius & Fernando Campos addressed global disparities in access to care—especially in low- and middle-income countries—emphasizing the importance of building local patient networks, improving early diagnosis, and ensuring inclusive research participation.

Finally, in Part III the panelists Winette van der Graaf, Gabi Ott, Jonathan Fletcher, Bill Tap and Markus Wartenberg explored patient-partnered research models, challenges in integrating advocates into research governance, and shared best practices for meaningful engagement.

2. Importance and Impact of Patient Data

Patient-reported outcomes (PROs) and real-world data were discussed as essential tools for improving research relevance and healthcare decision-making. The session also covered how artificial intelligence (AI) could support better data collection, interpretation, and integration into clinical practice. SPAGN shared findings from its global sarcoma diagnosis survey, revealing delays and misdiagnoses that significantly impact patient outcomes.

3. Clinical Trials: Chances, Challenges, and Pitfalls

This session explored barriers and opportunities in clinical trials for rare cancers. Silvia Stacchiotti, Uchenna Iloeje, Roger Wilson and Denise Robinson shared challenges, wishes and visions for future clinical trials in sarcoma. They highlighted the need for patient advocates to be deeply involved not only in recruitment but in the design of trials to ensure they are meaningful and accessible. Innovative trial models and early regulatory engagement were discussed during the panel discussion of the speakers, joined by Martha Donoghue from the Food and Drug Administration FDA.

4. Advances in Soft Tissue Sarcomas

The session on Advances in Soft Tissue Sarcomas covered several key areas.

Margarita Raygada advocated for the importance of universal genetic testing for sarcoma patients, highlighting significant gaps in current clinical guidelines that can hinder personalized treatment options.

Silvia Stacchiotti discussed the unique challenges surrounding ultra-rare sarcomas, particularly focusing on drug approval processes and the necessity for global cooperation to advance research in this area.

Jon Trent shared updates on the latest developments in immunotherapy, emphasizing the potential of combining different immune therapies to enhance treatment efficacy and underscoring the need for continued innovation in this field.

5. Bone Sarcomas: Research, Care, and Advocacy

The Bone Sarcoma Alliance was introduced by Kathrin Schuster, outlining a collaborative effort to amplify the bone sarcoma patient voice globally.

Patrick Grohar kicked off the session *Bone Sarcomas: Research, Latest Developments & More (Part I)*, presenting compelling examples of how discoveries in the lab are being translated into clinical trials, particularly in Ewing sarcoma and osteosarcoma. He emphasized the critical role of patient advocates in supporting research biopsies, promoting international data-sharing, and helping overcome barriers in trial access for rare cancers.

Kurt Weiss followed with a focus on patient-centered decision-making in surgical care. As a surgeon and sarcoma survivor, he highlighted the significance of multidisciplinary teams, precision oncology, and survivorship care for bone sarcoma patients.

The discussion *"Are Multidisciplinary Teams (MDTs) focused on patients or diseases?"* raised crucial questions about the balance between patient-centered care and disease-specific treatment approaches. Experts explored whether MDTs are effectively addressing the needs of individual patients or prioritizing disease-specific treatments, especially in the context of rare cancers like bone sarcomas.

6. Desmoid: Research, Latest Developments & More

This session covered the latest updates in Desmoid tumor research, with Bernd Kasper providing an in-depth look at innovative research and emerging therapeutic approaches for these rare tumors.

Fernando Campos shared the challenges of managing Desmoid tumors in Brazil, exploring regional disparities and the unique difficulties in treatment access. Speakers from different Desmoid patient groups followed with an open discussion on advocacy strategies, patient-centered care, and effective communication models.

7. GIST: Research, Latest Developments & More

In this session, Jon Trent navigated the current treatment and clinical trial landscape in Gastrointestinal Stromal Tumors (GIST), highlighting both challenges and promising opportunities for new therapies.

Experts Andrew Blakely and John Glod discussed the rare subtypes of GIST, including non-KIT/PDGFR-mutated GISTs, providing insights into their distinct molecular characteristics and the implications for treatment. The session concluded with a discussion of key learnings and findings from the GISTT Summit by Jonathan Fletcher.

8. The Marketplace Sessions

In a dynamic and interactive format, participants were invited to explore their top three out of five engaging 30-minute “market booth” sessions, each offering practical tools, experiences, and inspiration to support sarcoma advocacy.

🎙️ *Storytelling*

Katja Winter (Germany) explored the power of personal narrative, guiding attendees on how storytelling can create impact, build empathy, and foster stronger advocacy within the sarcoma community.

📞 *Sarcoma UK: Running a Sarcoma Support Line*

Carly McDonald (UK) shared firsthand experience operating a national support line, highlighting challenges, best practices, and the profound impact of providing a listening ear to patients and families.

🏛️ *The Power of Lobbying*

Brandi Felser (USA) unpacked the essentials of effective lobbying, equipping advocates with practical strategies to influence policy and drive systemic change for rare cancer communities.

🔬 *Starting Your Own Research: What to Consider*

Verena Loidl (Germany) and Denise Robinson (USA) provided a roadmap for advocates interested in initiating patient-led research, covering ethical considerations, collaborations, and key steps to get started.

⚖️ *Sarcoma UK Health Technology Assessment (HTA): What Is It?*

Adela Maghear (Turkey) demystified the complex world of HTA, explaining how health systems evaluate new treatments—and why patient voices must be part of that process.

With just five minutes between booths, participants navigated a fast-paced afternoon rich in ideas, practical advice, and opportunities to connect across borders and experiences.

9. Beyond Systemic/Medical Therapies: What Other Disciplines Have to Offer for Sarcoma Patients

This session highlighted the critical role of non-systemic disciplines in sarcoma care, focusing on key innovations that enhance diagnosis, treatment, and outcomes. Experts from imaging, surgery, and radiotherapy, Eva Dombi, Kurt Weiss and Ashleigh Guadagnolo, presented the latest advancements in their fields, from cutting-edge imaging techniques that support early detection and monitoring and surgical innovations improving resection outcomes to developments in radiotherapy that offer more precise, effective treatment with fewer side effects.

10. Capacity Building and Empowerment

The SPAGN Advocacy in Action Awards 2025 recognized inspiring projects that have made significant contributions to raising awareness, improving care, and strengthening patient communities.

The session also highlighted the SPAGN Blog as a platform for advocates to share personal stories and insights, showing how storytelling can shape culture, influence decision-makers, and drive systems change from a patient perspective.

11. Special Topic — The Young Sarcoma Population

🎗️ This year's *Special Topic* shone a spotlight on adolescents and young adults (AYA) living with sarcoma, a group often underrepresented in cancer care conversations.

Brian Pennerola opened the session by addressing the rarity of AYA cancers and the gaps in existing systems that often leave young patients feeling isolated. He stressed the need for improved communication across care teams, as well as age-appropriate psychosocial support tailored to the transitional nature of this life stage.

Patient advocates Lennie Woods and Matt Sha powerfully shared their lived experiences, shedding light on the emotional and practical realities of navigating a sarcoma diagnosis as a young person. Their stories highlighted the importance of peer connection, mentorship, and community in building resilience and fostering hope.

III. Awards 🏆

Lifetime Achievement Awards 2025

SPAGN proudly honored the following outstanding individuals for their lifetime contributions to sarcoma research, care, and advocacy:

🏅 Winette van der Graaf, MD, PhD (The Netherlands)
🏅 Estelle Lecointe-Artzner (France)
🏅 Norman Scherzer (USA)
🏅 Jonathan A. Fletcher, MD (USA)

Their leadership and tireless dedication have transformed patient care, advanced research, and inspired countless advocates worldwide.

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Advocacy in Action Awards 2025

🥇 First Prize – ASARGA (Spain): Sarcoma: Bringing the Invisible into Focus
Political advocacy success in Spain, leading to the adoption of a non-legislative proposal for sarcoma care.

🥈 Second Prize – Bone Cancer Research Trust & Sarcoma UK (UK): The National Sarcoma Awareness Project
Educated young doctors to improve sarcoma detection and diagnosis across the UK.

🥉 Third Prize – Patiëntenplatform Sarcomen (Netherlands): Only Together: From Nothing to Treatment Protocol
Patient-driven initiative that successfully created national guidelines for phyllodes tumors.

Paola Gonzato Memory Award 2025

🌟 Winner – Bone Cancer Research Trust (UK): Bone Cancer Awareness Week 2024: Ever Heard of Bone Cancer?

- A highly successful public campaign, engaging patients, raising awareness, and strengthening the community around bone sarcomas.

IV. Conclusion

The SPAGN Annual Conference 2025 was a powerful reminder of what we can achieve when we come together—through collaboration, research, and patient advocacy. By building stronger connections across countries, specialties, and communities, SPAGN is helping to grow a united global voice for everyone affected by sarcoma. The energy was real, the commitment was strong, and the momentum is only growing.

Participants' feedback

"SPAGN is providing us all with the feeling of belonging to a global common 'home'."

"That was my first SPAGN meeting and I thoroughly enjoyed myself. A lot of learnings to bring back. I appreciate all you and SPAGN continue to do for sarcoma patients."

"I do hope we collaborate more in the future – there's a lot we can learn from SPAGN."

"I really enjoyed the meeting – I thought it was terrific! Very informative and great to see a lot of familiar faces and make some new connections."

"Congratulations on an amazing conference last week. It was just phenomenal. Thank you so much for all of the hard work you and your team put into it!"

"It was a great conference and it was recorded, so we can share the information that was so impactful for advocates—for patients to hear. The speakers were so passionate about patient advocacy intertwined with research initiatives and hopeful progress in treatment and care. It was a powerful meeting for all! STRONGER TOGETHER is what it's all about."

"Thank you for the opportunity. I connected with many members of the advocacy groups and learned a lot from the presentations. I look forward to future interactions to move the needle forward in bringing sarcoma care to the forefront of oncology."

"This conference was extremely meaningful and impactful to me, and I made so many new connections."

"Thank you for the kind invitation to take part in the SPAGN Annual Conference 2025. It was truly inspiring, and being surrounded by so many people committed to improving sarcoma care has left me even more motivated to push for meaningful progress in our region."

"Thank you again for our conversation and all the work you put into organizing everything. Being part of the SPAGN family means a lot to me."

"Just wanted to pass on our thanks and congratulate you on an excellent conference last week in the US. The caliber of speakers was excellent and we made so many new connections from advocacy groups all over the world."

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Our List of Speakers

Full Name	Country
Adela Maghear	Belgium/Turkey
Alice Chen	USA
Andrew Blakely	USA
Ashleigh Guadagnolo	USA
Bernd Kasper	Germany
Bill Tap	USA
Brandi Felser	USA
Brian Pennarola	USA
Brigitte Widemann	USA
Carly McDonald	UK
Denise Robinson	USA
Douglas Lowy	USA
Estelle Lecointe-Artzner	France
Eva Dombi	USA
Fernando Campos	Brazil
Gerard van Oortmerssen	Netherlands
John Glod	USA
Jon Trent	USA
Jonathan Fletcher	USA
Kathrin Schuster	Germany
Katja Winter	Germany
Kurt Weiss	USA
Lauren Pretorius	South Africa
Margarita Raygada	USA
Markus Wartenberg	Germany
Mary Frances Wedekind Malone	USA
Patrick Grohar	USA
Satish Gopal	USA
Silvia Stacchiotti	Italy

Uchenna Iloeje	USA
Verena Loidl	Germany
Gabriele Ott	Germany
Winette van der Graaf	Netherlands