

We publish this newsletter quarterly, with information on what's new in MPN care and research. Each issue we bring together MPN advances and news, and keep you up to date with the work of the Canadian MPN Group. Comments, ideas and suggestions can be sent to [info@mpncanada.com](mailto:info@mpncanada.com)

## Spotlight – MPN Horizons 2017 – MPN Advocates Network

### MPN Advocates Network



*MPN Advocates Network steering committee*

#### **Cheryl Petruk, Chairperson Canadian MPN Network & Secretary, MPN Advocates Network (MPNAN).**

The MPNAN is comprised of MPN patient organizations from across the world, whose mission is to provide resources and education for their country and local MPN patient advocacy and support groups. Representatives from several MPN patient support groups founded the MPNAN to foster and strengthen collaboration between these organizations and provide a platform for joint activity. MPN Patients across the world share the same issues regardless of country, and the MPN Advocates Network aims to make those resources accessible to all patients.

The MPNAN's objective is to enhance MPN patient care by collaboratively:

- Acting as an international collective representative of MPN patient groups, interacting with healthcare funding, treatment approval, and treatment research organisations
- Sharing best practice of support and advocacy activities between all patient groups
- Sharing available information on all current treatments, technologies and research findings
- Encouraging co-operation between advocates, researchers, clinicians and health care organizations

MPNAN operates solely to benefit MPN patients and acts independently of any other organization or company.

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## Spotlight... continued from page 1

MPNAN aims to source support from a broad sponsorship and funding base.

### Leukemia Patient Advocates Foundation

The MPNAN is part of the Leukemia Patient Advocates Foundation (LePAF). LePAF is a patient-led non-profit foundation in Switzerland. Its mission is to improve the lives and survival of patients affected by Leukemia. It is a platform for discussion and sharing best practice for Leukemia patient groups worldwide. The foundation collaborates with all stakeholders involved in research, policy, treatment and care. They host the global CML Advocates Network, MPN Advocates Network, CLL Advocates Network and Acute Leukemia Advocates Network. The Canadian MPN Network is a member organization of MPN Advocates.

### MPN Horizons

MPN Horizons is a global patient advocacy conference hosted by the MPN Advocates Network. Two MPN Horizon

conferences have been held, one in Belgrade in 2016 and in Frankfurt in 2017, with plans now underway for MPN Horizons 2018 to be held in September 2018. Medical speakers at the MPN Horizons conferences have welcomed MPN experts Dr. Claire Harrison, Dr. Ruben Mesa Dr. Rainier Raymakers, Dr. Martin Ellis, and Dr. Carles Besses, among other European MPN Doctors and Medical Clinicians. Over 60 patient advocate groups were represented at the MPN Horizons 2017.

Topics presented at the 2017 MPN Horizons Conference included: current and active trials, MPN best practices, MPN mutations, psycho social issues of patients and caregivers, 'MPN 101' and 'MPN 201' sessions, as well as many others.

Visit the MPN Advocates website at [www.mpn-advocates.net](http://www.mpn-advocates.net) for more information and to locate member organizations.

The poster features a central graphic of three interlocking gears: a yellow gear labeled 'Pharma', an orange gear labeled 'Physicians', and a red gear labeled 'Patients'. Curved arrows indicate a clockwise flow between them. Below the gears, the text reads: 'Vision: Better lives for all Canadians with a myeloproliferative neoplasm (MPN) disorder.' This is followed by the 'Mission' statement: 'We are a patient-led organization committed to improving the lives of all Canadians living with myeloproliferative neoplasms through patient advocacy, patient support groups, and patient communication while connecting with the MPN medical community and providing up-to-date information on research, treatments and clinical studies.' Below the mission are the 'Goals' listed as: 'Patient communication: Provide reliable and accurate information about MPNs for Canadian patients through many platforms.', 'Patient advocacy: Inform healthcare decision-makers about MPNs and the needs of Canadians living with them.', 'Annual conference: Hold an annual conference that will allow Canadian patients to connect with other patients and medical experts.', and 'Regional support groups: Encourage the development of patient groups in every region of Canada.' At the bottom, it says 'Collaboration with: MPN medical community: Engage the Canadian MPN medical community to provide patient perspective and seek collaboration on effective communications.'

**Canadian MPN Network**

 [www.canadianmpnnetwork.ca](http://www.canadianmpnnetwork.ca)

Winning poster, submitted by the Canadian MPN Network

# Meeting updates

## Highlights from the American Society of Hematology (ASH) Annual Meeting 2017

### ***MIPSS70 a: mutation-enhanced prognostic system for MF (abstract #200)***

Alessandro Vannucchi and colleagues presented a new prognostic scoring system to evaluate disease risk for patients under 70 years of age with myelofibrosis that incorporates mutational information. MIPSS70 incorporates information on leukocytosis, thrombocytopenia, presence of and number of high risk mutations, anemia, circulating blast cells, constitutional symptoms, and CALR type-1 mutation. These data are published in Guglielmelli et al. *Journal of Clinical Oncology*. 2017 Dec 9 (published online ahead of print).

### ***Ropeginterferon Alfa-in PV: 2-year results (abstract #320)***

The PROUD-PV study compared ropeginterferon alfa-2b (Ropeg) and hydroxyurea in PV patients. This abstract presented data from the follow-up study CONTI-PV (after 2 years of treatment). The study data suggests that Ropeg treatment results in durable hematologic and symptom improvement and a reduction in the mutant JAK2 burden. The authors suggest that Ropeg may provide another option as a safe long-term treatment option for PV patients.

### ***Pegylated Interferon Alfa-2a for patients with high-risk PV or ET (abstract #321)***

This study, MPD-RC protocol 111, was a large (total 115 patients) trial to investigate pegylated-interferon alpha-2a (PEG) as a therapy in patients with essential thrombocythemia (ET) or polycythemia vera (PV). The data presented suggest that PEG is an effective agent to treat ET/PV patients and that CALR mutation presence was associated with a better response, though a number of adverse events occurred.

### ***Long-term survival in MF after bone marrow transplant (abstract #199)***

This analysis of 110 patients with MF that underwent allogeneic hematopoietic cell transplant (HCT) with a fludarabine/melphalan (FluMel) conditioning regimen, the largest single centre experience to date. MF HCT outcomes are relatively poorer compared to some other diseases. However, the overall survival in this study was 64% at 5 years, with a low risk of relapse (17% at 5 years post-transplant). Data from the study also suggested that use of pre-transplant use of ruxolitinib increased the risk of grade III-IV acute graft versus host disease (GVHD)

## An update on pacritinib

Further clinical trials may be on the horizon for pacritinib, an investigational JAK2/FLT3 inhibitor developed by CTI BioPharma. The FDA lifted its clinical hold in 2017, leaving open the possibility of further development of this drug. Details of MPN clinical trials in Canada are on our website.

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## An update on fedratinib

The JAK2 inhibitor, previously in development for treatment of myelofibrosis, may once again enter active development. The drug was put on clinical hold by the FDA in 2013 due to cases of Wernicke's encephalopathy (WE) in several patients participating in fedratinib clinical trials. A case series by Claire Harrison and colleagues, presented at ASH 2017 (abstract #4197), suggests that fedratinib does not increase the risk of thiamine deficiency, a cause of WE. Furthermore, analysis of clinical trial data by the drug's developers resulted in the lifting of the clinical hold in 2017. Cellegene, who recently acquired fedratinib as part of their acquisition of Impact Biomedicines, announced that they plan New Drug Application (NDA) submission for fedratinib in myelofibrosis for mid-2018.

## MPN e-SIMPLE

The MPN e-SIMPLE app was developed with the support of Novartis. The app provides data, resources and guidance to assist Canadian physicians in daily management of MPNs. The goal is to improve the management of MPNs across Canada by providing point-of-care guidance to our colleagues on therapeutic approaches for each MPN patients.

The app includes disease risk calculators (IPSS, DIPSS, DIPSS Plus and IPVS), resources for MPN diagnosis and risk assessment, and information on treatment options. At present the app covers MF and PV, with ET coming soon. MPN e-SIMPLE can be used through your web browser or downloaded (Android & iOS, optimized for tablets) at [www.mpnesimple.ca](http://www.mpnesimple.ca)



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