



Sarcoma
Patients
EuroNet

10th SPAEN Annual Conference for Organizations
Representing Patients with Sarcomas, GIST or Desmoid-Tumours
31st of Jan. – 2nd of Feb., 2020
Marriott Hotel, Milan/Italy

Connected to the “ESMO Sarcoma and GIST Symposium”, 3 – 5 February 2020 in Milan/Italy

Preliminary PROGRAMME (Status: 22.10.2019)

DAY 1 – FRIDAY January 31st 2020	
17:00	Opening of the Registration Desk
19:00	Italian Get Together (Room: tbc)
DAY 2 – SATURDAY February 1st 2020	
08:30	OFFICIAL START OF THE CONFERENCE
08:30 (30)	<p>Welcome to Milan/Italy on behalf of the SPAEN Board, the Italian Sarcoma Patient Community and ESMO.</p> <p><i>Markus Wartenberg (DE), Ornella Gonzato (IT) and Chair of the ESMO Symposium (P. Casali conf, P. Dei Tos or J.Y. Blay)</i></p>
09:00 (90)	<p>Chair: SPAEN Board Member</p> <p>Sarcoma Treatment in the age of “Precision Oncology or Precision Medicine”</p> <p>Understanding the Concept of “Precision Oncology” in a patient-friendly language (25) <i>Speaker: Sonja Loges (DE)</i></p> <p>Where are we in Sarcomas? Whole genome sequencing of sarcomas? Why do it? What are we learning? Can we really make a difference? (25) <i>Speaker: Adrienne Flanagan (UK)</i></p> <p>Precision Oncology: Chances & Challenges from the Patients and the Patient Advocacy Perspective (25) <i>Speaker: Markus Wartenberg (DE)</i></p> <p>Discussion (15)</p>
10:30 – 11:00 COFFEE BREAK (30 min.)	
11:00 (75)	<p>Chair: Board Member</p> <p>News/Developments/Updates from the International Sarcoma Community:</p> <p>Introducing the “US Sarcoma Coalition” <i>Speaker: Denise Reinke (US) conf</i></p> <p>The SELNET Project: Sarcoma as a model to improve diagnosis and clinical care of rare tumours through a European and Latin American multidisciplinary network <i>Speaker: Nadja Hindi (ESP) + Olga De La Laana (ESP)</i></p> <p>Quality of Life Update <i>Speaker: Rachel Taylor (UK) conf + Olga Husson (NL) conf</i></p>

<p>12:15 (75)</p>	<p>Chair/Moderator: Amy-Bruno Lindner (AT)</p> <p>How can we improve the way we communicate with our patients? Improving Patient Advocate-Patient Communication: Techniques for Sharing Information <i>Speaker: Amy-Bruno Lindner (AT) confirmed</i></p> <p>How to run an effective and supportive "helpline" for patients? The UK Experience <i>Speaker: (Sarcoma UK)</i></p>
<p>13:30 – 14:30 LUNCH and NETWORKING (60 min.)</p>	
<p>14:30 (90)</p>	<p>MARKET PLACE SESSION – CAPACITY BUILDING</p> <p>Three cycles / rounds a 25 mins. In between 5 mins break for the changing the booth...</p> <ul style="list-style-type: none"> • Booth 1: Finding, managing and motivating volunteers <i>Host/Presenter: Vandana Gupta (IND)</i> • Booth 2: Organising successful patient meetings <i>Host/Presenter: Michi Geissler (DE)</i> • Booth 3: Value assessment for better patient-doctor-communication <i>Host/Presenter: Gerard van Oortmerssen (NL)</i> • Booth 4: Future-proofing your organisation <i>Host/Presenter: Markus Wartenberg (DE)</i> • Booth 5: How to read an interpret scientific data <i>Host/Presenter: Roger Wilson (UK) & Bernd Kasper (DE)</i>
<p>16:00 – 16:30 COFFEE BREAK (30 min.)</p>	
<p>16:30 (90)</p>	<p>Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2019/2020</p> <p>All Conference Participants are welcome! (Rights for SPAEN Members only...)</p> <p>This session has an official invitation / agenda – important topics are:</p> <ul style="list-style-type: none"> • Report of the Board of Directors (2019) • Financial Report (2019) • Elections • Outlook 2020 and beyond <p><i>SPAEN Board</i></p>
<p>18:00 BREAK BEFORE DINNER</p>	
<p>19:30</p>	<p>Internal Dinner</p> <p>Including Award ceremony "Sarcoma Action Award 2019"</p>

DAY 2 – SUNDAY February 2nd 2020

07:30 (50)	EARLY Breakfast Session: Sharing Practical Experiences... (For whom it applies and who is interested...) Standards of Excellence for Patient Organizations Setting the Scene (15) <i>Markus Wartenberg (DE)</i> The South African Experience (25) <i>Lauren Pretorius (ZA) conf</i> Questions (10)		
08:30 (60)	Chair: SPAEN Board Member Key Note Lecture: What is the status of sarcoma research so far and what needs to be changed in the future from an expert perspective? <i>Speaker: Robert G. Maki (Northwell Health Cancer Institute, US) confirmed</i>		
09:30 (60)	Chair: SPAEN Board Member First Key Findings from the “Intl. Sarcoma Priority Setting Partnership Survey” <i>Speaker-Team: Olga Husson conf, Kathrin Schuster, Gerard van Oortmerssen</i>		
10:30 – 11:00 C O F F E E B R E A K (30 min.)			
	GIST-Track Chairs: 2 SPAEN Board Members	Sarcoma-Track Chairs: 2 SPAEN Board Members	Desmoide-Track Chairs: 2 SPAEN Board Members
11:00 (75)	<i>Improving the outcome of GIST-treatment: 6 case stories - presented by intl. GIST-experts: Peter Reichardt (DE) conf Stefan Sleijfer (NL) N.N.</i>	Profiles of Sarcoma Subtypes: <u>Chondrosarcoma (30)</u> <i>Jeremy Whelan (UK)</i> WSN: Sarcoma of the Year 2019: <u>DSRCT Desmoplastic Small Round Cell Tumour</u> <i>Jean Yves Blay (FR)</i>	In patient friendly language: Understanding the biology of Desmoids. Are we talking about one disease or different types of desmoids? <i>Eva Wardelmann (DE) conf</i>
12:15 (60)	Research-Forum GIST Update on new targets /agents / ongoing / upcoming clinical trials in GIST <i>Sebastian Bauer (DE) Jonathan Trent (US)</i>	Research-Forum Soft Tissue Sarcomas Update on new agents / ongoing/upcoming clinical trials in STS <i>Bernd Kasper (DE) conf</i>	Radiotherapy in Desmoids: - Potential Use - Operational Process - Side Effects Practice > Case Stories <i>Rick L. Haas (NL) conf</i>
13:15 – 14:15 L U N C H and NETWORKING (60 min.)			
14:15 (45)	In patient friendly language: Understanding the biology, genetics and process of mutational analysis in GIST <i>Paolo Dei Tos (IT)</i>	<u>Summaries from intl. roundtables and projects:</u> The NLMSF Intl. LMS Research Roundtable (Leiomyosarcomas) Sept. 2019 in Miami/FL <i>Annie Achee (US), expert TBC</i> Drug development in paediatric oncology: Fostering Age Inclusive Research (FAIR) Trials <i>Chris Copland (UK)</i>	Therapy- and Side Effect Mgmt. of Targeted Therapies such as Imatinib or Sorafenib... - The Expert Experience <i>Bernd Kasper (DE) conf</i> - The Patient Advocacy Experience from other diseases <i>Markus Wartenberg (DE)</i>
15:00 (60)	Using “Social Media” in Sarcomas – Panel Discussion: Moderator: <i>Kathrin Schuster (DE)</i> Panellists: <i>Jonathan Trent (US), Winette van der Graaf (NL) Italian Desmoid Group, Annika Laakso (FIN)</i>		
16:00	Closing Remarks – End of Meeting SPAEN Board		

16:30 (90)	<p>Additional session - on a voluntary basis</p> <p>Roundtable: Ethics in Research – the patient approach</p> <p>Moderator: Roger Wilson (UK)</p> <p>14 Panellists: Ian Judson (UK), George Demetri (US), Peter Hohenberger (DE), Winette van der Graaf, Paolo Casali (IT), Peter Reichardt (DE) conf</p> <p>Zoltan Kalo (HUN), Gerard van Oortmerssen (NL), Sarah McDonald (UK), Lotta Vade (NOR), Vandana Gupta (IND), Markus Wartenberg (DE) Ornella Gonzato (IT)</p>
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MONDAY February 3rd 2020

	<p>Depending on individual planning:</p> <ul style="list-style-type: none"> - Departure or Participation at the ESMO Training Sessions (Beginners and Advanced) Access the online programme here <p>ESMO Preceptorship Course on Sarcoma & GIST (Beginners) One-day meeting designed to provide young oncologists with a brief outline of both STS & GIST. It could be a first contact with these diseases for oncologists who are interested to know more about them and to have an introduction to the high-profile Conference in the two days afterwards.</p> <p>or parallel</p> <p>ESMO Advanced Course on Sarcoma & GIST One-day event offering an intensive discussion of a set of clinical cases of STS & GIST for professionals who are already familiar with these diseases. Attendees will benefit from discussions about challenging clinical cases with specialists from both the EU and USA, leveraging the different perspectives and expertise across continents. This course is the ideal preparation for clinicians joining the Sarcoma & GIST Conference, 4-5 February.</p>
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TUESDAY/WEDNESDAY February 4th – 5th 2020

	<p>ESMO Sarcoma & GIST Symposium 2020</p> <p>The goal is to merge the clinical and the translational perspectives into a single high-profile educational event. It is a unique opportunity in rare cancers such as STS & GIST. The Conference is known as an excellent place for international networking and collaboration, featuring discussions with the key opinion leaders in the field.</p> <p>Though it will be deeply and convincingly multidisciplinary as all previous editions, the 2020 program will look at the disciplines, one by one. The challenge, in fact, will be to do so with a multidisciplinary attitude and preserving the biological/clinical integration which marks this event. A world-renowned faculty will attract an audience of experts in sarcomas, but will also teach a lot to oncologists mainly dealing with more frequent conditions while also treating sarcomas within collaborative networks.</p> <p>Access the programme as PDF here</p> <p>Access the online programme here</p>
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