

**2020  
VIRTUAL  
MEETING**



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

The virtual New Horizons GIST meeting will be hosted on a special section of the SPAEN-Website...

- Live-Sessions (Episodes) via Zoom – up to 300 participants
- The Sessions will be recorded in two parts:
  - Part A – made available for public – after the meeting
  - Part B – made available for patient advocates/participants, sponsors etc. after the meeting

Each GIST-Episode will be given in two parts:

**Part A** Basic knowledge for patient advocates (patient level) 20 - 30 min.

What do we know? Where are we today with diagnosis, treatment, care and follow-up?

*Advantage: We will have the opportunity to put the “A-Parts” online and make them available for a broad range of English speaking patients/ patient advocates globally...*

**Part B** Special knowledge: Deeper knowledge, special topics and discussions 20 - 30 min.

What are unanswered questions, unmet needs and challenges in different countries or general for the patient advocacy work? What are “core messages/needs/tasks” for the Global GIST-Patient Community?

**Global Conference-Timing (start time for some selected locations):**

<b>08:00</b> New York / Toronto	<b>09:00</b> Santiago de Chile
<b>13:00</b> London	<b>14:00</b> Berlin (CET)
<b>17:30</b> Mumbai	<b>21:00</b> Tokyo

To find the timing for a specific locations – please use available online-tools such as:  
<https://www.worldtimeserver.com/meeting-planner.aspx>

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<b>THURSDAY September 10, 2020</b>	
<b>08:00/14:00 CET OFFICIAL START OF THE ONLINE MEETING</b>	
<b>08:00 – 08:30</b> <b>14:00 – 14:30</b> (30)	<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>Short Welcome Notes from our Sponsor-Partners</i>
<b>08:30 – 09:30</b> <b>14:30 – 15:30</b> (60)	<b>GIST Episode 1: Introduction – Overview</b> <i>Moderator / Patient-Chair: Martin Wettstein (CH)</i> <i>Suggested Speaker/s: tbc</i> <ul style="list-style-type: none"><li>• History of GIST - Numbers - Facts – Overview</li><li>• Diagnosis/Examination - Imaging – Lab Values</li><li>• Main Treatment Options (brief treatment algorithms)</li><li>• General important tips/core recommendations for patients</li></ul>
<b>09:30/15:30 BREAK FROM ON SCREEN (30 min.)</b>	
<b>10:00 – 11:00</b> <b>16:00 – 17:00</b> (60)	<b>GIST Episode 2: Biology – Genetics – Pathology</b> <i>Moderator / Patient-Chair / Speaker: David Josephy (CDN)</i> <ul style="list-style-type: none"><li>• Biology/Genetics/Targets of/in GIST</li><li>• Role of the pathologists in GIST</li><li>• Mutational Analysis / Genotyping</li></ul>
<b>11:00/17:00 BREAK FROM ON SCREEN (30 min.)</b>	
<b>11:30 – 12:30</b> <b>17:30 – 18:30</b> (60)	<b>GIST Episode 3: Localized, operable primary tumor</b> <i>Moderator / Patient-Chair: Markus Wartenberg (DE)</i> <i>Suggested Speaker/s: tbc</i> <ul style="list-style-type: none"><li>• Surgery of primary tumors at multiple sites</li><li>• Risk stratification for adjuvant therapy and follow-up</li><li>• Neoadjuvant and adjuvant Imatinib (Gleevec) therapy (incl. 10 years data for 36 months adj. treatment)</li></ul>
<b>12:30 / 18:30</b>	<b>End of Online-Meeting</b>



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FRIDAY September 11, 2020

08:00 – 09:00 14:00 – 15:00 (60)	<b>GIST Episode 4: Metastatic (advanced) disease</b> <i>Moderator / Patient-Chair: David Josephy (CDN)</i> <i>Suggested Speaker/s: tbc</i> <ul style="list-style-type: none"><li>• First-line treatment with Imatinib (Glivec/Gleevec)</li><li>• Main side effects and drug interactions</li><li>• Response to therapy and monitoring</li><li>• What to do with initial/early Imatinib intolerance?</li><li>• The role of surgery in metastatic disease</li><li>• Mutation D842V: Treatment with Avapritinib (Ayvakit™) (= brief overview) (Reference to more information in Episode 6)</li></ul>
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09:00/15:00 BREAK FROM ON SCREEN (30 min.)

09:30 – 10:30 15:30 – 16:30 (60)	<b>GIST Episode 5: Progression of metastatic disease under drug treatment</b> <i>Moderator / Patient-Chair: Laura Occhiuzzi (USA)</i> <i>Suggested Speaker/s: tbc</i> <ul style="list-style-type: none"><li>• Reasons for resistance e.g. secondary mutations</li><li>• Verification of tumor progression and overview current available treatments</li><li>• Treatments with Sunitinib (Sutent™) and Regorafenib (Stivarga™)</li><li>• Main side effects and drug interactions</li><li>• Locally ablative procedures to remove single progressive lesions (surgery, chemo-embolization, RFA/microwave, IRE, SIRT...)</li></ul>
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10:30/16:30 BREAK FROM ON SCREEN (30 min.)

11:00 – 12:00 17:00 – 18:00 (60)	<b>GIST Episode 6: Introducing new treatment options in GIST</b> <i>Moderator / Patient-Chair: Sara Rothschild (USA)</i> <i>Suggested Speaker/s: tbc</i> <p>Targets – Treatments – Clinical Trial Data – Side Effects – Study-Outlook</p> <ul style="list-style-type: none"><li>• NEW against Mutation D842V: Introducing BLU-285/Avapritinib/Ayvakit™</li><li>• NEW 4<sup>th</sup> Line treatment: Introducing DCC-2618/Ripretinib/Qinlock™</li></ul>
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12:00 / 18:00 End of Online-Meeting



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**SATURDAY September 12, 2020**

<p>08:00 – 09:00 14:00 – 15:00 (60)</p>	<p><b>GIST Episode 7: Challenges in approaching a non-KIT/PDGFR mutated GIST</b>  <i>Moderator / Patient-Chair: Jayne Bressington (UK) tbc</i>  <i>Suggested Speaker/s: tbc</i></p> <ul style="list-style-type: none"> <li>• Understanding the term “wild-type”</li> <li>• Understanding the heterogeneity of subtypes in GIST today &gt;&gt;&gt; sub-types, biology, targets, etc.</li> <li>• Practical experiences: How to treat the various subtypes?</li> </ul>
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**09:00/15:00 BREAK FROM ON SCREEN (30 min.)**

<p>09:30 – 10:30 15:30 – 16:30 (60)</p>	<p><b>GIST Episode 8: Following the research journey in GIST</b>  <i>Moderator / Patient-Chair: Jerry Call (USA)</i>  <i>Suggested Speaker/s: tbc</i></p> <ul style="list-style-type: none"> <li>• Nilotinib, Everolimus, Dasatinib, Ponatinib and others: Therapies that have never been approved for GIST - but could be options (e.g. off label use)</li> <li>• What role does Larotrectinib (Vitrakvi) play in GIST treatment?</li> <li>• Current &amp; upcoming agents / clinical trials in GIST</li> </ul>
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**10:30/16:30 BREAK FROM ON SCREEN (30 min.)**

<p>11:00 – 12:00 17:00 – 18:00 (60)</p>	<p><b>GIST Episode 9: Quality of diagnosis, treatment &amp; care</b>  <i>Moderator / Patient-Chair: Ginger Sawyer (USA) / Piga Fernandez (CHI)</i>  <i>Suggested Speaker/s: tbc</i></p> <ul style="list-style-type: none"> <li>• Adherence: The importance of professional therapy and side effect management: Getting the best out of the treatments. The Patient Perspective AND The Expert-Perspective...</li> <li>• Discussion: Living with the disease Influencing Factors such as Nutrition, Complementary Therapies, Coping etc. Challenges for patients, carers (incl. long term survivors)</li> </ul>
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<p>18:00</p>	<p><b>Wrap Up &amp; Farewell - OFFICIAL END OF THE CONFERENCE and END OF TRANSMISSION</b></p>
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**12:15 / 18:15 End of Online-Meeting**

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## Special “Patient Advocacy Sessions” (Capacity Building)

Important and interesting for GIST-Patient Advocates and Sarcoma-Patient Advocates  
Hosted by GIST New Horizons and SPAEN

Date in <b>OCTOBER 2020</b> - to be defined	
08:00 – 09:30 14:00 – 15:30 (90)	<p><b>Capacity Building / Background &gt;&gt;&gt; Submitted Presentations/Abstracts</b></p> <p><i>Moderator / PA-Chair: tbc</i></p> <p><b>“We can learn from projects/activities that others do...”</b></p> <p><b>Interesting projects, initiatives from the international GIST-patient community...</b></p> <p><b>6 – 8 short presentations:</b> <i>Speakers from: tbc</i></p> <ul style="list-style-type: none"> <li>• Topic 1 <i>???</i></li> <li>• Topic 2 <i>???</i></li> <li>• Topic 3 <i>???</i></li> <li>• etc.</li> </ul>
Date in <b>NOVEMBER 2020</b> - to be defined together	
08:00 – 09:30 14:00 – 15:30 (90)	<p><b>Capacity Building / Background</b></p> <p><i>Moderator / PA-Chair: tbc</i></p> <p><i>Speakers: tbc</i></p> <p><b>The age of “Digital Health”, Smart Hospitals and Big Data has already started</b></p> <ul style="list-style-type: none"> <li>• Understanding Digital Health (introduction / overview / review)</li> <li>• Opportunities, examples of using Digital Health for/with patients</li> <li>• Are there experiences to run “Clinical Trials” digital/virtually?</li> <li>• Why and where should/can patients/advocates be involved?</li> </ul>
Date in <b>DECEMBER 2020</b> - to be defined together	
08:00 – 09:30 14:00 – 15:30 (90)	<p><b>Capacity Building / Background</b></p> <p><i>Moderator / PA-Chair: tbc</i></p> <p><i>Speakers: tbc</i></p> <p><b>What are the opportunities for advocacy and political lobbying?</b></p> <p>e.g speaker from Sarcoma UK tbc</p> <ul style="list-style-type: none"> <li>• What are good practices?</li> <li>• What are opportunities for change?</li> </ul> <p><b>What does “Evidence Based Advocacy (EBA)” mean?</b></p> <ul style="list-style-type: none"> <li>• Why to do it and what are important success factors?</li> <li>• Examples of EBA-Projects...GIST-/Sarcoma-community</li> </ul>