2024 SPAGN ANNUAL CONFERENCE

April 19-21 | Rome, Italy

14th SPAGN Annual Conference Report

Gathering in the historic city of Rome, Italy, from April 19th to 21st, 2024, the SPAGN community convened for our 14th annual conference. The event was particularly special as we celebrated 15 years of SPAGN's dedication to advancing sarcoma care. This year's Annual Conference brought together more than 130 sarcoma patient advocates, experts and partners from over 30 countries.

This report gives an overview of the various sessions and activities during the three days: There were five technical sessions in the plenary, five specialist technical tracks organized by type of sarcoma, three working groups & discussions, a market place with five booths covered by representatives of member organizations and the SPAGN team, the presentation of award winners of the SPAGN Advocacy in Action Award as well as the Annual General Meeting of SPAGN.

Recording of sessions are available here.

I. Introductory Session: 15 years of SPAEN/SPAGN

On April 19, 2024, Ornella Gonzato, President of the Paola Gonzato – Rete Sarcoma Foundation and SPAGN Board Member, welcomed about 130 participants to Rome for the 14th Annual Conference. Roger Wilson, founding member and Honorary President of SPAGN, then reviewed the last 15 years, recalling the formation of a European sarcoma group in the early 2000s. He and Markus Wartenberg authored a paper that led to the establishment of Sarcoma Patients EuroNet (SPAEN) in April 2009. Wilson honored doctors, researchers, and scientists who have collaborated with SPAEN since its inception.

Markus Wartenberg, Co-chair of the SPAGN Board, concluded the introductory session by emphasizing the organization's passion for change and unity when engaging with experts and pharmaceutical partners. He highlighted the importance of learning, sharing, and supporting each other. With 68 member organizations, SPAGN considers different country contexts and the 170 types of sarcomas defined by the WHO (World Health Organization). Wartenberg mentioned ongoing collaborations with EURACAN and the Connective Tissue Oncology Society (CTOS), where patients, advocates, and experts work together. He also called for volunteers to join SPAGN and help expand its work. (Watch here)

II. Technical sessions (plenary)

The Conference covered five topics that are relevant in current discussions about improving sarcoma diagnosis and therapies, each presented by several specialists and gave space and time for participants to ask questions about:

- real-world data
- molecular diagnostics
- surgery of sarcomas
- patient involvement in sarcoma clinical trials
- artificial intelligence in sarcomas

II.1. Real-world data & evidence

Ana Amariutei, Researcher at the European Patient Advocacy Institute (EPAI) and member of the Workgroup of European Cancer Patient Advocacy Networks (WECAN), helped participants appreciate the relevance and importance of Real World Data (RWD) for sarcoma patient advocacy work. A cancer survivor herself, she emphasized the need to collect, analyze and interpret data to create robust information, both qualitative and quantitative, to enhance credibility, develop a better understanding of patient needs, ensure transparency, optimize resources and increase impact. Subsequently, she discussed different types of data to be collected and analyzed, such as Patient Reported Outcomes (PRO) and Patient Experience Data (PED).

Patient organizations can play a crucial role in supporting surveys and interviews. Ms. Amariutei highlighted key points in data collection and shared open-access data sources. The WECAN academy offers courses on evidence-based advocacy and patient involvement in publications. The discussion emphasized challenges in creating real-world data, such as finding validated questions from the EORTC question library or other patient organizations. Concerns included overburdening patients with surveys, creating statistically valid data, and bias towards educated female respondents. Data collection in low and middle-income countries is challenging due to limited digital access and resources. Bias in data from predominantly white, high-income, and female respondents undermines its validity. Privacy, confidentiality, information sharing, and success stories were also discussed. WECAN is analyzing how patient-reported outcomes (PRO) collected by advocacy organizations impact health systems, demonstrating the power of this data. (Watch here)

II.2. Molecular diagnostics – an introduction

The second topic of great interest was the introduction of molecular diagnostics by Eva Wardelmann, Director of the Institute of Pathology at University Hospital Münster, Germany. Her presentation, “Pathology as Key Point of Interdisciplinary Cancer Treatment,” began by listing the materials pathologists use, such as swabs, body fluids, fine needle aspirates, and tissue in various forms. Eva Wardelmann explained the pathologists' diagnostic workflow, highlighting the time required due to several steps and procedures to determine the subtype. She discussed how molecular pathology uses tumor tissue to analyze DNA, RNA, and gene regulators for mistakes leading to specific diseases. Examples of molecular aberrations in bone and soft tissue tumors were provided, such as translocations, mutations, and amplifications like MDM2 in liposarcoma. New research is constantly increasing the list of specific aberrations, influencing treatment decisions. She emphasized the need for adequate equipment, training, and review by interdisciplinary tumor boards. Wardelmann noted that methods for multigene analysis are scarce in many parts of the world and that whole genome analysis is not necessary for most tumor diagnoses. (Watch here)

II.3. Surgery of sarcomas

Sylvie Bonvalot, Head of Sarcoma Surgery at the Curie Institute in Paris, France, discussed the challenges and pitfalls of sarcoma surgery. She emphasized the importance of imaging and multiple core needle biopsies, advising against frozen-section techniques due to their potential to mislead. For soft tissue sarcomas, surgical biopsies should be avoided to prevent opening the tumor. Identifying the presence, location, and type of sarcoma can be challenging, and different sarcomas require different surgeries. A common mistake with retroperitoneal sarcomas is leaving behind differentiated mass; excising only the tumor is insufficient without a margin. Incomplete resections and insufficient margins can lead to piecemeal resections, reducing success rates. Some surgeries require reconstruction, necessitating a plastic surgeon on the team to enhance the patient's quality of life. Bonvalot cited academic articles highlighting the benefits of performing sarcoma surgeries in reference centers, stressing the need for thorough pre-surgery discussions.

Jendrik Hardes from the University Clinic in Essen, Germany, emphasized the importance of patient participation in surgical oncology and the complexities of decision-making in sarcoma surgery. He noted the close proximity of success and failure in surgery and the need for surgeons to understand their own limitations. Patients should be informed about the knowledge and uncertainties of surgeons and oncologists, and the implications of their options. For instance, osteosarcoma treatment requires both chemotherapy and surgery, with patients needing to understand risks like mutilation. Other factors, such as age, overall health, and patient preferences, should also be considered. Patient participation involves multiple discussions, not just a single conversation, and consulting with other patients with similar experiences can be beneficial. (Watch here)

II.4. Patient involvement in sarcoma clinical trials

Emine Hatipoglu from the Royal Marsden Hospital in London highlighted the challenges of planning and conducting clinical trials for rare and ultra-rare cancers. Around 10% of the global population is affected by a rare disease, yet only 5% have approved treatments. Developing new therapies can take 13-14 years, if they reach approval at all. Recruitment for rare disease trials is lengthy, complicated, and expensive. The US leads in the number of clinical trials for rare diseases, followed by France, Canada, Italy, the UK, and Germany. Pharmaceutical companies have little incentive to develop orphan drugs (therapeutic agents to treat rare diseases), though recent analysis shows emerging applications globally. Public funding is necessary but limited.

Roger Wilson, Founder of Sarcoma UK and Honorary President of SPAGN, emphasized with a mini-survey among participants the relevance of patient involvement and the need to ask good research questions. He illustrated basic principles behind methodologies applied in survey, e.g. adequate sampling and the definition of the control group. Inclusion and exclusion criteria can be tricky. For example, for a long time people above 65 were excluded from trials in the UK. The definition of endpoint and outcome measures is critical, and so are treatment schedule, possible side effects, follow up, acceptability of tests, the need to judge benefit versus burden. The question to ask oneself is: would you enter this study?

Subsequently, Bernd Kasper from the NCC Heidelberg in Germany, led the audience through a session on case studies: Clinical trials – what questions do you need to ask? These include general and study-specific questions. (Watch here)

II.5. Artificial Intelligence in sarcomas

Gerard van Oortmerssen, Co-chair of SPAGN, introduced patient advocates to what he called the next wave of digital revolution. Digital technology has changed all aspects of our life and will increasingly do so. Artificial intelligence (AI) and data science are presenting new challenges and opportunities. He illustrated the power of ChatGPT by asking the question: “Clinical trial - what does it mean for me?”. Furthermore, he demonstrated how algorithms can be used to extract patient experience data from social media.

Maria Brandt from the German Sarcoma Foundation discussed AI tools, focusing on ChatGPT. She highlighted how prompting techniques enhance query results but cautioned about its limitations, such as generating fictional results when unable to find solutions. Currently, ChatGPT uses data up to 2023, not real-time. Ms. Brandt referenced a March 2024 article in "Frontiers" relevant to sarcoma. She emphasized the need for patient advocates to ensure ChatGPT recognizes SPAGN as a reliable information source. Ms. Brandt advised three strategies: maintain up-to-date online presence, recommend reputable websites, and nurture professional networks.

Sandro Pasquali from the Department of Experimental Oncology, Molecular Pharmacology, in the National Tumor Institute in Milan, Italy followed up to give a practical example of AI application in sarcoma research. He did a study on high grade and deep-seated sarcoma, trying to understand the effect of anthracycline-based chemotherapy on different areas by using a machine learning method – the adaptive index models for marker-based risk stratification (Tian and Tibshirani). He developed a Sarcoma Immune Index for each tumor area, potentially aiding in identifying tumor sections more responsive to anthracycline-based chemotherapy. AI can also enhance the speed and accuracy of MRI image analysis. (Watch here)

III. Specialist tracks by different types of sarcoma

A full afternoon April 20, 2024 was dedicated to understanding and discussing the latest developments in different types of sarcomas:

- Soft Tissue Sarcomas
- GIST
- Bone Sarcomas
- Desmoid
- Tenosynovial Giant Cell Tumor (TGCT)

III.1. Soft tissue sarcomas

The soft tissue sarcoma track offered a research and medical update by Denise Reinke, Research Director at the University of Michigan, US, and SPAGN Board member, to ascertain what's new in soft tissue sarcomas. Her contribution was complemented by Sandro Pasquali who reported from the lab about the role of biomarkers, focusing on a specific case of EHE, which is a malignant vascular tumor, whereas Emine Hatipoglu gave details on recent advances in medical oncology for soft tissue sarcomas. The intricacies of organ-specific

sarcomas were introduced by Gerard van Oortmerssen, SPAGN Co-Chair, leading to patients being caught between disciplines. Taking it from there, Marloes van Esterik from the Dutch Phyllodes group provided guidance on navigating the journey of being a patient between disciplines. Roberta Sanfillippo of Italy's National Tumor Institute gave patient advocates insight into Uterine LMS, and Frederike van Dujnhoven, oncological surgeon at the Antoni van Leeuwenhoek hospital in the Netherlands, on Phyllodes. (Watch part 1 and part 2)

III.2. Bone sarcomas

This track was kicked off by SPAGN Board member Ornella Gonzato and Zoe Davison, Head of Research and Information at the Bone Cancer Research Trust, as they presented the results of the Bone sarcoma survey and the work of the recently established Bone Sarcoma Alliance. Afterwards, Domenico Andrea Campanacci, Head of oncological and reconstructive orthopedics in Florence, Italy, gave insights into technological advances for more tailored approaches and better functional outcomes in precision surgery of bone sarcomas. The role of proton therapy and carbon ion radiotherapy in bone sarcomas was discussed by Maria Rosaria Fiore of the National Centre for Oncological Treatment in Italy while Uta Dirksen, Head of the pediatric sarcoma center in Essen, Germany, talked about what's new in immunotherapy and targeted therapies in bone sarcomas. Sue Burchill, from the Leeds Institute of Medical Research in the UK, explained the current status of using biomarkers from early diagnosis to prognosis, clinical decision-making and response monitoring. The session was concluded by Uta Dirksen with a reflection on survivorship and quality of life, especially on how to manage long-term side effects and psychological aspects of survivorship in different age groups. Chair Ornella Gonzato announced a bone sarcoma award for the future.

III.3. GIST

The Gastrointestinal Stromal Tumor (GIST) track had Eva Wardelmann expanding on molecular and genomic drivers of GIST, followed by an overview of current developments in GIST research by Mehdi Brahmi. Peter Reichardt, Director of the Helios Clinic and its sarcoma center in Berlin, Germany, helped the audience to get an appreciation of how to better navigate GIST in 2024 by explaining implications of new findings and treatments for patients. The track was concluded by a panel discussion of the three experts.

III.4. Desmoid

The Desmoid track benefitted from patient representatives reporting on new and innovative projects in several countries, followed by a discussion on challenges with research grants for desmoid tumors. Marco Vitellaro from the National Tumor Institute in Italy then spoke about Familial Adenomatous Polyposis (FAP) and Desmoids, while Bernd Kasper presented the latest edition of the Desmoid Consensus Paper.

III.5. TGCT

The Tenosynovial Giant Cell Tumor (TGCT) track started with a lecture on differentiating between localized and diffuse TGCT by Emanuela Palmerini of the Department of Biomedical and Neuromotor Sciences in Bologna, Italy. Thereafter, Jendrik Hardes elaborated on surgical management of TGCT. Giacomo Baldi, medical oncologist at Prato, Italy, highlighted the do's and don'ts of systemic therapy in TGCT. How to navigate clinical trials in TGCT was the topic of Mehdi Brahmi's lecture. A panel discussion concluded the afternoon.

IV Working groups & Discussion Sessions

IV.1. Clinical trials: challenges and opportunities for patient organizations

This interactive session highlighted key takeaways for participants. Denise Reinke asked the participating patient representatives about their experiences with clinical trial research. Various contributions revealed challenges such as participation burden, access disparities, and gaps in understanding trial rationale and processes. There are concerns about patients feeling like guinea pigs due to inadequate information on risks and benefits.

Denise Reinke also underscored global disparities in trial access, noting Vietnam's low trial numbers contrasted with the US's high count. Europe similarly lacks equal trial access, with underrepresented groups by age, gender, and ethnicity. There are opportunities for patient advocates to be involved in the process of clinical trial development. The question is how could or should SPAGN and other patient advocacy groups play a role in general and specifically to help reduce the gaps was raised.

The goals of academically driven and industry driven clinical trials may be different and hence impact the design and inclusion of the broadest group possible of patients. Academics prioritize scientific advancement and treatment improvement, while industry balances patient benefit with business interests.

Exchange of clinical trial protocols should be explored. The bias of prevalence of clinical trials affects countries with different conditions. In order to improve the situation, the issue is how to prepare the different parties, both patients as well as doctors and researchers, and how to communicate.

This session provided an opportunity to begin this discussion and highlights a need to develop a strategic approach to determine the most effective approach to include the patient voice in clinical trial research recognizing clinical trial research is a critical path towards testing and ultimately approving new therapies.

IV.2. Sarcoma Awareness

Cory Archibald, Director of Communications of SPAGN, and Kathrin Schuster led a working group discussion on the topic of Sarcoma Awareness Month. The advocates discussed their goals for awareness activities, the different groups they aim to reach with their messaging, and the desired outcome. The also discussed possibilities for future planning and coordination so that the whole SPAGN community could unite behind a single theme for each year, in order to better amplify the message and raise awareness on commonalities and disparities in the experience of sarcoma patients around the world.

IV.3. Sarcoma Intelligent Specialist Networks

Roger Wilson announced the upcoming publication of the article "What is a sarcoma specialist center? Multidisciplinary research finds the answer" during the plenary session. This article summarizes discussions held at the 13th SPAGN Annual Conference in Dublin, where experts contributed to defining essential principles for a globally accepted definition of sarcoma expertise. Additional consultations in summer 2023 informed revisions to the discussion paper. An abstract was presented at the Connective Tissue Oncology Society (CTOS) conference in November 2023, gathering further feedback. The paper was finalized in April 2024 and is currently undergoing peer review. It has since been published in the academic journal [Cancers].


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Article

What Is a Sarcoma 'Specialist Center'? Multidisciplinary Research Finds an Answer

The proposed term is “Sarcoma Intelligent Specialist Network”. Roger Wilson recalled the main elements defined. The overriding objective is that patients should get an accurate diagnosis and receive safe and high-quality treatment, as close to their home as possible. He then indicated the resulting three Core Principles: treatment of sarcoma patients by a multi-disciplinary team of experts, availability of imaging including MRI as appropriate, and review by an experienced sarcoma specialist pathologist. Given that only 9% of the population have access to sarcoma centers and only 16% of the world population have access to sarcoma experts at all, there is a clear need to create incentives and targets to improve access for the larger part of the world population. The notion of a single-site concept should be complemented by a network approach, which for many countries, especially smaller ones, could be more effective. Key features complement the core principles and provide a guide to the fuller development of a network or center.

Patient advocacy groups have an important role in promoting the concept. Actions can include promoting the article and the Core Principles, engaging healthcare systems in the concept, making it known to doctors, helping specialist multidisciplinary teams to do the checklist, encouraging development of specialist care using the Key Features. It can be an important advocacy tool.

V. Marketplace Sessions

A marketplace was organized on April 20 with five booths to give patient advocates the opportunity to learn from experiences of their peers in smaller groups, ask questions or give their own input. They could choose three topics of interest and rotate every 20 minutes from one booth to another.

V.1. Fundraising - the US example

Brandi Felser, Chief Executive of the Sarcoma Foundation of America, hosted the booth on the topic of fundraising, and shared her insights on her organization's work the US, ranging from fundraising events and a toolbox shared with individuals to working with corporations and big foundations.

V.2. Standards of Excellence for patient organizations

Lauren Pretorius, Chief Executive Officer of Campaign4Cancer from South Africa, talked about standards of excellence for patient organizations.

V.3. Social media

Maria Brandt of the German Sarcoma Foundation led a discussion on social media tactics to improve reach and performance of social media posts, including: choosing the right platform or platforms to engage with, hashtag strategies, and content styles to generate attention and engagement from followers. Maria Brandt and Cory Archibald also showcased a variety of tools to help busy advocates save time and make the most of their efforts while producing high quality content, including the use of ChatGPT to assist with drafting posts. The group also discussed the importance of fact checking and reviewing the quality and content of any work produced with the assistance of AI or from volunteers.

V.4. Peer-to-peer support

Zoe Davison, Head of Research, Information & Support, and Kathleen Kane, Research and Engagement Officer, both at the Bone Cancer Research Trust, discussed the value of peer-to-peer support as evidenced in the research and, more importantly, through the lived experiences of patients and families in the bone sarcoma community. They highlighted case studies from the Bone Cancer Research Trust and Bone Sarcoma Peer Support, another UK based charity, prompting the group to share their own experiences of facilitating and engaging in peer-to-peer support, as well as discussion of varying methods of delivery and potential challenges and key considerations for facilitators.

V.5. Storytelling

Roger Wilson and Gabi Ott from the editorial team of SPAGN’s blog “Voices of Sarcoma” gave some tips on what to consider when writing a story. Identifying the key message and the supporting elements or facts is critical when starting. Keeping it simple and avoiding unnecessary detail is often more easily said than done. The two volunteer editors illustrated their take-aways with practical examples and invited participants to write a blog or join the team of the Voices of Sarcoma.

VI. Sharing Best practices – Advocacy in Action Awards

Board member Ornella Gonzato announced six winners of the 2023/2024 Advocacy in Action Awards. A jury composed of healthcare professionals and patient advocates had reviewed submissions with respect to criteria like impact, outreach, potential of adaption and replicability, sustainability, funding strategies and innovation. (Watch here)

VI.1. First prize

The first prize went to the work of Sydney Stern and her colleagues of the TGCT support program of the Life Raft group to help improve quality of life through better research on the Tenosynovial giant cell tumour (TCGT) – a rare, locally aggressive cancer that causes patients to experience pain, swelling and limited mobility. They collected information from over 900 patients in 32 countries to create the largest database on TGCT patients worldwide.

VI.2. Second prize

The second prize went to a collaborative initiative of the Bone Cancer Research Trust and Sarcoma UK, presented by Zoe Davison. To improve diagnosis of sarcoma, including on the use of biomarkers or artificial intelligence as well as strategies for improving health systems, they have launched a funding call for a total of 500,000 British pounds.

VI.3. Third prize

There were four winners of third prizes announced.

One of them was V Care based in Mumbai, India, whose project was presented by Jyoti Patil Shah. Among many other services, V Care provides patients in rural areas with reader-friendly booklets in local languages on topics such as loneliness, understanding cancer, coping with guilt, sex and cancer, hair loss, moving forward, chemo, radiation, or diet.

The German Sarcoma Foundation was awarded for running an Instagram channel with the aim of disseminating reliable information about sarcoma via social media. Maria Brandt explained how readers can be sure that what they find there is expert-verified knowledge.

The Bone Cancer Research Trust (BCRT) received a third prize for producing a guide for follow-up care after a patient's treatment for bone sarcoma has ended. Kathleen Kane explained their cooperation with the University of Sheffield to address aspects of managing longer-term and late effects of therapies and life-altering surgeries including psychosocial impact.

Last but not least, the Polish Sarcoma and Melanoma Association received a third prize for its psycho-oncological training program dedicated to the various groups of people helping cancer patients, as presented by Kamil Dolecki. Participants are given tools and knowledge to establish and manage relationships with patients, which may have a significant impact on the patients' quality of life.

VII. Annual General Meeting

The Annual General Meeting was attended by 34 of the 68 voting members. Markus Wartenberg, Chair of the SPAGN Board, provided an overview of the organization's status and thanked the Board, SPAGN team, volunteers, and sustaining partners. He encouraged interest in board positions and volunteering, and announced new community advisory boards for better collaboration with pharmaceutical companies.

Kathrin Schuster, Executive Director, highlighted 2023 activities including publications, conferences, and advocacy efforts. She emphasized enhancing member communication and involvement, expanding outreach to South and Central America, and establishing Community Advisory Boards. Focus areas for the future include the Bone Sarcoma Alliance and Adolescents and Young Adults (AYA). Schuster urged members to contribute to the 2024 Sarcoma Awareness Month focused on early diagnosis.

Treasurer Kai Pilgermann reported balanced finances with a solid reserve, mainly from partnerships, projects, and donations. The financial report, audited and approved, led to formal approval of the Board's work. Gerard van Oortmerssen was reelected Co-Chair and Cristina Baumgarten as Secretary. The meeting concluded with remarks from Chair Markus Wartenberg on April 21, 2024.

Photos: Uli Deck/ARTIS

Report: Gabriele Ott, Kathrin Schuster, Michi Geißler and Ivana Angelovska

Recordings of the sessions are available on the SPAGN YouTube channel. Visit **https://bit.ly/SPAGN2024videos** or scan the QR code to access the entire playlist.

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Thank You