

The CANADIAN MPN Newsletter

A joint publication from the Canadian MPN Network (CMPNN) and the Canadian MPN Research Foundation (CMPNRF) for MPN patients, care partners, and their families.

Like so many other organizations and businesses, the **Canadian MPN Network** has continued to adapt to the challenges of operating in the Covid 19 environment.

Our Patient Support Groups have implemented Zoom and Facebook meetings until in-person meetings can resume in each respective region. They also continue to counsel Members by phone and email.

We have upgraded our website and it now provides a more extensive range of information - an important resource for MPN patients diagnosed with ET, PV or MF.

Our various committees - Advocacy, Group Support, IT, Conference, Communications, and Finance - have remained very active as well with a number of projects underway.

During Blood Cancer month in September 2021, we held our National Conference via Zoom. Presentations were made by two outstanding MPN specialists: Dr. Naveen Pemmaraju from the MD Anderson Cancer Centre in Houston on Quality of Life, and Dr. Shireen Sirhan from Jewish General in Montreal on **Canadian MPN Updates**. A Q & A with the virtual audience followed. (The conference can be viewed on YouTube. French subtitles available.)

We are currently preparing for our next virtual National Conference in September, 2022. (See pg. 6 for details). On behalf of the CMPNN Board of Directors I would like to wish you all the best for 2022!

Joanne McKinley, **Chair, Canadian MPN Network**



It is a very exciting time for the Canadian MPN Community! The MPN Genie app is LIVE! It has been created for the entire MPN community, for patients to track their quality of life symptoms, for physicians to be able to see the quality of life symptoms of their patients on a longitudinal basis, and use the information in their ongoing treatment and diagnosis. It can be used for the research community to anonymize data to help them come up with new treatment options for MPN Blood Cancers. We hope that all Canadian MPN patients will download the app for their iOS or Android. For more details on the MPN Genie app, visit <https://www.cmpnrf.ca/genieapp>.

We are also excited to update our community about the Sole 2 Soul Trek which took place in August. This was a very inspirational, impactful, meaningful opportunity to not only raise funds but also to bring the needed attention to those afflicted with a MPN Blood Cancer.

Cheryl Petruk, **Executive Director**

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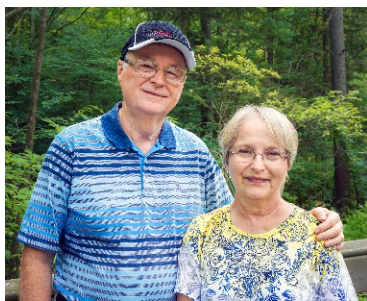
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Tribute to a Pioneering Canadian MPN Hero



Donna with husband Bob

DONNA WEST, a champion for MPN patients, in Canada, passed away on June 22nd, 2016 in Hamilton, Ontario at the age of 69 from complications related to her MPN. First diagnosed with ET more than 30 years before, which transformed

into PV and eventually MF, Donna used her background as a practicing nurse to become very knowledgeable about MPNs at a time when little was known about them. She was an adherent to the Patient Power motto that “knowledge is the best medicine of all”.

My first contact with Donna was through MPD-NET (now MPN -Net) in 1996, shortly after I was diagnosed with Polycythemia Vera. She immediately responded to the many questions I posed concerning this mysterious disease and calmed my fears - something she did countless times over the years for other MPN patients. Little did I know she had been doing the same thing for other MPN patients for quite some time.

In 2008 Donna underwent an allogeneic stem cell transplant at the Fred Hutchison Cancer Center in Seattle and enjoyed four years of good health following the transplant but unfortunately relapsed in 2012 and her health began to decline.

Donna had a long and often difficult MPN journey, but not once did I hear her feel sorry for herself. Instead, she used her time to help other patients and their care partners by establishing the MPN Ontario Patient Support Group in 2012 and it quickly become one of the most successful patient-run MPN support groups in Canada, reaching out to patients and caregivers all around Southern Ontario.

Everyone who either met Donna in person at one of our meetings or was counselled by her by telephone or email knew what a truly special person she was. Her compassion for others, her amazing knowledge of MPNs and ability to convey that knowledge in a caring and supportive way was amazing. When one of our MPN Ontario members underwent a transplant, Donna and husband Bob unhesitatingly opened their home to both the patient and her care partner for months, enabling her to stay close to the hospital for pre and post-transplant care.

When Donna shared her “patient story” with others at our Ontario MPN meeting on June 4, 2016, little did we know that she would enter the hospital later that day for the last time.

Stories shared by friends and family of their affection for Donna at a crowded Celebration of Life service on July 9, 2016, demonstrated how special many people thought she was and that her compassion extended far beyond the MPN community. Donna, like the many other patient support group leaders in our MPN community continue to do, touched many people through her efforts to improve the lives of MPN patients.

John Clark - Coordinator, MPN Ontario

Introducing... The CMPNN Advocacy Committee

Our Mission is to advocate for CMPNN members by supporting medical professionals in their efforts to access new and off-label treatments for MPN patients.

We identify and pursue our advocacy initiatives in collaboration with our Board, Executive Director, and Support Group Coordinators.

Our Committee Members include CMPNN Regional Support Group Coordinators, CMPNN Board Members, and MPN Patients.

Our 2020 - 2021 initiatives included:

- Developing a “roadmap” to help MPN patients request financial support for off-label drugs and treatments.
- Created a database of hematologists currently treating Canadian MPN patients.
- Conducted a direct-mail outreach campaign to Canadian MPN hematologists to increase awareness of our ability to A) assist them with their MPN patient advocacy initiatives, and B) connect them with CMPNN Members for MPN clinical trials.

The Canadian Hematology Society subsequently included an article on the CMPNN's advocacy abilities in its newsletter to its Members.

- Organized with other Canadian support groups to encourage provincial governments (Minister of Health, Chief Medical Officers (to offer expedited doses of the COVID-19 vaccine for vulnerable blood cancer patients and stem cell transplant patients.

Going forward we'll continue to focus on providing ongoing assistance for MPN patients and their treating physicians to access recommended treatments not covered by provincial health agencies.

If you would like to help us in our efforts and join the Committee, please get in touch with [John Clark](#), Advocacy Committee Chair.

A PATIENT'S JOURNEY: Meet Wim Smits

A note from the Executive Director: It is with deep gratitude that we thank Wim and other MPN patients for sharing their deeply personal stories. Their willingness to impart the intimate details of their journeys hopefully provides other MPN patients and their families with hope, clarity, a sense of community, and a roadmap for their own journeys.

Part 1 - The Diagnosis

On Tuesday, November 27, 2018, the news came as quite a surprise. Neither I nor my wife had ever heard of a rare bone marrow cancer disease called Primary Myelofibrosis. Now we're being told that I have it and it is terminal. The only potential cure is a high-risk bone marrow transplant. The statement by my Hematologist/Oncologist, that this disease would likely "impact my longevity," was quite shocking. I knew she didn't mean that it would impact my longevity in a positive way.

As a relatively active and otherwise healthy 65-year-old male, I was not prepared to hear that. I was still biking, swimming, working out at the gym and sea kayaking on Lake Superior. I was enjoying retirement, travelling and having a great time being an 'opa' to my grandkids. I was not experiencing any of the known effects of this disease and was, and still am, in no pain and symptom free. I know I'm not invulnerable but this diagnosis didn't seem possible.



This all began in July of 2018, when routine blood work done during my annual physical, revealed that I had some abnormal blood counts. Repeating the blood tests confirmed the counts. As a result, my family doctor referred me to Dr. Nicole Laferriere, a Hematologist, Chief of Oncology and Medical Director at Regional Cancer Care Northwest, at the Thunder Bay Regional Health Sciences Centre for further testing. The referral to the cancer centre I was told, did not mean that I had cancer. It was just the place where the Hematologists work. At the cancer centre, more detailed blood work was done which included a CAT scan, an abdominal ultrasound and a bone marrow biopsy. These tests revealed that I had this rare cancer.

Dr. Laferriere did her best, in the short time we had, to explain the basics of this disease. One significant thing she pointed out was that there was at least a potential cure in a successful bone marrow/stem cell transplant. She also asked if I would like to be referred to Dr. Gupta, a world-renowned expert in this disease, at Princess Margaret Cancer Centre (PMCC) in Toronto. Unfortunately, due to my sister's previous experience with Princess Margaret Cancer Centre during her battle with breast cancer, I was aware of the excellent care provided there. I agreed without hesitation. We were also offered, and took advantage, of counselling at the Thunder Bay Regional Health Sciences Centre.

Of course, when we got home, we immediately began searching out information on this disease in an effort to understand it as best we could. We needed to know what we were dealing with. Among the many sources of information available online, we found the Canadian Myeloproliferative Neoplasm Research Foundation (CMNPRF). We are glad we did.



After learning as much as we could, we had to face the difficult task of informing our family. We felt that this diagnosis could not and should not be kept a secret. The first challenge was informing our now adult (28 yrs. old) children. Fortunately, one of our closest friends was a public health nurse. So, after first informing her and her husband of the diagnosis, we asked if they would assist us in telling our children. Being the great friends that they are, they agreed. As I said, it was a difficult thing to do. I choked, tears flowed, but with the support of these friends, we got through it.

The next step was to inform my brother and sister in southern Ontario. Living as we do in Thunder Bay, it was not easy to inform them in person. Having lost one sister already to cancer, the news of this cancer striking me would not be easy for me to share or for them to receive. To ease the burden, we decided to first inform two of my medically trained nieces and then have them break the news to my siblings. I think that went about as well as it could. Subsequently, we used email and phone calls to inform the rest of the extended family members.

That's how this journey started. Four years later, I am still on it. It is still evolving...



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 (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! Please see the chart below for contact information for your area.

[Would you like to start 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 (Western Canada): doug.chisholm@canadianMPNnetwork.ca

John Clark (Eastern Canada): john.clark@canadianMPNnetwork.ca

Region	Contact Info	Leaders
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MPN Ontario Patient Support Group Profile

The MPN Ontario Patient Support Group was formed in 2012 by two MPN patients, Donna West and John Clark, with the support of the group's medical advisor, Dr. Brian Leber, an MPN specialist at Juravinski Cancer Centre in Hamilton. Our group joined with the Canadian MPN Network in 2014 and is now one of nine support groups across the country.

Although based in Hamilton, our membership includes MPN patients and their care partners throughout Southern Ontario - from Windsor to east of Toronto and north to Georgian Bay and Sudbury.

Normally we meet three times a year at the Wellwood Juravinski House in Hamilton but during this COVID pandemic we get together virtually using Zoom until it's safe to meet in-person again. Although meeting online is not the same as in-person, it has allowed members to attend who are not able to travel to our Hamilton meeting and this is something we hope to continue to offer once in-person meetings resume.



As well as meetings, we also keep our members informed of new developments and treatments for MPNs, clinical trials and studies, and to provide personal support by email or phone, including to newly diagnosed patients and those about to undergo stem cell transplants.

A recent addition is our private MPN Ontario Facebook page that is open to all MPN patients in Ontario, including those in our group and our sister groups, MPN Barrie and MPN Ottawa. The page offers a venue where patients and their care partners can ask questions and share their experiences in a friendly, safe, and secure location.

Over the years our group has formed a real sense of community by supporting one another through difficult times and being able to understand what it is like to live with a rare chronic disease that most people have never heard of. Many members have even formed close personal friendships, and who could ask for more than that.

If you or someone you know is interested in learning more about our group or wishes to become a member, please contact us at mpnontario@canadianMPNnetwork.ca. Marie Grenier Davis, Joanne McKinley and John Clark: MPN Ontario Coordinators.

Announcements!

MPN Genie App
Launched April 2022



The Canadian MPN Research Foundation (CMPNRF) has developed an app that will change the way patients, physicians and researchers generate, share, and utilize MPN data. It will provide PATIENTS with the ability to track Quality-of-Life indicators and download that information to their physicians; this longitudinal data will let PHYSICIANS know how their patients are doing between appointments (rather than just how they present at clinic visits) and use that information in the ongoing development of the patient's treatment plan; and it will provide the MPN RESEARCH COMMUNITY with anonymized data that can be used to develop new treatment options.

The app will be available in both English and French, and for both android (Google Play Store) and iOS (App Store). For more details please [click here](#).

New Fundraising Effort To Support MPN Research

The CMPNRF is embarking on a new fundraising effort to raise funds for MPN research and to bring attention to the needs of those affected by an MPN Blood Cancer. This will be a very inspirational, impactful, and meaningful opportunity for patients, care partners, family, friends and other supporters - and all will be able to participate. More details soon! In the meantime, please consider [donating now](#).

Intravenous Aviptadil (VIP) Clinical Trial

An important Canadian clinical trial ('VIP study') is underway to determine how much immunity blood cancer patients - including MPN patients - have after receiving the Covid vaccinations.

Our February

NATIONAL CONFERENCE

is now available on YouTube
in English & French

Our next National Conference is in SEPTEMBER
All MPN patients, care partners & families are welcome!

Canadian MPN Champion Awards

The MPN CHAMPION AWARDS recognize patients, healthcare professionals, care partners, advocates and organizations that contribute to bringing understanding, compassion and strength to the Canadian MPN community. NOW is the time to start thinking about that person who has made a positive difference in your MPN journey!



Nomination forms will be available on the CMPNRF website soon. Winners will be announced at our September conference.

American Society of Hematology (ASH) DEC 2021 Conference Update

Each year at this annual conference new and innovative information about MPN Blood Cancers is presented to members of the global MPN Hematological community, including doctors, nurses, researchers, patient advocates, and other stakeholders from around the world.

Abstracts on hundreds of research initiatives into the causes and reasons why some people acquire an MPN were made available including, investigations into genetic factors, hereditary causal effects, germline mutations, etc.

Promising highlights included a new treatment option for patients with lower platelet counts using Pacritinib as a JAK inhibitor, and using Ropen interferon for existing interferon patients to transfer to, and as a new treatment option for MPNs.

It is encouraging to see how active the MPN hematological community of physicians and researchers are. Many of their abstracts are now available on the CMPNRF website if you would like to do some research of your own!

HELPFUL LINKS

Canadian MPN Network www.canadianmpnnetwork.ca

Canadian MPN Research Foundation www.cmpnrf.org

Patient Power www.patientpower.info

PV Reporter www.PVreporter.com

Facebook Canadian MPN Network

Our February National conference was held via Zoom on February 26. Our theme for the Conference was **Quality of Life**.

Dr. Kristina Gowin DO from the University of Arizona was a guest speaker. Following her informative presentation on strategies for improving quality of life, she answered questions from the audience.

Our second presenter was Dr. Dawn Maze MD from the Leukemia & Related Blood Disorder Program at Princess Margaret Hospital. She provided an update on MPNs and COVID.

Our February 2022 Conference is now available on YouTube in English and with French subtitles. Our next National Conference will take place via Zoom in September 2022.