



13th SPAGN ANNUAL CONFERENCE REPORT

Dublin, Ireland
May 11-13, 2023



For the first time ever, sarcoma patient advocates met face-to-face as a global network from 11-13 May 2023 in Dublin at the SPAGN 13th annual conference, Ireland, after having formalized the transition from a European to a global entity in 2022.

Now with about 60 member organizations, nearly 80 participants attended the 2023 SPAGN conference, with some traveling from as far as India, Japan, South Africa, and the United States of America.

Participants were welcomed by Sorrel Bickley on behalf of the SPAGN Board and the representatives of the Sarcoma Cancer Ireland as one of the newest members and the host country of the meeting. Ms. Bickley underlined that the meeting should provide an opportunity to share experiences, build and maintain relationships, and strengthen patient organizations. In addition to informing about medical updates, it is intended to serve as a source of inspiration and motivation for all. Finally, she expressed gratitude to the SPAGN sustaining partners for their support. ([Watch here.](#))



Experts' insights into sarcoma research updates

Once again, this year's conference provided an excellent platform for updating member organizations on developments in sarcoma research and practices in sarcoma treatments:



Bernadette Liegl-Atzwanger (Austria) shed light on the crucial work done in the background by **pathologists** to ensure correct sarcoma treatments. She also pointed to the challenge that the community of qualified sarcoma pathologists is getting smaller and smaller for a disease that has an incidence of less than 1 per 1 million people. She stressed that international collaboration among the sarcoma pathologist community is particularly important for small countries. ([Watch here.](#))



Stefan Fröhling (Germany) presented two examples of research programs, both aiming at providing better and tailored treatments by using **precision oncology**. The Molecularly Aided Stratification for Tumor Eradication ([MASTER](#)) program builds on a precision oncology network with more than 100 partners, while the [HEROES-AYA](#), with a multidisciplinary team of 14 experts, looks specifically at adolescents and young adults as a vulnerable and underserved patient population.



Subsequent discussions raised concerns as to whether genomic sequencing is applicable to sarcoma patients, as the expert community did not seem to be unanimous on this point, and the question was raised as to whether health insurance systems are paying for it. ([Watch here.](#))

Rob Horne (United Kingdom) asked “Have you taken your pill today?” and examined the challenges and causes of **non-adherence with oral therapies**. Non-adherence among cancer patients is quite prevalent, e.g., 30-35% of breast cancer patients.

Typically, patients start off at 100% compliance, but this percentage declines after a few months. An information-action gap was detected, meaning that information does not necessarily guarantee adherence.





Rob Horne identified two major reasons why people do not take their medicine:

- **They can't** (ability and practicalities)
- **They don't want to** (motivations and perceptions)

Many patients doubt their need, and real reasons are not communicated. Dr. Horne stressed that managing the tolerability of cancer treatments is essential. ([Watch here.](#))



Wolfgang Fendler (Germany) spoke on the topic of using **nuclear medicine** in diagnosis and therapies. He illustrated how Positron-Emission-Tomography (PET) can magnify one specific part of a CT, and thus be useful for the initial diagnosis of sarcoma. ([Watch here.](#))

A special session was dedicated to bone sarcomas. Members were informed that SPAGN is in the process of forming the Bone Sarcoma Alliance to bring together patients and advocates from different bone sarcoma communities, and that a kick-off meeting will take place shortly.



Three speakers provided information on research in osteosarcomas and Ewing sarcomas (**Emanuela Palmerini, Italy**), the European Osteosarcoma Survey (**Jazzmin Huber, United Kingdom**) and the specific challenges faced by Adolescents and Young Adults (**Winette van der Graaf, Netherlands**). ([Watch here.](#))



With respect to soft tissue sarcoma subtypes,

a panel of four high-level specialists presented the latest findings and promising studies that might change the standards of treatment. **Robin Jones (United Kingdom)** talked about several studies examining the role of chemotherapy in leiomyosarcomas. **Peter Reichardt (Germany)**

looked at ongoing trials for liposarcoma and found that the inhibition of MDM2 with two agents being studied was currently the most interesting.



[here.](#))

Bernd Kasper (Germany) presented a landmark trial that in his view would probably change the whole treatment of Desmoid tumors. **Jon Trent (USA)** talked about several sub-types of sarcomas in the context of precision oncology. A rather lively debate among the experts on trial designs illustrated for patient advocates that there is no truth cast in stone, even among the experts. ([Watch](#)

The patient in the room. Are we really listening?

The conference dedicated three sessions to the need to **involve patients in research.**

Winette van der Graaf (Netherlands) highlighted the value of patients' input in



sarcoma research and raised the provocative question as to whether researchers are truly answering the burning questions a sarcoma patient generally has: How long will I live? Are there treatments? What will my quality of life be like? There have been several papers and initiatives trying to address the question of what is truly meaningful to patients and how to include patient-reported outcomes in trials. But there are also challenges and limitations, for example instability of participation, limited number of cases because of the rare nature of the diseases, difficulty of measuring quality of life in such heterogenous diseases, etc. The subsequent discussion



raised even more issues, such as the need to apply language that is comprehensible and actionable for a layperson, the need for more intentional effort to bring patients on board, implications when a pharmaceutical company is running the trial, etc. ([Watch here.](#))

Markus Wartenberg (Germany) informed the participants about two recent initiatives to advance patient involvement in cancer research in Germany, after past initiatives had failed to really make progress in this field compared to other countries.



The first [initiative by Germany, Portugal and Slovenia looks at principles of successful patient involvement in cancer research.](#)

A second initiative is the establishment of [National Centers for Tumor Diseases \(NCT\)](#) in several locations in Germany, including patient-related research and patient involvement. Within this framework a [Patient Expert Academy \(PEAK\)](#) has been created which will focus on patients as research partners, the management structure and development of patient structures, evidence-based advocacy, and the co-shaping of digital health. ([Watch here.](#))

Silvia Stacchiotti (Italy), taking the example of Tenosynovial Giant Cell Tumors (TGCT), presented a joint patient-expert initiative that resulted in a consensus paper. The rarity and heterogeneity of TGCT poses challenges to the research design because data is limited, and randomization is not feasible. As a result, there are only few clinical studies and few approved drugs available. It was necessary to reach a consensus on and harmonize the clinical approach. ([Watch here.](#))





The multidisciplinary work on the TGCT consensus paper was launched in June 2022 after a literature review carried out in a multidisciplinary workshop organized by SPAGN in Frankfurt. and resulted in the publication of „[Best Clinical management of Tenosynovial Giant Cell Tumor: A consensus paper from the community of experts.](#)“

This paper was subsequently translated into a patient-friendly version by **Sydney Stern (USA)**, who shared her story at the conference as a TGCT patient and researcher. ([Watch here.](#))

The patient-friendly version of the consensus paper is available on the [TGCT Support website](#) and will soon be available in multiple languages.

The SPAGN Market Place Sessions

A series of rotating 25-minute sessions were held in which participants were able to choose three sessions to explore different topics. There were five booths in total.

This allowed participants to interact with one another in a more relaxed environment to exchange experiences, challenges and learn from each other.



Booth 1: How can patient advocacy groups support clinical trials?
Markus Wartenberg (Germany)

Booth 2: Patient involvement in HTA processes: The UK experience
Jayne Bressington (UK)

Booth 3: Working with social media
Cory Archibald (Kuwait/USA)



Booth 4: How is a scientific publication (abstract) structured and how is it created?
Bernd Kasper (Germany) and Roger Wilson (UK)

Booth 5: What to consider when working with pharmaceutical companies
Sara Rothschild (USA)



Working Session: Global Sarcoma Care Center Charter 2023

Roger Wilson (UK) and Kathrin Schuster (Germany) led a working group with all participants in discussion of minimum global standards for diagnosis, treatment, and care for specialized sarcoma centers.

During the session participants shared experiences and best practices from their home countries while notes were taken.





Awarding outstanding advocacy initiatives: Three prizewinners for the SPAGN Advocacy in Action Award



Three outstanding practices of patient advocacy received this year's awards. Winners were announced by [Ornella Gonzato \(Italy\)](#), Member of the SPAGN Board and sponsor of this year's awards.

[DigiSwasthya Foundation's \(India\)](#) project on telemedicine for cancer care in India received the first prize (€2,000).

This year, two 2nd prizes were awarded (€1,250 each): [Info Sarcomes \(France\)](#) was awarded the prize for its Sarcoma Symptoms Awareness Campaign, and [Fundación Mari Paz Jimenez Casado \(Spain\)](#) was recognized for its program for Scholarships/Aid for Training and Research in Sarcomas.

All of the finalists presented their programs at the conference, and the three winners were recognized at a special dinner celebration later that evening. ([Watch here.](#))

Congratulations to the three winners and to the many worthy projects submitted by our member community!





Networking and improving outreach – Agenda for the future (AGM)



Within the framework of the conference, SPAGN held its **Annual General Meeting (AGM)**.

The Chair of the SPAGN Board, **Markus Wartenberg (Germany)**, congratulated **Kathrin Schuster (Germany)** who took up the position of Executive Director of SPAGN in 2022, for the excellent work she has done so far.

He also welcomed **Cory Archibald (Kuwait/USA)** who joined the SPAGN team recently as the Communications Director.

He also thanked **Michi Geissler (Germany)** as the chief organizer of the conference.

Reviewing the past year's achievements, Mr. Wartenberg underlined the importance of SPAGN's collaborations and networking, such as the multi-stakeholder initiative to put rare cancers on the European policy agenda [Rare Cancers Europe](#) or the Workgroup of the [European Cancer Patient Advocacy Networks \(WECAN\)](#).

Subsequently, Executive Director Kathrin Schuster gave an account of the major work done in the past year and called upon members to promote the participation phase II of a [survey](#) to support sarcoma research, which is now available in 12 languages.

She also informed member organizations that SPAGN will place emphasis on increasing outreach to countries where sarcoma patient advocacy is missing in the future.





13th SPAGN ANNUAL CONFERENCE REPORT

Dublin, Ireland
May 11-13, 2023



During the AGM, a detailed financial overview, including income sources, operational expenditures, and project costs was provided for 2022.

The data affirms that SPAGN is a financially healthy organization which offers the opportunity to invest in new projects and/or human resources in the future.

The 2022 accounts were approved by the membership. Finally, members elected **Jürg Forster (Switzerland)** and **Kamil Dolecki (Poland)** as auditors for the next term.

Summary

All participants left the conference feeling energized by new possibilities for the work we can do together to benefit Sarcoma patients around the world. It was great to see the high level of commitment of every participant – whether they were a patient, a patient advocate, a clinical expert, or an industry representative – to take part in “Changing the World” and contributing their share to make a difference for the benefit of Sarcoma patients. Let’s keep going!

Recordings of the sessions are available on the SPAGN YouTube channel. Visit bit.ly/SPAGN23playlist or scan the QR code below to access the entire playlist.



Authors: Gabi Ott, Cory Archibald