

MPN Horizons

13-15 October
Zagreb, Croatia

2023

Understanding the
New Complexity of MPNs

8th International Conference



Friday 13th October 2023

MPN 101 - Virtually, uploaded on the registration platform - Martin Ellis

12:00-13:00	Welcome Lunch
13:00-13:30	<p>Welcome Werner Zinkand, Giora Sharf & Marko Lucijanić (20 min)</p> <p>MPN AN Update Kapila Vigés (10 min)</p>
13:30-15:00	<p>Advocacy Session 1: Regional Meetings - Breakout session and report (60 min meeting + 10 min report from each region)</p> <ul style="list-style-type: none"> Western & Eastern Europe - Werner Zinkand & Felice Bombaci, Jon Mathias, Dražen Vinček Australia, Asia & Africa - Ken Young & Bahija Gouimi North & Latin America - Kapila Vigés & Lyat Granati Espinosa
15:00-15:30	Coffee Break
15:30-17:00	<p>Medical Session 1: New Challenges in Diagnosing MPN Chairs: Kapila Vigés and Werner Zinkand</p> <ul style="list-style-type: none"> Diagnostic Criteria for ET, PV & MF, biological aspects Susanne Isfort (20 min) New learnings in diagnostics, CHIP Martin Ellis (20 min) How does a genetic understanding of MPNs affect prognosis for ET, PV & MF Claire Harrison - Virtually (20 min) <p style="text-align: right;">Q&A 30 mins</p>
19:00	Dinner at the Hotel



Contact us

Marija Stefkova
+38 977 859 659
doneva@mpn-advocates.net
www.mpnadvocates.net



@GMPNAN



@MPNAdvocatesNetwork



Saturday 14th October 2023

8:45-10:30	<p>Medical Session 2: The Complexity and Combinations in Treating MPNs Chairs: Giora Sharf and Jon Mathias</p> <ul style="list-style-type: none">• PV - What is the current standard of treatment? Gabriela Hobbs - Virtually (20 min)• MF - Combinations in treatment Naveen Pemmaraju - Virtually (20 min)• ET - The future of treatment Claire Harrison (20 min)• Cardiovascular risk factors in MPN patients Marko Lucijanić (15 min) <p>Q&A 30 mins</p>
10:30-11:00	Coffee Break
11:00-12:30	<p>Medical Session 3: Special Problems in MPNs Chairs: Kapila Vigés & Lyat Granati Espinosa</p> <ul style="list-style-type: none">• The growing complexity of MPN mutations Martin Ellis (20 min)• How to talk to patients about MPN? Gabriela Hobbs - Virtually (20 min)• Special cases: skin cancers & thrombosis Claire Harrison (20 min) <p>Q&A 30 mins</p>
12:30-14:00	Group Photo and Lunch
14:00-15:30	<p>Advocacy Session 2: Patient Engagement in drug development and clinical trials Chairs: Felice Bombaci and Dražen Vinček</p> <ul style="list-style-type: none">• The Life cycle of drug development Scott Weir - Virtually (20 min)• PROs - What is the role of the patient organisation using the PROs? Zack Pemberton-Whiteley - Virtually (20 min)• The role of patients in the design of a clinical trials Giora Sharf (20 min) <p>Q&A 30 mins</p>
15:30-16:00	Coffee Break
16:00-17:30	<p>Advocacy Session 3: Marketplace Empowering Patient Advocates Introducing the session: Ken Young</p> <ul style="list-style-type: none">• Educational programme for patient advocates Felice Bombaci (15 min + 5 min Q&A)• Using social media in advocacy Anil Nagpal (15 min + 5 min Q&A)• Measuring Efficiency and setting up key measurement points (KPIs) Vicki Idzinski - Virtually (15 min + 5 min Q&A)• How can we collaborate with other patient organisations? Jon Mathias (15 min + 5 min Q&A)
19:00	OFF SITE DINNER -TAVERN "POD MIRNIM KROVOM"

Sunday 15th October 2023

9:00-10:30	<p>Advocacy Session 4: Living with a chronic, life threatening, rare condition</p> <p>Chairs: Ken Young and Felice Bombaci</p> <ul style="list-style-type: none">• A patient story: From patient to advocacy Werner Zinkand (20 min)• The Caregiver's role and how are they involved in the journey Guy Tavori - Virtually (20 min)• Complementary therapies Susanne Isfort - Virtually (20 min) <p>Q&A 30 mins</p>
10:30-11:00	Coffee Break
11:00-12:30	<p>Advocacy Session 5: Best Practise Session</p> <p>Chairs: Lyat Granati Espinosa and Ken Young</p> <ul style="list-style-type: none">• Patient Health Engagement & Sources of Information on Myeloproliferative Neoplasms: A Survey Conducted by the Italian Patient Association (AIPAMM) Valentina Biagioli (10 min + 5 min Q&A)• Dar AL AMAL, one year of services Cancer patients in Morocco Bahija Gouimi (10 min + 5 min Q&A)• Patient advocates in cancer research (Association of Cancer Patients in Finland) Matti Santalahti (10 min + 5 min Q&A)• RED SEPTEMBER: Blood Cancer Awareness Month in France (VIVRE AVEC UNE NMP) Karin Tourmente-Leroux (10 mins + 5 mins Q&A)• The buddy system of MPN Voice Jonathan Mathias (10 min + 5 min Q&A)• 3 key stakeholders' engagement in research Kapila Vigés (10 min + 5 min Q&A)
12:30-13:00	<p>Best poster award</p> <p>Closing Remarks</p> <p>Completion of Feedback Questionnaire Q & A Werner Zinkand and Giora Sharf</p>
12:30-14:00	Farewell lunch
14:00	City Tour

MPN Horizons 13-15 October 2023
Understanding the New Complexity of MPNs Zagreb, Croatia
8th International Conference



Contact us

Marija Stefkova

+38 977 859 659

doneva@mpn-advocates.net

www.mpnadvocates.net



@GMPNAN



@MPNAdvocatesNetwork

