



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

PROGRAMME

DAY 1 – FRIDAY January 31st 2020	
17:00	<i>Opening of the Registration Desk</i>
19:00	<i>Italian Get Together (La Brasserie)</i>
DAY 2 – SATURDAY February 1st 2020	
08:30	OFFICIAL START OF THE CONFERENCE (Room Foscolo)
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 Paolo Casali (IT) Chair of the ESMO Symposium</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>Short introduction to the Concept of “Precision Oncology” Where are we in Sarcomas? Whole genome sequencing of sarcomas? Why do it? What are we learning? Can we really make a difference? (45) <i>Adrienne Flanagan (UK)</i></p> <p>Precision Oncology: Chances & Challenges from the Patients and the Patient Advocacy Perspective (30) <i>Markus Wartenberg (DE)</i></p> <p>Discussion (15)</p>
10:30 – 11:00 C O F F E E B R E A K in GAZEBO (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” (25) <i>Denise Reinke (US)</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 (25) <i>Nadja Hindi (ESP) + Piga Fernandez (CHILE)</i></p> <p>Quality of Life Update (25) <i>Lesley Storey (UK) + Olga Husson & Dide den Hollander (NL)</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 (30) <i>Amy-Bruno Lindner (AT)</i></p> <p>How to run an effective and supportive “helpline” for patients? The UK Experience (30) <i>Helen Stradling (Sarcoma UK)</i></p>
<p>13:30 – 14:30 L U N C H and NETWORKING in GAZEBO (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) conf</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 C O F F E E B R E A K in GAZEBO (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 B R E A K B E F O R E D I N N E R</p>	
<p>19:30</p>	<p>Internal Dinner (Room “Le Baron2”)</p> <p>Including Award ceremony " Advocacy in 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)</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>Robert G. Maki (Northwell Health Cancer Institute, US)</i>		
09:30 (60)	Chair: SPAEN Board Member First Key Findings from the “Intl. Sarcoma Priority Setting Partnership Survey” <i>Olga Husson & Marije Weidema, Kathrin Schuster, Gerard van Oortmerssen</i>		
10:30 – 11:00 C O F F E E B R E A K in GAZEBO (30 min.)			
	GIST-Track (Room Foscolo) Chairs: 2 SPAEN Board Members	Sarcoma-Track (Room Porta) Chairs: 2 SPAEN Board Members	Desmoide-Track (Room Parini) Chairs: 2 SPAEN Board Members
11:00 (75)	<i>Improving the outcome of GIST-treatment: 6 case stories - presented by intl. GIST-experts:</i> <i>Peter Reichardt (DE)</i> <i>Alessandro Gronchi (IT)</i> <i>Mikael Eriksson (SWE)</i>	Profiles of Sarcoma Subtypes: <u>Chondrosarcoma (30)</u> <i>Kenneth Rankin (UK)</i> WSN: Sarcoma of the Year 2019: DSRCT Desmoplastic Small Round Cell Tumour <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)</i>
12:15 (60)	Research-Forum GIST Update on new targets /agents / ongoing / upcoming clinical trials in GIST <i>Sebastian Bauer (DE)</i> <i>Jonathan Trent (US)</i>	Research-Forum Soft Tissue Sarcomas Update on new agents / ongoing/upcoming clinical trials in STS <i>Bernd Kasper (DE)</i>	Radiotherapy in Desmoids: - Potential Use - Operational Process - Side Effects Practice > Case Stories <i>Rick L. Haas (NL)</i>
13:15 – 14:15 L U N C H and NETWORKING in GAZEBO (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>	Summaries from intl. roundtables and projects: The NLMSF Intl. LMS Research Roundtable (Leiomyosarcomas) Sept. 2019 in Miami/FL <i>Annie Achee (US)</i> <i>Scott Okuno (US)</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)</i> - The Patient Advocacy Experience from other diseases <i>Markus Wartenberg (DE)</i> <i>Christina Baumgarten (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)</i> <i>Italian Desmoid Group, Annika Laakso (FIN)</i>		
16:00	Closing Remarks – End of Meeting <i>SPAEN Board</i>		

16:30 (90)	<p>Chordoma Foundation Europe/Patientenplattform Sarcomen & SPAEN invite to an informal meeting:</p> <p>Bone tumour patient advocacy - synergy through cooperation</p> <p>Everybody, who has an interest is welcome to attend – patient advocates and experts</p>
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MONDAY - WEDNESDAY February 3rd – 5th 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>Preceptorship Course on Sarcoma & GIST (Beginners): 9:00 – 13:30 Le Club Room Half-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>Advanced Course on Sarcoma & GIST: 8:30 – 13:30 Room Washington A Half-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 ESMO Sarcoma & GIST Symposium 3-5 February.</p> <p>14:15 Official start of ESMO Sarcoma & GIST Symposium 2020 Room Washington</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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