

The CANADIAN MPN Newsletter



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On behalf of the Canadian MPN Research Foundation (CMPNRF) and the Canadian MPN Network (CMPNN), it is our pleasure to welcome you to our inaugural and much anticipated newsletter. This quarterly newsletter will be dedicated to keeping you up-to-date on the latest MPN research, advocacy, and support initiatives in Canada, and around the world.

This year has been like no other. It has been a year filled with challenges in all aspects of our lives. But our focus and commitment have remained steadfast during this unprecedented time and we are proud of our progress in the areas of research, patient and physician support, and pharmaceutical partnerships.

You are not alone. We are here to stand with YOU as your partner, advocate, and friend in the fight against the group of blood cancers collectively known as 'myeloproliferative neoplasms'.

Join us on this journey and we will be stronger together.

Best wishes,

Merrill E. Pierce, Chair, Canadian MPN Research Foundation
Joanne McKinley, Chair, Canadian MPN Network

A PATIENT'S JOURNEY:

Advocacy for Marie

by John Eastly & Marie Grenier-Davis

Marie Grenier-Davis is always on the go. "I have a hard time slowing down," she says. In 2016 she was recovering from breast cancer and getting back to work as a global IT manager for Kraft Heinz. "I loved my team, the travel, working with suppliers like Microsoft. I had a great manager. This job was my life." She was struggling, however, with fatigue all the time.

While educating herself with breast cancer, Marie discovered a trending pattern of elevated platelet levels. Her family doctor at the time attributed it to fighting the flu. When Marie correlated her labs back to 2010, she discovered a definitive trend. She switched family doctors to the walk-in clinic physician, Dr. Rana, who shared her concerns. Marie presented her findings to her oncologist, Dr. Strang, who was attentive and compassionate. They reviewed her lab results spreadsheet after which she was referred to hematology. After running bloodwork, Dr. Hillis, her hematologist, diagnosed Marie with Essential Thrombocythemia (ET), JAK2 positive.

Learning that she had a Myeloproliferative Neoplasm (MPN) came as a shock, coming on the heels of her successful treatment for breast cancer. "With breast cancer, you have surgery, you take the treatments, and then you move on" she said. "But with an MPN, it's not curable. You have it forever. It's very frightening."

After Dr. Hillis diagnosed her, Marie realized that she had been dealing with MPN symptoms for years: bruising, bleeding, pins and needles in her hands and feet, fatigue, and night sweats.

"The night sweats were unbelievable," says Marie. "I was 52, so people thought it was menopause." The pins and needles in her feet had been diagnosed as Plantar Fasciitis.

Dr. Hillis prescribed Aspirin 81mg twice daily along with Hydroxyurea (HU) and urged her to go on disability. Although she was reluctant to give up her job, the demands were too much to handle given her constant fatigue caused by ET.

Despite the Hydroxyurea her platelet levels continued to climb. In less than a year, they jumped from 500,000 to 800,000. "At this time, I had a lot going on. The HU was to alleviate the MPN symptoms: to stop the bleeding, the pain, the night sweats." Her immune system was weakened and she couldn't fight infections. She experienced 10-15 urinary tract infections (UTIs) in a year. She had several back-to-back ear infections, and repeated styes in her eyes. "Nobody was looking at my health holistically. Dr. Hillis stepped in and really took charge of my overall health, in collaboration with Dr. Rana, my family physician, who is concerned about me and really wants to learn more about Myeloproliferative Neoplasms."

In 2019 they tried Anagrelide, a drug specifically used to control the overproduction of platelets. This drug caused her heart to race and chest pain. Her platelets kept climbing. Having determined that the limited number of approved medications was unsuccessful with Marie, Dr. Hillis thought that Marie was a good candidate for Pegasys.



Pegasys is a long-acting interferon. Interferons are proteins that modify the response of the body's immune system to help fight infections and severe diseases. Pegasys is used to treat chronic hepatitis B or C, which are viral infections of the liver. Pegasys is not approved in Canada for treating MPNs, but studies and experience from other countries show that it can be effective for MPNs. In Europe, Pegasys is one of the first-line treatments to treat MPN diseases. Using an approved drug for a different disease is called off-label access. Marie submitted applications to her corporate health insurance for off-label access to Pegasys, as well as to her husband Bill's corporate insurance. She was rejected by both. They appealed to both, and were rejected again.

That's when the Canadian MPN Network (CMPNN) stepped in to help advocate for Marie. Dr. Hillis applied to Cancer Care Ontario for Pegasys. Sarah Fernandes, a Drug Access Facilitator at the Juravinski Cancer Centre, worked very hard to help Marie through the application process. The CMPNN and MPN Ontario provided advocacy letters, along with references to the various studies that show how Pegasys can be an effective treatment to treat MPN diseases. Sarah attached these letters to the applications.

In November 2020, after more than a year of struggling through the application process with the invaluable support of the Juravinski team, Marie started weekly injections of Pegasys. Pegasys has a reputation of triggering depression, which was a great concern to Marie; Dr. Hillis was agreeable to starting her on a low dose but it was critical to be able to show progress to Cancer Care Ontario, so they ramped up the dosage based on her tolerance. "Pegasys activates your immune system, so you have flu-like symptoms: aching, tiredness, headache." The first three weeks were very tough, Marie would be knocked down for a couple of days after each dose. Over the following weeks, in consultation with Dr. Hillis, Marie gradually increased the dosage until she reached the prescribed dose of 90mcg in January 2021.



"It's too early to tell what impact it will have," says Marie; "Pegasys is a long-term drug. It can take many months before you start seeing progress." But she is hopeful of improvement. "I live in fear of heart attack and stroke because my platelets are so high. Easing that fear would be such a relief." Reducing other symptoms, like tingling, fatigue, and bleeding, would also be welcome. "I went from a highly functional professional to a woman who is trapped at home. Freeing me from these symptoms would give me my life back."

The process of going to compassionate care is complex. "There are regulations on how the drug has to be administered, by whom, and where. Remember, you're off-label, so you're not covered by your provincial health care." Marie is deeply grateful to the people who helped her navigate through the process. "It's so important to find the right people to support you. Dr. Hillis, my hematologist, is extraordinary: he listens to me, looks deeply for answers, and fights for his patient's best care. Sarah Fernandez knows the ins and outs of applying for off-label treatment and compassionate care. Kirk, the pharmacist at the Juravinski Cancer Centre, monitors my medications and makes sure everything gets delivered on time. They are all amazing people."

Some people don't have access to this kind of support team: a hematologist who knows MPNs, a cancer centre, specialists like Sarah who can guide you through the system. "If your doctor isn't an MPN specialist, do they know how to advocate for an off-label drug? How will they even know about the off-label treatments that could help you?"

Marie feels lucky: she has a supportive husband, three amazing daughters, and a group of close friends. She is also grateful to be supported by MPN Ontario, the Canadian MPN Network, and her MPN family.

For MPN patients like Marie, the Canadian MPN Network can provide information and contacts to help guide them through the process. "If you suffer from an MPN; knowledge is gold," says Marie. "The more information you have about your disease, the more you're in control and the more you can advocate for yourself. And if you can't, the Canadian MPN Network is there, with an experienced team to support and advocate with you."

The 6th Annual
CANADIAN

MPN Network Patient Conference

If you missed the conference in
September you can catch it on
YouTube.
Now with French subtitles!

Part 1



Part 2



If you would like to
**subscribe to our
Newsletter**
or just give us some
feedback, please email us
at admin@cmpnrf.ca
and put 'Newsletter' in
the subject line.

Interested in joining us?

Both the Canadian MPN Network
&
the Canadian MPN Research Foundation
are looking for new Board and Committee members.
We welcome your interest and questions – just send an email to either:

canadianmpnnetwork@gmail.com

or

admin@cmpnrf.ca

**Click here to check out the latest
CANADIAN
MPN
CLINICAL TRIAL
Information**



How to Double Your Donation: The PM Hope Fund

In the fall of 2018, Wim Smits and his wife Harriet Randall, created the Primary Myelofibrosis (PM) HOPE FUND to support new research, better treatment options, and hopefully a cure for PM. Wim and Harriet will generously **match every dollar donated**, up to \$10,000.00. **Click here** to donate to the fund. Your donation is greatly needed and much appreciated.

Our **PATIENT SUPPORT GROUPS** are for Canadian MPN patients, their families and care partners.

They are patient-run and dedicated to providing education and support.

Meetings are either held in person, 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, please get in touch with the closest group in your region:



British Columbia	vancouver@canadianmpnnetwork.ca
Alberta	southernalberta@canadianmpnnetwork.ca northernalberta@canadianmpnnetwork.ca
Manitoba	manitoba@canadianmpnnetwork.ca
Ontario	mpnontario@canadianmpnnetwork.ca (Southwest ON incl. GTA) barrie@canadianmpnnetwork.ca (North of GTA) ottawa@canadianmpnnetwork.ca (East of GTA)
Quebec	quebec@canadianmpnnetwork.ca
Atlantic	atlantic@canadianmpnnetwork.ca

Interested in starting a Patient Support Group in your area?

Our Support Group Co-ordinators will help you get started, provide you with guidelines, documentation, and on-going support. For more information please get in touch with either:

Doug Chisholm for Western Canada at doug.chisholm@canadianmpnnetwork.ca
John Clark for Eastern Canada at john.clark@canadianmpnnetwork.ca

THANK YOU, DOCTORS!!

We would like to take this opportunity to send a big *Shout Out* to all the doctors that have participated in our Support Group Meetings to answer our members' questions and concerns – they are:

Dr. Sonia Cerquozzi

Clinical Assistant Professor, University of Calgary

Dr. Lynda Foltz

MPN Specialist, St Paul's Hospital, University of British Columbia

Dr. Michelle Geddes

Hematologist and Clinical Assoc. Professor, University of Calgary and Tom Baker Cancer Centre

Dr. Christopher Hillis

MPN Specialist, Juravinski Cancer Centre, Hamilton

Dr. Brian Leber

MPN Specialist, Juravinski Cancer Centre, Hamilton

Dr. Shireen Sirhan

Assistant Professor, Oncology, McGill Hematologist and Medical Oncologist, Jewish General Hospital, Montreal

Dr. Pierre Villeneuve

Assistant Professor, Faculty of Medicine, University of Ottawa

About us...



The **CANADIAN MPN NETWORK**

(CMPNN) is a patient-led organization. Our Mission is to improve

the lives of all Canadians living with myeloproliferative neoplasms (MPNs) 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.

A highlight of this year was our National Conference which was held online for the first time due to Covid 19. Our guest speaker was Dr. Claire Harrison, an international expert in the MPN field, who provided the latest MPN research developments from a global perspective. We were also honoured to have Dr. Vikas Gupta, from The Canadian MPN Centre at Princess Margaret Hospital in Toronto, who provided a Canadian perspective and answered questions from the audience.

And I am pleased to report we now have 9 Patient Support Groups across the country. (Please see the article on Support Groups for more information).

Our Board meets regularly to discuss developments and issues related to Our Mission and is supported by our 5 hard-working Committees: Finance, Communications, Advocacy, Education, and Conference.

Much has been accomplished this year but there is still much to do!

Sincerely,
Joanne McKinley

Chair, Canadian MPN Network



At the **CANADIAN MPN RESEARCH**

FOUNDATION (CMPNRF) we are committed to standing with you in the fight against polycythemia vera (PV), essential thrombocythemia (ET,) and myelofibrosis (MF) – the group of blood cancers collectively known as myeloproliferative neoplasms (MPNs).

Our Scientific Advisory Board plays a key role in ensuring that our research strategy and our annual grant programs are aligned with the Foundation's mission – to stimulate critical research and ultimately a cure for MPNs.

Our Executive Director, Cheryl Petruk, (who is also the Executive Director for the CMPNN) advocates for new drugs on a national level.

Our Board of Directors is comprised of MPN patients, MPN patient family members, and leaders among industry and non-profit organizations. Their expertise guides the governance of the Foundation as we make decisions on research and patient advocacy initiatives.

The CMPNRF is a Registered Charity with Canada Revenue Agency. Donations can be designated for research, patient advocacy, or special funds - as well as 'In Honour of' donations to commemorate a person or event, and 'In Memory of' donations to mark the passing of a loved one. We issue Official Tax Receipts for all donations.

On behalf of the CMPNRF Board of Directors, we wish you the very best and ask that you stand with us as together we are so much stronger.

Best,
Merrill E. Pierce

Chair, Canadian MPN Research Foundation