NEWSLETTER

Bloodline *MPN*

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

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Welcome to The Bloodline MPN

In this issue:

MPN & Myelofibrosis Community Update – Canada
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Submitted By: Merrill Pierce CMPNRF Board Chair

What's New in Canada: Myelofibrosis (MF) & Blood Cancer Research

1. Canadian Treatment Landscape & New Approvals

- Treatment of Myelofibrosis in Canada follows guidelines such as those published by the Canadian MPN Group: diagnosis involves blood count testing, bone-marrow biopsy, mutation testing (JAK2/CALR/MPL) and risk scoring. Alberta Health Services+1
- The drug Ruxolitinib (brand name JAKAVI®) was approved in Canada for MF in 2012, marking the first treatment option for Canadians. mpnresearchfoundation.org
- More recently, Momelotinib (brand name Ojjaara®) was approved by Health Canada in November 2024 for adult MF patients with moderate to severe anemia and other symptoms. Life Sciences British Columbia+1
- Ongoing Canadian clinical trials include e.g. a Phase 3 study of Pacritinib versus physician's choice in MF with severe thrombocytopenia in Canadian centres. providenceresearch.ca

What this means: If you or a loved one are in Canada with MF, there are multiple approved therapies and active trial opportunities — especially if blood counts (anemia, platelets) are problematic. Ask your hematologist about locally approved options and trials.

2. Focus Not Just on Symptoms - Improving Quality of Life

- According to the Canadian Cancer Society, MF may often start slowly — if you have no symptoms, you may be closely monitored ("watch & wait"). Canadian Cancer Society
- A key Canadian guideline notes that in patients with intermediate or high-risk MF, symptomatic disease should be treated (commonly with a JAK inhibitor) rather than only supportive care. Alberta Health Services
- With the approval of momelotinib, Canada now has therapy targeting both spleen/constitutional symptoms and the important complication of anemia (low red- cells)

What this means: When discussing care with your doctor, ask: "What is the goal of my- treatment?" — symptom relief (spleen size, night sweats, fatigue) and/or improving blood counts and quality of life.

3. Clinical Trials & Research in Canada

- Rare disease status: MF is very rare in Canada (approximately 1,400-2,200 people estimated to live with it). Life Sciences British Columbia+1
- Research efforts in Canada include national programs for MPNs (myeloproliferative neoplasms) which include MF, offering access to clinical trials and expert centres. Personal Health News+1
- Example: Canadian centres are recruiting for the pacritinib Phase 3 trial (for MF with low platelets) through institutions such as UBC/St. Paul's Hospital. providenceresearch.ca

What this means: Clinical trials in Canada are accessible; ask your hematologist or contact MPN research groups about available trials in your province. Trials may offer novel therapies especially if standard treatment is no longer effective.

4. Practical Tips for Canadian Patients & Caregivers

- Mutation & risk-testing: Ask if you've had testing for JAK2, CALR, MPL, and what your risk classification is (e.g., low, intermediate, high risk) — these inform treatment decisions.
- Approved therapies: Know the approved options in Canada (e.g., ruxolitinib, fedratinib, momelotinib) — ask what is optimal for your situation.
- Trial conversation: At every visit, ask "Are there trials in Canada applicable to me?"

Share any interest in trial participation

- Symptoms & counts monitoring: Track key symptoms (fatigue, night sweats, bone pain, fullness under ribs) and blood counts (hemoglobin, platelets) — keep copies of labs.
- Support resources: Reach out to patient advocacy groups and MPN-specialist centres — they often provide info on Canadian clinical trials, peer support, and educational materials.

Canadian MPN Research Foundation (CMPNRF)

Working together for better treatments and a stronger future for everyone affected by MPNs.
Visit: cmpnrf.ca
Contact: info@cmpnrf.ca

Support Group Profile: Southern Alberta

The Southern Alberta MPN Support Group provides education, information and support to patients and care partners from Central Alberta (Red Deer) south to the U.S. border. We also support a number of patients from Central and Southern Saskatchewan. We now have an active Facebook Page – MPN Southern Alberta. The Coordinators of this active and growing group are Lyle Berge (care partner, Bev Berge) and Jane Burns (care partner, Susan Murray). Hybrid (in-person and Zoom) meetings occur three times annually in January, April and October and are held at the beautiful Wellspring Randy O'Dell House in Calgary (Seton). An additional two virtual (Zoom) meetings were added this year in July and September to support members who wish to connect, share experiences and build community in between our major meetings. In the spirit of Western hospitality, we also hosted a Spring BBQ at Wellspring Carma House, in advance of the greatest outdoor show on earth, the Calgary Stampede.

The group has a strong patient education focus and we are very fortunate to have the commitment from two MPN specialists and Canadian MPN Network Champions, Dr. Sonia Cerquozzi and Dr. Michelle Geddes from the Arthur E. Child Comprehensive Cancer Care Centre, Canada's largest cancer research and treatment centre. We also receive excellent patient education on a wide variety of MPN-related topics from Nurse Practitioners/Nurses, specifically Baljit Randhawa, Alyssa Sellars, Rebecca Tidswell and Ashley Zhang based at the ACCCCC's Malignant Hematology and Bone Marrow Transplant Clinics. We also receive ongoing, dedicated support at our hybrid meetings from Desiree Naylor, Community Services Lead, LLSC. Along with this strong education focus, our goal is to increase opportunities for informal, social engagement.

In addition, we are striving for ways to better serve Young MPN Patients (aged 18-39) as we are seeing an increase in numbers and these patients have very unique needs. This perhaps speaks to Alberta demographics as one of the provinces with the highest number of young families. It is estimated that 10-12% of all MPN's are young patients, with 20% of PV patients being under the age of 40.

One of the unique features of this support group is the incredible spirit of volunteerism, MPN community involvement and teamwork, which makes the dream work.

We had 39 patients and supporters form Team MPN Southern Alberta for the LLSC's Light the Night Event in Calgary on October 18th. We joined together with our banner to raise awareness of MPN's, support and uplift the entire blood cancer community and to feel the love of family, friends and supporters as we raised our bright, colored lanterns to light the night skies. As the saying goes, "*Hope is not about wishful thinking, it is about taking action*" and in the words of MPN Specialist, Dr. Gabriela Hobbs, "What we need in the treatment of MPN's is not an evolution but a revolution!" *Submitted by Jane Burns*

Acknowledgments go to the following individuals in recognition for volunteer hours freely given:

Meropi Mordacq – young patient serving on the CMPNN Board of Directors and Advocacy Committee

Erika Takahasi – young patient serving on the Education/Conference Committee

Stephen Carroll – Team Captain, MPN Southern Alberta, LLSC Light the Night Event

Svetla Minkova – researches MPN-related articles and studies

Darcy Carrick – pit boss/grill master

From the CMPNRF and Physicians Group – we are happy to share a listing of clinical trial's currently underway.

Title/Description	Trial Name	Canadian Site(s)	Sponsor(s)
Odyssey: A Phase 2 Open-Label Study of Momemlotinib in Combination with Luspatercept in Patients with Transfusion-Dependent Myelofibrosis	Odyssey	Jewish General Hospital MUHC	GSK
Phase 3: Pacritinib vs best available therapy in severe Thrombocytopenia	PACIFICA	Jewish General Hospital UBC	CTI BioPharma/SOBI
Phase 1/2: Nuvisertib (PIM kinase inhibitor) in Post - JAKi Myelofibrosis	BBI - Tp3654	Jewish General Hospital MUHC	Sumitomo Pharma Oncology
Bispecific anti-CALR antibody (Johnson & Johnson - title pending)	anti - CALR(Bi)	Jewish General Hospital MUHC	Janssen/J&J
Monoclonal anti-CALR antibody (academic or pharma - title depending)	anti - CALR(Mono)	Jewish General Hospital MUHC	Unknown
AlloSCT vs best available therapy in Transplant - Eligible MF patients (Investigator - Initiated)	ALLO - BAT	Jewish General Hospital MUHC	PM Cancer Centre/ Canadian Academic
Selinexor in frontline MF (JAK - naive patients) - Platlet cutoff being amended to allow broader inclusion	XPORT - MF - 044	Jewish General Hospital MUHC	Karyopharm Therapeutics

Exciting Announcement - Young MPN Patients Canada
I am thrilled to announce the creation of a new CMPNN support group. Young MPN Patients Canada will be a virtual, national support group that addresses the needs of young MPN patients aged 18-39 across Canada. The group's primary focus will be psycho-social support, patient education that is specific to the young population and young MPN patient awareness. This is about creating a safe space where young people can connect, share their experiences and learn about their illness in a spirit of camaraderie and friendship. This group could also help inform and shape future initiatives related to young patients in the areas of advocacy, research, pharma and academia. But the ultimate goal of this group is to create and build strong resiliency for young MPN patients who face decades ahead of living with this illness.

The Inspiration
I am deeply and personally committed to supporting and developing our young patients. When I became a support group leader in Calgary three years ago, I noticed a rising number of young patients accompanied by some challenges with young patient engagement. As I grappled with how best to serve this overlooked and sometimes unseen population, two young members became involved in the support group. They have gone on to take roles on the Advocacy Committee, Education Committee and Board. Their stories were compelling and I knew I needed to respond in a way that challenged me as a "traditional" group leader of an older population. When I attended the Global MPN Advocacy Network Conference in Warsaw, Poland in 2024, shivers went up my spine as an unassuming young lady from MPN Voice UK took to the stage to talk about the establishment of a Young Patient Network in the UK. Some heroes don't wear capes and she is one, Alice Watson was diagnosed at 21 is now a professor at Oxford University, England. Everything she talked about lined up with what I was experiencing in the interactions within my own support group. I began researching the topic in 2024 and have gathered up all the articles and studies I could find, which is not much at all, sadly. My final inspiration is Sean Carroll, a young MPN patient from the Maritimes, with ET that progressed to MF and within 4 months, progressed to AML. Sean died before transplantation could occur and his brother, Stephen, volunteers with our support group, carrying a gold lantern and our Team MPN Southern Alberta banner at the recent LLSC Light the Night Event. My inspiration is every young patient living with an MPN and the long journey ahead of them as they navigate life with a chronic blood cancer.

The Young MPN Patient Population - Overall
It is important to note that while WHO diagnostic criteria and guidelines for the diagnosis of young patients under 40 do exist, the European guidelines are currently under development and are being re-written as we speak, based on new learnings about young patients. Some European countries, such as Germany, have chosen not to classify young MPN patients into ET, PV or MF due to the many blurred indicators and the tendency for patients to move back and forth between types. It will be interesting to see how this all plays out. It is generally thought that 10-12% of all MPN patients are young, but for PV that figure is 20%. MF is rarer in young patients. Triple negative ET patients are more common in the young population, as are females and those with CAL-R mutations. Numbers of young patients are increasing due to better diagnostics and more frequent blood testing. Medical concerns include optimal treatment regime, long-term toxicity of medications and disease progression. It is hard to estimate and extrapolate young population numbers, but in the UK (population 60 million) there are approximately 220 actively engaged young patients in their Network. We might predict that Canada, with a population of 41 million, could have as many as 150 young patients.

Medical
Young patients are discovered and present with more serious complications. They experience much higher rates of venous thrombosis and higher risk of hemorrhagic events. Special considerations need to be given for fertility (male and female) and family planning when treating. There is an increased risk for transformation to AML but this generally occurs well into adulthood. They will live with an MPN for decades and not much is known about long-term toxicity of drug treatments. Bleeding complications from trauma are more at risk due to engagement in sports and other activities. Work is going on in the UK and Europe related to the creation of a distinct symptom profile for young patients, as symptoms may present differently from the older population. Interferon has proved to be a promising treatment to reduce the JAK2 allele burden and induce molecular remission in young patients. Advancements are underway in the areas of genomics, the immunome, AI and big data, and drug treatments. There is a need to study meaningful endpoints, such as target hematocrit levels in young patients which are different from older patients, as well as prognostic criteria for transplant.

Psycho-Social

This is where the highest burden lies, as young people struggle with mental health, quality of life issues and navigating through various developmental life stages. These struggles take a toll on the body and minds of young patients and can further exacerbate the symptom burden and decrease resiliency and coping skills. Notwithstanding an MPN diagnosis, the statistics in Canada are staggering, with over 1 million young Canadians reporting significant mental health concerns like anxiety and depression. Add on an MPN and you have a disaster waiting to happen. Young MPN patients I have interacted with express the following concerns and questions:

- Will this shorten my life?
- Will I be able to continue my studies?
- Will I need to consider a career change given my physical limitations?
- Will this affect my dating life and when should I disclose this to a potential partner?
- Will I be able to get pregnant and have a family?
- Will I need to stay living at home and be a burden to my family?
- Will I be able to travel?
- Will I be able to obtain life insurance?
- Will this affect me financially and will I ever be financially independent?
- Will this affect my career prospects and my ability to obtain/maintain employment?
- Will this isolate me socially and impact my ability to make friends?
- Will I ever be able to live a normal life?
- Will I ever meet another young MPN patient like myself?
- Will I always have to attend a support group with people the same age as my parents, grandparents and even great-grandparents?
- Will I ever be able to participate in a support group that only meets Saturday mornings? That's when I have classes, or work, or have activities with my young children!!
- Will I be able to volunteer and contribute to my local support group and the CMPNN in a way that balances my obligations with school, employment and young family?

The Road Ahead

Starting in January 2026, the group will meet virtually 4 times annually. Watch for an announcement coming out in December. Speakers will be brought in to speak on a variety of topics of interest to young patients. A closed Facebook group will encourage connection and give voice to young patients. It will take some time to grow this new group, as with any initiative. The group will help supplement resources and programs already in existence for young cancer patients (all cancer types) within the health system and broader community, such as AYA, YACC and Wellwood/Wellspring. But as young one person told me, "I just want to talk to another young person with an MPN and similar issues to me". This new group aims to meet that need. Also, we have an opportunity to collaborate with the young patient group in the UK and they have been extremely positive and supportive of the Canadian initiative. Together, let's help our young MPN patients build their resilience!

Anyone interested in finding out more information about the group or helping support this initiative in any way, please contact Jane Burns at jane.burns@canadianMPNnetwork.ca.

Submitted by: Jane Burns, Vice-Chair CMPNN | Group Coordinator, Young MPN Patients Canada | Group Co-Coordinator, MPN Southern Alberta | Education Committee | Advocacy Committee | Ambassador and First Connector, LLSC

Our **PATIENT SUPPORT GROUPS** are for Canadian MPN patients, their families and care partners. They are patient-run and dedicated to provid ng education and support.

Meetings are either held in person (subject to a safe COVID environment), on Zoom, or on Facebook. All group members follow a Code of Ethics to protect participants' privacy. If you would like to join a Support Group, or just have a few initial questions, we would love to hear from you!