NEWSLETTER

Bloodline *MPN*

Brought to you by: Canadian MPNNetwork, Canadian MPN Research Foundation and MPN Doctors

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Welcome to The Bloodline MPN

Welcome to the first issue of The Bloodline, brought to you by the Canadian MPN Network, the Canadian MPN Research Foundation and the Canadian MPN Doctor's Group. This collaborative newsletter is the first initiative bringing together the three leading MPN groups in Canada to provide the MPN community with a single source of information.

By speaking with one voice, our combined efforts in patient advocacy, research and clinical care resonate on behalf of the patients, caregivers, and health care experts we serve. Truly, we are stronger working together!

Each edition will feature updates on new clinical trials and emerging research, offering a glimpse into the future of MPN treatment and care. We will also share patient resources and first-hand stories, providing personal insights into life with an MPN.

We hope you find the information we provide valuable and empowering. We look forward to keeping you informed as we continue working in partnership to improve the lives of all those affected by MPNs.

Warm regards,
Merrill Pierce, Chair, Canadian MPN Research Foundation
Patti Saluk, Chair, Canadian MPN Network
Dr. Shireen Sirhan, Canadian MPN Group

Research Spotlight

Dr. Vikas Gupta, MD, FRCP, FRCPP, is a leading MPN researcher in Canada, through his work with the Princess Margaret Cancer Centre in Toronto, Ontario. Recent research he has been conducting with the support of our friends at the MPN Research Foundation in Chicago, seeks to understand the most effective way to compare transplant therapies with the best available non-transplant treatments for patients with myelofibrosis.

You can read more about this research here.

The Board of the Canadian MPN Research Foundation had the honour of presenting research grants in person to Dr. Hubert Tsui of Sunnybrook Health Science Centre of Toronto, and Dr. Shireen Sirhan of The Jewish General Hospital of Montreal (not in attendance was grant recipient Dr. Natasha Szuber of Hôpital Maisonneuve-Rosemont of Montreal). The grants were presented at the end of 2023, with research projects progressing through 2024.

To learn about the grant program, click here.

Clinicians' Perspective

The Canadian MPN Group was founded by hematologists working in the field of MPNs as the first national collaborative effort between health professionals in Canada to improve MPN patient care and research.

The beginnings of the Canadian MPN Group lie in a discussion at a hematology meeting between several of our now National Executives on MPN patient care and research in Canada. Their discussion led them to the topic of the then current lack of a collaborative physician-driven MPN organization in Canada and the benefits it would bring to improve the care of MPN patients.

Since this meeting in 2011 the generous support of the late Mr. Ed Pascal has enabled us to establish the Canadian MPN Group as a national charitable organization in 2013 and we have, with support from our donors, pursued our mission of improving MPN research and care of patients with MPNs.

Our mission is to improve the care and research in patients with myeloproliferative neoplasms (MPN) through inter-professional collaboration.

We look forward to bringing you updates on clinical trials and medical news!

Visit the website

New PV Drug Therapy Coming To Canada

Good news for PV patients - FORUS Therapeutics is licensing BESREMi from PharmaEssentia, for the treatment of PV in Canada. FORUS will oversee the drug's registration and commercialization in Canada, including securing approval of BESREMi in PV.

"BESREMi is an important and significant development for clinicians who treat patients with PV. BESREMi as a potential future treatment option is particularly critical for Canada, where treatment options are notably limited for these patients," says Dr. Shireen Sirhan. "Canadian physicians have played a significant role in the clinical development program for BESREMi and we look forward to having this important treatment available in the clinic for our patients in need."

"This is very exciting news for the PV community across Canada," says Doug Chisholm and Patricia Saluk, the former and current Chair, Board of Directors of the Canadian MPN Network Patient Advocacy group. "Polycythemia vera is a rare blood cancer and the future commercialization of BESREMi in Canada offers highly anticipated new hope for patients, families, and their support networks. We hope the Canadian regulatory and payor systems will work as quickly as possible to ensure our patient community has access to this much needed new treatment regimen."

Read the press release

Inspiring Stories: Baseball for a cause

Max Peacock shares how his mother's MPN diagnosis inspired his annual Maxwell Hitswell fundraising tournament, and helped him discover the healing, strengthening power of community. Thank you Max for your fundraising efforts in support of the Canadian MPN Research Foundation's mission to stimulate original Canadian research in pursuit of new treatment options -- and ultimately
a cure -- for the blood cancers collectively known as 'MPNs'.

Read Max's Story

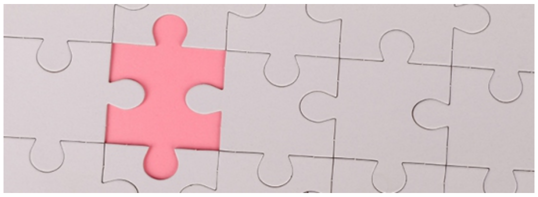
If you want to make a difference to MPN Research like Max has, the Canadian MPN Research Foundation is looking for volunteers! Whether you have skills in fundraising, research, marketing & communications, or law, you can support a Committee or Task Force that is impacting Canadian-based MPN research efforts. Please email us at info@cmpnrf.ca to learn how you can help.

Prospective donors can visit the Foundation's donor page to support future research projects funded by the Canadian MPN Research Foundation.

Patient Voice: MPN-U(Unspecificed): A Patient Perspective

By Jane Burns

I was diagnosed with MPN-U in 2019 following a bone marrow biopsy. This occurred 3 months after thyroid cancer surgery. I am triple negative, with no JAK2, CALR or MPL mutation. My chief symptoms are fatigue, bone pain, skin itch and recurring infections. I am immunodeficient and require monthly IVIG infusions at the Central Alberta Cancer Centre.



MPN-U is a heterogeneous rare disorder with no consensus on guidelines to manage and varying clinical approaches. While I grieved my forced medical retirement from a rewarding career, my family and I received amazing support from the Canadian MPN Network, Canadian Leukemia and Lymphoma Society, and Wellspring. I have a dedicated care partner, an occupational therapist and aspiring forest therapy guide. I have built an extensive support system around me and know that I do not make the blood cancer journey alone.

Despite this, there is a constant struggle to understand the dynamics of this rare disorder, optimal treatment plans and future prognosis. It is a mental game and my focus is on living my best life each day in joy and service to others. I have learned to live with uncertainty and trust that increased research will shed light on this medical mystery..

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If there is one thing I can leave the reader with, it is this: at my first MPN support group meeting in Edmonton, a member asked if the group was going to split into the 3 types (ET, PV and MF). I felt the dread of not fitting in to one group. The astute and compassionate group leader said “No, we have one individual who is unclassified”. The dread left me and we remained in one group circle.

Perhaps the kindest thing is to help MPN-U patients feel included and part of the MPN family. Our common humanity and MPN plight is greater than our differences and our labels.

Learn more about MPN subtypes, including MPN-U

Support Group Profile: British Columbia

The British Columbia MPN support group today hosts near monthly MPN zoom calls with patients/caregivers located throughout the province. We came into existence about 15 years ago with the help of the Leukemia and Lymphoma Society of Canada who hosted our gatherings for several years. However, with their office changes as well as Covid, we shifted to this online support group, which has enabled us to support patients throughout BC rather than only those in the lower mainland (greater Vancouver).

At a typical zoom meeting, we usually have 10-12 patients/caregivers join, and it’s generally just a place to discuss issues related to living with an MPN. Most are regulars but we do get the occasional newly diagnosed patient participating so we often will share some disease basics to help bring them into the fold. Various members often update the group with their prognosis and treatment, and we help share knowledge on various symptom treatments. It’s been a great forum to put many things in perspective.

Beyond the zoom meetings we also have a BC MPN Facebook page where members can post to the group to elicit feedback on their specific issue/question(s).

Later this fall, our local MPN specialist, Dr. Lynda Foltz, will be returning to make another presentation to our group. Dr. Foltz treats many of us, including myself, and regularly runs various clinical trials to expand/refine treatments for those living with an MPN. Patients are referred to our group by LLSC, through our BC Facebook page as well as the Canadian MPN Network. I am also a first contact with the LLSC and often speak to patients in other provinces where I’ll pass their contact details on to the support group in their area (with their permission).

We welcome new BC patients/caregivers - please contact Mark Williams at vancouver@canadianmpnnetwork.ca

This newsletter was produced in partnership by the Canadian MPN Network, Canadian MPN Research Foundation and Canadian MPN Group.