



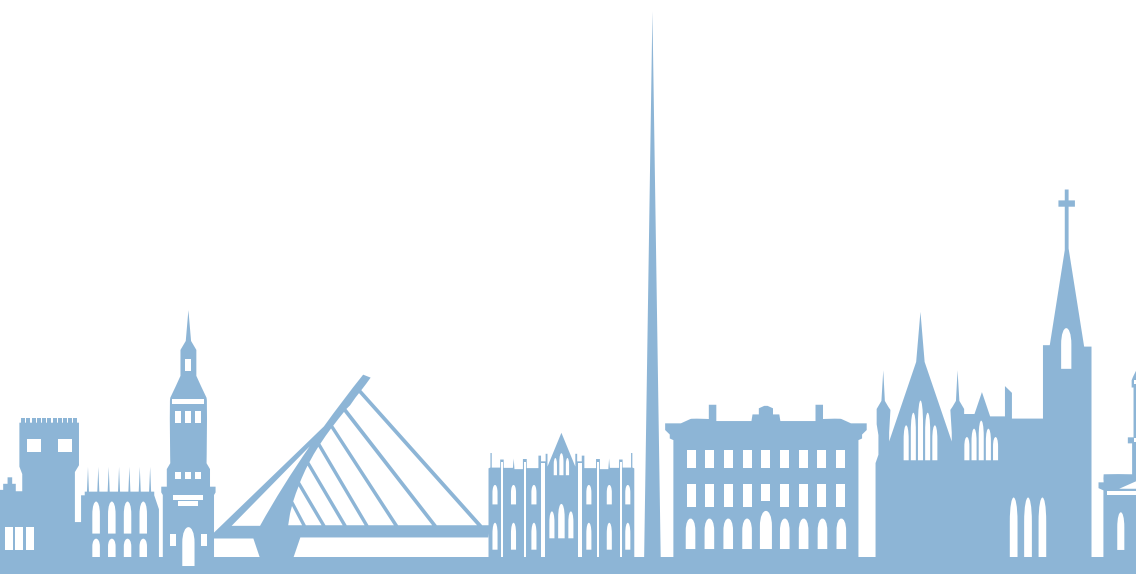
**Sarcoma
Patient Advocacy
Global Network**

Working together, making a difference.

**13th SPAGN
Annual Conference**

**May 11-13, 2023
Dublin, Ireland**

CONFERENCE PROGRAMME



PROGRAMME

Crowne Plaza Dublin
Blanchardstown
Blanchardstown Town Centre,
Dublin, Ireland

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 <i>Sorrel Bickley on behalf of the SPAGN Board of Directors</i>
12:45 (45)	<i>Chair: Gerard van Oortmerssen, Netherlands</i> What are the main tasks of pathologists in sarcoma today? From finding the correct diagnosis (sarcoma subtype) to molecular characterization <i>Bernadette Liegl-Atzwanger, Austria</i>
13:30 (60)	<i>Chair: Markus Wartenberg, Germany</i> We need more and better research in sarcomas. Learn about two examples of systematic programs <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 mins) Treatment resistance is a key problem in the treatment of cancer. The new national funded research project HEROES-AYA aims to discover how the molecular heterogeneity of sarcomas leads to treatment resistance in adolescents and young adults. (20 mins) <i>Stefan Fröhling, Germany</i>
14:30 – 15:00	C O F F E E B R E A K (30 mins)
15:00 (60)	<i>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>
16:00 (60)	<i>Chair: Vandana Gupta, India</i> Sharing Best Practice in Patient Support or Patient Advocacy. Selected abstracts/projects 10 minutes presentation time plus 5 minutes questions and discussion
17:00 – 17:15	S H O R T B R E A K (15 mins)
17:15 (max. 75)	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 “Get Together” (drinks & snacks) Award ceremony “Advocacy in Action Award 2022/23”



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DAY 2 – FRIDAY May 12, 2023

From 08:00	Breakfast: Meet Your Peers (...on a voluntary basis...) Breakfast tables according to subtypes: Soft Tissue Sarcomas, Bone Sarcomas, GIST, Desmoids
09:00	Welcome to Day 2
09:00	<i>Chair – Moderator: Roger Wilson, UK</i>
(60)	Keynote: The patient in the room. Do we really listen? (20 mins) <i>Winette van der Graaf, Netherlands</i> The patient / patient advocate perspective (10 mins) <i>Speaker: Roger Wilson, UK</i> Auditorium: Questions, Exchange of Experiences, Suggestions (30 mins)
10:00 – 10:30	C O F F E E B R E A K (30 mins)
10:30	<i>Chair: Ornella Gonzato, IT</i>
(90)	Bone Sarcomas: Focus on developments and special topics <ul style="list-style-type: none"> • AYAs (Adolescents and Young Adults) with sarcomas: An underserved community: Challenges and solutions (30 mins) <i>Winette van der Graaf, Netherlands</i> • Important research updates for Osteosarcomas and Ewing Sarcomas (30 mins) <i>Emanuela Palmerini, IT</i> • FOSTER (Fight Osteosarcoma Through European Research) Project and early results of an osteosarcoma survey (15 mins) <i>Jazzmin Huber, UK</i>
12:00 – 13:30	L U N C H and N E T W O R K I N G (90 mins)
13:30	Patient Involvement in Cancer Research
(45)	<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>
14:15	<i>Chair: Markus Wartenberg, Germany</i>
(60)	Diagnosis and therapy of cancer diseases by nuclear medicine. The role of nuclear medicine in sarcomas. <i>Wolfgang Fendler, Clinic for Nuclear Medicine, Germany</i>
15:15 – 15:45	C O F F E E B R E A K (30 mins)
15:45	The SPAGN “Market Place Sessions”:
(90)	Choose your 3 favourite sessions from 5 offers (market booths) (Each session = 25 mins, then 5 mins break to change tables) Booth 1: How can patient advocacy groups support clinical trials? <i>Estelle Artzner, FR</i> Booth 2: Patient involvement in HTA processes: The UK-experience <i>Jayne Bressington, UK</i> Booth 3: Working with social media <i>Cory Archibald, SPAGN</i> Booth 4: How is a scientific publication (abstract) structured and how is it created <i>Bernd Kasper, Germany and Roger Wilson, UK</i> Booth 5: What to consider when working with pharmaceutical companies <i>Sara Rothschild, USA</i>
17:15	B R E A K B E F O R E D I N N E R
19:30	External Dinner



DAY 3 – SATURDAY May 13, 2023

07:30 (45)

Early Breakfast Session (...on a voluntary basis...)

Chair: Markus Wartenberg, Germany

**Insights into a clinical trial center: What does it mean to plan, to organize, to conduct and to evaluate clinical trials in GIST/sarcoma?
What are the challenges in offering clinical trials today?**

Dr. Annette Reichardt answers YOUR questions.

Annette Reichardt is head of the study center at the Helios Clinic Berlin-Buch, a leading Sarcoma Center in Germany.

08:30

Welcome to Day 3

08:30

Chair: Kathrin Schuster, SPAGN

(45)

Tenosynovial giant cell tumor (TGCT):

Brief introduction to the disease TGCT/PVNS (10 mins)

Sydney Stern, USA

The TGCT Consensus Paper: A joint patient-expert initiative (25 mins)

Silvia Stacchiotti, IT

09:15

Moderator: Roger Wilson, UK, Chair: Kathrin Schuster, SPAGN

(60)

Working Session “Global Sarcoma Care Charter 2023”:

Minimum global standards for diagnosis, treatment and care in sarcomas.

Discussion

10:15 – 10:45

COFFEE BREAK (30 mins)

10:45

Chair: Sorrel Bickley, UK

(120)

The research forum for soft tissue sarcoma subtypes:

Latest findings or promising studies that might change the standards of treatment.

Jon Trent, Peter Reichardt, Robin Jones, Bernd Kasper

- Leiomyosarcomas
- Liposarcomas
- Desmoids
- Other selected subtypes (e.g., synovial, EHE, pecoma)

12:45

Closing Remarks – Farewell – End of Meeting

SPAGN Board of Directors

13:00 – 14:00

LUNCH and NETWORKING (90 mins)

14:00

Start of “New Horizons GIST”

SPAGN Sustaining Partners/Corporate Members



Bayer HealthCare



Boehringer
Ingelheim



Daiichi-Sankyo



IDRx



NOVARTIS



NEW HORIZONS GIST

MAY 13-14, 2023 – DUBLIN, IRELAND



**The NEW HORIZONS GIST Patient Advocacy Roundtable:
Improving access to treatment and quality of care
through global exchange**

Conference Programme

NEW HORIZONS GIST

MAY 13-14, 2023 – DUBLIN, IRELAND



PROGRAMME

Crowne Plaza Dublin
Blanchardstown
Blanchardstown Town Centre,
Dublin, Ireland

SATURDAY May 13, 2023

14:00 (15)	Opening & Welcome <i>NH GIST Steering Committee</i>
14:15 – 16:00 (105)	HYBRID <i>Session Chairs: Martin Wettstein & Piga Fernandez</i> How to treat GIST (Gastrointestinal Stromal Tumors) qualified today? The previous therapy algorithms: overview and changes/innovations <ul style="list-style-type: none">• The localized disease• The metastatic disease• The progressive disease <i>Robin Jones, UK</i>
16:00 – 16:30	COFFEE BREAK (30 mins)
16:30 – 18:15 (105)	HYBRID <i>Session Chairs: Sara Rothschild & Ginger Sawyer</i> Scientific evidence and expert evidence (= practical clinical experience) with the two latest approved GIST therapies: <ul style="list-style-type: none">• Fourth line: Ripretinib (Qinlock®)• For GIST Exon D842V: Avapritinib (Ayvakit® / Ayvakyt®) <i>Jon Trent, USA</i>
18:15 – 19:30	BREAK BEFORE DINNER (90 mins)
19:30	Onsite: Conference Dinner (external dinner)

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NEW HORIZONS GIST

MAY 13-14, 2023 – DUBLIN, IRELAND



SUNDAY May 14, 2023

10:00 – 12:30

(150)

incl. break (15)

Working Group

HYBRID

Session Chairs: David Josephy & Markus Wartenberg

GIST patients urgently need innovations and improvements for survival and better quality of life. What are the top research questions/priorities from the patient perspective? Let's identify and prioritize unanswered questions or evidence uncertainties in GIST!

A two-step process:

Phase 1: Before the conference, we will collect research questions and priorities from the global GIST patient advocacy community.

Phase 2: During the conference we will discuss a list of the most frequently mentioned topics with each other and with leading GIST-Experts.

Our goal: A 10-point list with the main research questions/priorities from the perspective of GIST patients.

(Mid-term-goal: A joint publication)

GIST-Experts onsite and online:

Peter Reichardt, Germany, Robin Jones, UK, Jon Trent, USA, Marco Baia, IT

12:30 – 13:30

L U N C H (60 mins)

13:30 – 15:15

(105)

HYBRID

Session Chairs: Jayne Bressington & Gerard van Oortmerssen

Right from the start, GISTs were one of the first cancer diseases for “precision oncology”. That means: The right therapy for specific mutations/target structures. One challenge today are rare and very rare GIST subtypes (e.g. rare exon mutations and non-KIT/-PDGFRA GIST).

• **General overview of rare and very rare GISTs -biology, genetics and profiles of the individual subtypes**

PatholoGIST: Florian Haller, Germany

• **How to treat rare GIST-subtypes – scientific & expert evidence**

OncoloGIST: Ramesh Bulusu, UK

• **Patients and experts are working closely together in rare GIST subtypes: The UK-experience**

Jayne Bressington, UK

• **Patients and experts are working closely together in rare GIST subtypes: The US-experience**

John Glod, USA

15:15 – 15:45

C O F F E E B R E A K (30 mins)



NEW HORIZONS GIST

MAY 13-14, 2023 – DUBLIN, IRELAND



SUNDAY May 14, 2023 *continued*

15:45 – 17:30

(105)

HYBRID

Chairs: David Josephy & Markus Wartenberg

Part A:

Where does the GIST research journey currently take us?

What's happening...

- in basic research (incl. ctDNA)
- in clinical research / in clinical studies

Cesar Serrano, ES

Questions/comments from the audience and from the virtual meeting room

Part B:

Morning results of this conference:

Findings from a survey among the global GIST patient advocacy community and from a workshop today with leading GIST-Experts:

A 10-point list with the main research questions/priorities from the perspective of GIST patients

David Josephy & Markus Wartenberg

Questions/comments from the audience and from the virtual meeting room...

17:30

Wrap Up & Farewell - OFFICIAL END OF THE CONFERENCE



Sponsors of the New Horizons GIST conference 2023

