

## AGENDA

| <b>DAY 1: Friday 27<sup>th</sup> October 2017</b> |  |
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| 11.00 – 12:30                                     | <p><b>MPN 101 session</b> - CBC reading</p> <p>Speaker: <a href="#">Jon Mathias &amp; Dr. Martin Ellis</a></p>   |
| 12:30 - 13:30                                     | <b>Lunch</b>   |
| 13:30 – 14:00                                     | <p><b>Opening</b></p> <ol style="list-style-type: none"> <li>1. <b>Welcome</b><br/>Speaker: <a href="#">Jon Mathias &amp; Giora Sharf</a><br/>Local Welcome: <a href="#">Werner Zinkand</a></li> <li>2. <b>Update on the MPN Advocates Network</b><br/>Speakers: <a href="#">Cheryl Jacobs – Petruk &amp; Jon Mathias</a></li> </ol>   |
| 14:00 – 15:30                                     | <p><b>Medical Session #1: Quality of Life</b></p> <p>Chairs: <a href="#">Cheryl Jacobs – Petruk &amp; Robi Zelig</a></p> <ol style="list-style-type: none"> <li>1. <b>Landmark Survey</b>: highlight of findings, further research, impact on clinical practice, how does that impact on advocacy.<br/>Speaker: <a href="#">Dr. Saghi Ghaffari</a></li> <li>2. <b>Psycho Social</b>: impact on patient &amp; families (how a chronic illness can affect a patient's psychological state &amp; what can be done<br/>Speaker: <a href="#">Prof. Ketti Mazzocco</a></li> <li>3. <b>Symptoms &amp; side effects management</b><br/>Speaker: <a href="#">Dr. Martin Ellis</a></li> </ol>  |
| 15:30 – 16:00                                     | <b>Coffee Break</b>  |
| 16:00 – 17:30                                     | <p><b>Advocacy Session #1 : Best Practices</b></p> <p>Chairs: <a href="#">Lidija Pecova and Peter Loffelhardt</a></p> <ol style="list-style-type: none"> <li>1. Fundraising (regional) &amp; Blood Cancer Awareness Month<br/>Speaker: <a href="#">Bill Crowley</a></li> <li>2. Abstracts <ul style="list-style-type: none"> <li>• Leukaemia CARE 2016 Patient Experience Survey (<a href="#">Bethany Thor, UK</a>)</li> <li>• Medical Mentoring - Personalized lecture and counselling (<a href="#">Chul Hwan Lee, Republic of Korea</a>)</li> <li>• Women and MPN (<a href="#">Marina Peed, USA</a>)</li> <li>• Australia – isolated by geography &amp; population size (<a href="#">Jolanda Visser, Australia</a>)</li> <li>• Working collaboratively with MPN Doctors (<a href="#">Cheryl Jacobs – Petruk, Canada</a>)</li> <li>• Volunteer regional fundraising organizers (<a href="#">Maz Campbell-Drew, UK</a>)</li> </ul> </li> </ol> |
| <b>19:00</b>                                      | <b>Reception &amp; Gala Dinner (at the Hotel's tower)</b>  |

**DAY 2: Saturday 28<sup>th</sup> October 2017**

|               |   |
|---------------|---|
| 08:45 – 10:15 | <b>Medical Session #2 Update on Clinical trial</b><br>Chairs: <b>Bill Crowley &amp; Felice Bombaci</b><br><ol style="list-style-type: none"> <li>Current Active Trials: Status, &amp; prospects<br/>Speaker: <b>Dr. Claire Harrison</b></li> <li>Update on mutations: - more depth on the MPN biology (MPN 201) what are the known mutations investigated now &amp; implications in terms of clinical disease<br/>Speaker: <b>Dr. Saghi Ghaffari</b></li> <li>New frontiers &amp; approaches: non-mutation inhibiting therapy strategies<br/>Speaker: <b>Dr Mary Frances McMullin</b></li> </ol>            |
| 10:15 – 10:45 | <b>Coffee break</b>   |
| 10:45 – 12:30 | <b>Advocacy Session #2: The Empowerment &amp; Professionalization of Advocates</b><br>Chairs: <b>Giora Sharf &amp; Werner Zinkand</b><br><ol style="list-style-type: none"> <li>Journey to a professional and empowered advocate<br/>Speaker: <b>Alfonso Aguarón</b></li> <li>Professionalizing Patients Advocates<br/>Speaker: <b>Šarūnas Narbutas</b></li> <li>Patients participation in the R&amp;D process – a panel discussion<br/>Panel: <b>Dr. Claire Harrison, Dr Mary Frances McMullin, Šarūnas Narbutas, Alfonso Aguarón, Novartis- Amber Spierer and Incyte- Dave Dubinsky</b></li> </ol>        |
| 12:30 -13:30  | <b>Lunch</b>  |
| 13:30 – 15:00 | <b>Medical Session #3: Guidelines of treatment &amp; Oxford style debate</b><br>Chairs: <b>Jon Mathias &amp; Cheryl Jacobs – Petruk</b><br><ol style="list-style-type: none"> <li>To Treat <b>Dr. Reinier Raymakers</b> or Not to Treat- <b>Dr Mary Frances McMullin</b><br/>Oxford style debate <i>and panel consisting of:</i> <b>Dr. Claire Harrison, Dr Mary Frances McMullin, Dr. Reinier Raymakers</b></li> <li>State of play across the globe: no standardized treatment guidelines for MPN's. Talk: what are the current efforts to create them.<br/>Speaker: <b>Dr. Claire Harrison</b></li> </ol> |
| 15:00 – 15:30 | <b>Coffee break</b>   |
| 15:30 -17:15  | <b>Advocacy Session #3: Patients &amp; Doctor Communications</b><br>Chairs: <b>Ilse Jans &amp; Peter Loffelhardt</b><br><ol style="list-style-type: none"> <li>Doctor – Patient relationship<br/>Speaker: <b>Prof. Ketti Mazzocco</b></li> <li>Introduction to Role Plays<br/>by Prof. <b>Ketti Mazzocco</b></li> <li>Role Play - <b>Dr Claire Harrison</b> playing role of patient and <b>Jon Mathias</b> playing the Dr<br/>Panel discussion: <b>Dr. Claire Harrison, Dr Mary Frances McMullin, Dr. Reinier Raymakers, Prof. Ketti Mazzocco, Jon, Ilse and Peter</b></li> </ol>                           |
| 17:15 – 17:30 | <b>“Overview of Steering Committee – Expression of Interest for 2019 – 2021 term”</b>   |
| 18:40         | <b>Departure for off-site dinner</b>  |
| 19:00 – 22:30 | <b>Off-site Dinner Cruise</b>   |



**DAY 3: Sunday 29<sup>th</sup> May 2017**

|             |   |
|-------------|---|
| 09:00-10:30 | <p><b>Advocacy Session #4: Market Place (Breakout sessions)</b></p> <ol style="list-style-type: none"> <li>Brain storm of MPN Advocates Network<br/>Speakers: <b>Jon Mathias &amp; Cheryl Jacobs – Petruk</b></li> <li>Daily living with an MPN<br/>Speaker: <b>Marina Sampees Peed</b></li> <li>Public Relations working with media<br/>Speaker: <b>Bill Crowley</b></li> </ol>  |
| 10:30-11:00 | <b>Coffee break</b>   |
| 11:00-12:30 | <p><b>Medical Session #4: In support of research</b></p> <p>Chairs: <b>Felice Bombaci &amp; Bill Crowley</b></p> <ol style="list-style-type: none"> <li>Patient Registry (MPN research foundation) update on the registry project. / other registries elsewhere / Can MPNAN help or contribute to it.<br/>Speaker: <b>Dr Claire Harrison and Lindsey Whyte</b></li> <li>Change your prognosis: patients' involvement in research- The Dutch experience<br/>Speaker: <b>Dr. Reinier Raymakers</b></li> <li>Clinical data–Mosaic study- Epidemiology data in MPN data<br/>Speaker: <b>Dr Mary Frances McMullin</b></li> </ol> |
| 12:30-13:00 | <p><b>Best poster award</b></p> <p><b>Q &amp; A – Closing Remarks - Jon Mathias &amp; Cheryl and Bill</b></p> <p>Introduction of the Steering committee</p>   |
| 13:00-14:00 | <b>Farewell lunch</b>   |
| 14:00       | <b>Debrief Session with sponsors</b>  |
| 15:00       | <b>Offsite Tour</b>   |

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