

**11<sup>th</sup> SPAEN Annual Conference for Organizations  
Representing Patients with Sarcomas, GIST and Desmoids  
22-24 April 2021 – Virtual Meeting**

The meeting will be held live and online via Zoom.  
Zoom-Link: <https://zoom.us/j/94014588224>

**Global Conference-Timing (for some selected locations) – please check your individual time zone:**

- **08:00** New York / Toronto EST
- **13:00** London
- **17:30** Mumbai
- **09:00** Santiago de Chile
- **14:00** Berlin CEST
- **21:00** Tokyo

## PROGRAMME

DAY 1 – THURSDAY April 22	
<b>14:00 CEST / 08:00 EST</b>	<b>OFFICIAL START OF THE MEETING</b>
14:00 – 14:30 08:00 – 08:30 (30 min)	<b>COVID-19: Conferences in the age of a global pandemic...</b> <b>Opening, Welcome, Organizational &amp; Technical Issues, Thanks to the Sponsors, etc.</b> <i>Markus Wartenberg, DE &amp; Gerard van Oortmerssen, NL (SPAEN Chairs)</i>
14:30 – 15:30 08:30 – 09:30 (60 min)	<b>Session 1: Spotlight on...</b> <i>Moderator / Patient-Chair: Kai Pilgermann, DE</i>  - <b>New WHO-classification of sarcomas</b> - <i>Paolo Dei Tos, IT</i> - <b>Biopsy: How is it done? Quality/mistakes, prognosis/center</b> - <i>Piotr Rutkowski, POL</i> - <b>Diagnosis: Insights from Sarcoma UK / BCRT</b> - <i>Sorrel Bickley/Tobi Firth, UK</i>
<b>15:30 / 09:30</b> BREAK FROM SCREEN (30 min.)	
16:00 – 17:00 10:00 – 11:00 (60 min)	<b>Session 2: Development and diagnosis of metastasis, disease-specific patterns and local treatment options</b> <i>Moderator / Patient-Chair: Roger Wilson, UK</i>  <b>Radiologist (diagnosis)</b> – <i>Nicos Fotiadis, UK</i> <b>Oncologist</b> - <i>Robin Jones, UK</i> <b>Local ablative therapies &amp; surgery</b> – <i>Myles Smith, UK</i>
<b>17:00 / 11:00</b> BREAK FROM SCREEN (30 min.)	
17:30 – 18:30 11:30 – 12:30 (60 min)	<b>Session 3: Immunotherapy incl. gene cell therapy: An overview</b> - <i>Joanna Szkandera, AT</i> <i>Moderator / Patient-Chair: Markus Wartenberg, DE</i>

**18:30 / 12:30** End of Day 1

DAY 2 – Friday April 23				
14:00 – 14:30 08:00 – 08:30 (30 min)	<b>Award-giving ceremony for the SPAEN Advocacy in Action Award 2020</b> <i>Roger Wilson, UK &amp; Estelle Lecointe-Artzner, FR</i>			
5 - 10 min. time for participants to change to Zoom breakout room for parallel tracks				
Moderators / Patient Chairs	<i>Gerard van Oortmerssen, NL</i>	<i>Roger Wilson, UK</i>	<i>Sorrel Bickley, UK Caroline Kooy, NL</i>	<i>Christina Baumgarten, DE Jessica Garcia, ESP</i>
14:30 – 15:30 08:30 – 09:30 (60 min)	<b>Main room GIST Track</b>  <b>New compounds in GIST: Avapritinib &amp; Ripretinib</b> <i>Jon Trent, US</i>	<b>Zoom Room 1 STS Track</b>  <b>Elderly outcomes in clinical trials and priorities of patients starting palliative chemotherapy</b> <i>Eugenie Younger, UK</i>  <b>Clinical trials in elderly metastatic sarcoma patients; challenges and future directions</b> <i>Winette van der Graaf, NL</i>	<b>Zoom Room 2 Bone sarcoma Track</b>  <b>Introduction</b> <i>Andreas Leithner, AT</i>  <b>Improving the understanding of primary bone cancer</b> <i>Judith Bovee, NL</i>	<b>Zoom Room 3 Desmoid Track</b>  <b>Challenges in exploiting medical therapies for desmoid tumors</b>  <i>Bernd Kasper, DE</i>  <b>Updates Italian studies pregnancy and desmoids</b> <i>Desmoid Foundation IT</i>
15:30 / 09:30 BREAK FROM SCREEN (30 min.)				
16:00 – 17:00 10:00 – 11:00 (60 min)	<b>Case Studies</b> <i>Mikael Eriksson, SWE</i>	<b>Uterine LMS – Profile, diagnosis and challenges</b> <i>Roberta Sanfilippo, IT</i>	<b>Oncology (treatments) and biomarker landscape</b> <i>Sue Burchill, UK</i>	<b>Quality of life project</b> <i>Anne-Rose Schut, NL</i>  <b>Results from Cryodesmo Study</b> <i>Jean-Emanuel Kurtz, FR</i>
17:00 / 11:00 BREAK FROM SCREEN (30 min.)				
17:30 – 18:30 11:30 – 12:30 (60 Min)	<b>Long-term survivorship on TKIs</b>  <b>Clinical aspects</b> <i>Hans Gelderblom, NL</i>  <b>Quality of Life</b> <i>Dide den Hollander &amp; Deborah van der Wal, NL</i>  <b>Patient discussions on forums as data source for adverse drug reaction</b> <i>Anne Dirkson, NL</i>	<b>Research Update</b> <i>Robin Jones, UK</i>	<b>Clinical trials</b> <i>Sandra Strauss, UK</i>  <b>Patient story on resilience</b> <i>Kate Surman, UK</i>	<b>Networking</b>

<b>DAY 3 – SATURDAY April 24</b>	
<b>14:00 CEST / 08:00 EST      OFFICIAL START OF THE MEETING</b>	
14:00 – 14:05 08:00 – 08:05 (5 min)	<b>Welcome and introduction to day 3</b>
14:05 – 15:30 08:05 – 09:30 (85 Min)	<p><i>Moderator / Patient-Chair: Estelle Lecointe-Artzner,, FR</i></p> <p><b>Session 1: Patient Involvement in clinical research</b></p> <ul style="list-style-type: none"> <li>• <b>Introduction</b> (<i>Markus Wartenberg, DE</i>) – 15 min</li> <li>• <b>Overview &amp; Case Study</b> (<i>Roger Wilson, UK</i>) – 15 min</li> <li>• <b>PPRN Survey: Overview &amp; Results</b> (<i>Gerard v. Oortmerssen, NL / Olga Husson, NL</i>) – 15 min</li> <li>• <b>Discussion</b> – 30 min</li> </ul>
<b>09:30/15:30      BREAK FROM SCREEN (30 min.)</b>	
16:00 – 17:00 10:00 – 11:00 (60 min)	<p><i>Moderator / Patient-Chair: Annika Laakso, FIN</i></p> <p><b>Session 2: Evidence</b></p> <ul style="list-style-type: none"> <li>• <b>Definition of Evidence</b></li> <li>• <b>Evidence from a scientific point of view</b> (Scientific evidence – evidence level – Challenges in rare diseases – criteria of regulators) <i>Jaap Verweij, NL</i></li> <li>• <b>Evidence-based advocacy</b> – <i>Zack Pemberton-Whiteley, UK</i></li> </ul>
<b>17:00 / 11:00      BREAK FROM SCREEN (30 min.)</b>	
17:30 – 18:45 11:30 – 12:45 (75 min)	<p><b>SPAEN AGM</b></p> <ul style="list-style-type: none"> <li>• <b>Board &amp; financial report 2020</b></li> <li>• <b>Elections</b></li> <li>• <b>Discussion</b></li> </ul>

**18:45 / 12:45      End of Day 3**