

**9th SPAEN Annual Conference for Organizations
Representing Patients with Sarcomas, GIST or Desmoid-Tumours
1 – 3 February, 2019
Radisson Blu Park Hotel, Athens/Greece**



**Sarcoma
Patients
EuroNet**

Supported by:
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PROGRAMME

DAY 1 – FRIDAY February 1, 2019			
09:00	<i>Opening of the Registration Desk</i>		
11:30	<i>Lunch buffet (hotel restaurant "Gallo Nero")</i>		
12:30 OFFICIAL START OF THE CONFERENCE – Room Green Garden			
12:30 – 13:00 (30)	<p>Welcome to Athens/Greece on behalf of the SPAEN Board and the Greek Sarcoma Expert Community <i>Speaker: Markus Wartenberg (DE) & Dr. Vasilis Ramfidis, GRE</i> <i>My story of courage & hope - Nikhil Guhagarkar (IND) (5 Min.)</i></p>		
13:00 – 14:30 (90)	<p>Chair: Kai Pilgermann, DE</p> <ul style="list-style-type: none"> • Understanding the biology and genetics in Sarcomas/GIST • Metastases in cancer (in Sarcomas/GIST) and why/how/where they arise • The role of pathologists in Sarcomas/GIST <p><i>Speaker: Dr. Bernadette Liegl-Atzwanger, AT Prof. Dr. Eva Wardelmann, DE</i></p>		
14:30 – 15:00 COFFEE BREAK (30 min.)			
15:00 – 16:00 (60)	<table border="0" style="width: 100%;"> <tr> <td style="width: 50%; background-color: #D9E1F2;"> <p>BEGINNER Clinical Trials 101: A basic introduction to Clinical Trials and Good Clinical Practice (GCP)... <i>Speaker: Prof. Dr. Bernd Kasper, DE</i></p> </td> <td style="width: 50%; background-color: #D9E1F2;"> <p>EXPERIENCED Clinical Trials 101: For Non-Statisticians: Understanding statistics in Sarcoma Clinical Trials... <i>Speaker: Catherine Fortpied, EORTC, BE</i></p> </td> </tr> </table>	<p>BEGINNER Clinical Trials 101: A basic introduction to Clinical Trials and Good Clinical Practice (GCP)... <i>Speaker: Prof. Dr. Bernd Kasper, DE</i></p>	<p>EXPERIENCED Clinical Trials 101: For Non-Statisticians: Understanding statistics in Sarcoma Clinical Trials... <i>Speaker: Catherine Fortpied, EORTC, BE</i></p>
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16:00 CHANGING THE ROOMS (15 Min.)			
16:15 – 16:45 (30)	<p>Chair: Roger Wilson, UK</p> <p>Quality of Life: Listening to the patients... <i>Speaker: Dr. Ana Martins, UCL, UK</i></p>		
16:45 – 18:00 (75)	<p>Chair: Roger Wilson, UK</p> <p>What makes a good Clinical Trial? <i>Important factors for designing and conducting a CT? Accessing CT across borders? Experiences: What worked well and what did not work? Information and Communication? What are innovative/provocative ideas for the future of CT? etc.</i> <i>Panel Discussion: Bernd Kasper, DE - Olivier Mir, FR – Catherine Fortpied, EORTC, BE – Jeremy Whelan, UK</i></p>		
18:00 BREAK BEFORE DINNER			
19:30	<p>Internal Dinner (hotel restaurant: "St' Astra Rooftop") Including Award ceremony "SPAEN Advocacy in Action Award"</p>		

DAY 2 – SATURDAY February 2, 2019

08:30 (5)	GIST-Track (Room Green Garden) Chairs: K. Pilgermann (DE) and N. Guhagarkar (IND) <i>My story of courage & hope – Kai Pilgermann, DE (5 Min.)</i>	Sarcoma-Track (Room Atlantis A) Chair: Markus Wartenberg (DE) <i>My story of courage & hope – Sami Sandakly, FR (5 Min.)</i>	Desmoid –Track (Room Atlantis B) Chair: C. Baumgarten (DE) Introduction of the different Desmoid groups (30 min.)
08:35 (55)	1998: More than 20 years of GIST as a separate diagnosis / disease: Developments and treatments: Past – Present – Future... <i>tbd</i>	An update on Bone Sarcomas: <ul style="list-style-type: none"> • Introduction/Overview • Standard Treatments • Outlook: Promising research paths • <i>Prof. Dr. Jeremy Whelan, UK</i> 	Current status of our Desmoid Paper (60 min.) <i>Prof. Bernd Kasper, DE Prof. Peter Hohenberger, DE</i>
09:30 (60)	Research-Forum GIST: Update on new agents / ongoing / upcoming clinical trials in GIST <i>PD Dr. Peter Reichardt, DE</i>	Research-Forum Soft Tissue Sarcomas: Update on new agents / ongoing/upcoming clinical trials in STS <i>Dr. Robin Jones, UK</i>	Low dose chemotherapy: experience in sporadic and FAP- related desmoid tumors (30 min.) <i>Elena Palassini, IT</i>
10:30 – 11:00 C O F F E E B R E A K (30 min.)			
11:00 (60)	GIST Case Discussion: Examples of three long-term cases – by getting the best out of the available treatment options <i>PD Dr. Peter Reichardt, DE.</i>	Soft Tissue Sarcoma Case Discussion: Two cases/stories per expert (30 min. each) <i>Prof. Dr. Bernd Kasper, DE Prof. Dr. Mikael Eriksson, SWE Prof. Dr. Olivier Mir, FR</i>	An update on cryoablation and other French trials and projects for DT (30 min.) <i>Prof. Jean-Emmanuel Kurtz, FR</i> Quality of Life (30 min.) <i>M.J.M. Timbergen, NL</i>
12:00 (60)	Following the different stages of GIST: Discussing and completing a practical checklist for patients (and doctors)... <i>(Basis: Working doc. before the conference!)</i> <i>PD Dr. Peter Reichardt, DE</i>	Examples of tissue banks in Sarcomas: VORTEX: An UK-experience (30 Min) <i>Prof. Dr. Catharine West, UK.</i>	“Can wait and see be the standard of care for initial approach to primary sporadic desmoid tumors?” (30 min.) <i>Chiara Colombo, IT</i> Brainstorming: Future Projects and open questions (30 min.)
13:00 – 14:00 L I G H T L U N C H and NETWORKING (hotel restaurant “Gallo Nero”).			
14:00 (60)	Chair: <i>Jessica Garcia, ESP</i> Opportunities and innovations for local interventions <i>Speaker: Prof. Dr. Peter Hohenberger, DE</i>		
15:00 (75)	Chair: <i>Gerard van Oortmerssen, NL</i> Role of radiotherapy in Sarcomas, GIST and Desmoide-Tumours <ul style="list-style-type: none"> • Proton beam technology <i>Prof. Dr. Beate Timmermann, DE</i> • Radiotherapy for soft tissue sarcomas; where do we stand in 10 years from now? <i>Dr. Rick Haas, NL</i> 		
16:15 – 16:45 C O F F E E B R E A K (30 min.)			

16:45 (90)	MARKET PLACE SESSION – CAPACITY BUILDING Three cycles / rounds a 25 mins. In between 5 mins break for the changing the booth... <ul style="list-style-type: none"> • Topic 1: Working with pharma industry <i>Host/Presenter: Markus Wartenberg (DE)</i> • Topic 2: Patient Groups & Data Opportunities <i>Host/Presenter: Gerard van Oortmerssen (NL)</i> • Topic 3: Social Media Tools: An overview <i>Host/Presenter: Kathrin Schuster (DE)</i> • Topic 4: Setting up and running a Sarcoma helpline <i>Host/Presenter: Helen Stradling (UK)</i> • Topic 5: How can patient advocacy groups support clinical trials <i>Host/Presenter: Roger Wilson (UK)</i>
18:15	<i>BREAK BEFORE DINNER</i>
19:30	External Dinner (in walking distance)

DAY 3 – SUNDAY February 3, 2019

08:00 – 09:30 (90)	Sarcoma Patients EuroNet Assoc. GENERAL ASSEMBLY 2018/2019 All Conference Participants are welcome! (Voting Rights for SPAEN Members only...) This session has an official invitation / agenda – important topics are: <ul style="list-style-type: none"> • Report of the Board of Directors (2018) • Financial Report (2018) • Outlook 2019 and beyond <i>SPAEN Board</i>
09:30 – 10:00	<i>COFFEE BREAK (30 min.)</i>
10:00 – 10:45 (45)	Chair: Markus Wartenberg Overview: How is the international Sarcoma/GIST Expert Community organized? Initiatives – Networks/Working Groups – Conferences – EU Activities <i>Speaker: Prof. Dr. Peter Hohenberger, DE and Prof. Dr. Paolo Casali, IT tbc.</i>
10:45 – 12:00 (75)	Chair: SPAEN Board Member EXPERT-PANEL: SPAEN-FORUM for better quality and better organisational factors in diagnosis, treatment and follow up of for sarcomas Plenary Bursts: <ul style="list-style-type: none"> • Treatment in specialized centres vs. non-specialized centres, <i>Prof. Dr. Paolo Casali, IT tbc.</i> • Sarcomas between different disciplines (interfaces, role of MDTs) e.g. • Skin Sarcomas and Gynae Sarcomas, <i>Prof. Dr. Peter Hohenberger, DE</i> • Comorbidities, multiple diseases, <i>Prof. Mikael Eriksson, SWE</i> Discussion & Exchange
12:00 – 13:00 (60)	Chairs: Roger Wilson & Markus Wartenberg, SPAEN Brainstorming >>> Let's think forward: What are ideas / activities / projects to support our patients at the end of the day? <ul style="list-style-type: none"> - By improving the “sarcoma landscape”, - by doing research in a different more patient-led way, - by working closer with our expert colleagues together, - by better supporting one another (the member organisations)?
13:00	Closing Remarks – End of Meeting <i>SPAEN Board</i>
13:15– 14:15	<i>LIGHT LUNCH</i>