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Canadian MPN Network **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.

Une publication conjointe du Réseau canadien du NMP (RCNPP) et de la Fondation canadienne de recherche sur le NMP (FCRNPP) pour les patients du NMP, les partenaires de soins et leurs familles.



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Message from Past Chair - *Joanne McKinley*

Welcome to the Spring 2023 edition of our MPN Newsletter. As the past Chair of the Canadian MPN Network Patient Advocacy I would like to introduce our new Chair, Doug Chisholm who is a Board member, patient and the leader of the Southern Alberta Support Group. Doug brings his enthusiasm and fresh ideas to our Canadian MPN Network Patient Advocacy.

Joanne McKinley - Past Chair of the MPN Network

MPN AI Project by Cheryl Petruk

The Khure Health and Canadian MPN Research Foundation are proud to announce the launch of their new MPN AI project. This project is a groundbreaking initiative that has the potential to revolutionize the way we diagnose and treat patients with myeloproliferative

neoplasms (MPN). MPN is a type of blood cancer that affects approximately 1 in 10,000 Canadians. It is a complex, chronic disease that can be difficult to diagnose and treat. With this new project, the Khure Health and Canadian MPN Research Foundation are utilizing the latest artificial intelligence (AI) technology to better understand the disease and develop better treatments. The project involves using AI to analyze large amounts of data from patient records, diagnostic tests, and disease-related studies. This data is then used to create a predictive model that can accurately identify patients with MPN and suggest treatments that are tailored to the individual. The project is a collaboration between the Khure Health and Canadian MPN Research Foundation, and is expected to have a major impact on the field of medical research. This project is an exciting advancement in the diagnosis and treatment of MPN. It is expected to lead to improved patient outcomes and better quality of life for those living with the disease. The Khure Health and Canadian MPN Research Foundation are proud to be at the forefront of this revolutionary new technological breakthrough.

Health E-Matters: Elevating Online Voices – Conference Report

October 27th – 29th, 2022
Toronto, Ontario

Kristen Hummel – CMPNN Board Member
Group Coordinator – Barrie Ontario MPN Support Group

Overview

The purpose of the Health E-Matters conference is to create and enhance online dialogues around cancer awareness and advocacy, while addressing the stigmas associated with cancer.

This conference was sponsored and presented by Myeloma Canada, and Myeloma patients were well-represented. However, cancer patients and advocates with many different diagnoses were present. I was the only representative for MPNs. Many pharmaceutical representatives were also present. Although this was the 2nd annual Health E-Matters Conference, the first one occurred in April 2022.

Accommodations, meeting rooms and all meals were provided by Radisson Blu Toronto. The was an excellent facility and I had no complaints whatsoever. I was particularly impressed with the close attention paid to various food allergies and other dietary restrictions by the hotel caterers. There were food options provided for whatever your dietary requirements.

Overall Impressions

There are 32 million social media users in Canada.

I do feel I walked away from this conference with greater tools and information regarding online cancer advocacy.

The message woven throughout this conference was “utilize your personal social media to engage with other cancer patients, caregivers and advocates.”

Although I was the only participant representing MPNs, it is important that MPN patients have a voice and space among other cancer diagnoses. Most other patients and advocates with whom I interacted had never heard of MPNs. One pharmaceutical rep indicated to me that polycythemia vera “is not really a cancer.” I quickly corrected this inaccuracy.

One criticism I have of the conference (which I communicated on my feedback form), was around the focus upon the use of personal social media, versus developing social media accounts for patient advocate groups and organizations. I am unsure whether I would

be willing to use my personal accounts for MPN advocacy; nor am I completely opposed to the idea. It just requires further thought on my part. Despite this, I felt the E-Matters Conference was very well-done and informative. A representative from CMPNN should consider attending in future.

Key Takeaways

- The CMPNN must consider how to leverage social media and online platforms in order to raise awareness, to better connect with MPN patients and to recruit new members. We currently have no social media presence, and we cannot afford to ignore this crucial tool in expanding the reach of the CMPNN.
- Creating and managing social media platforms can be a time-consuming job. The CMPNN should consider how best to tackle this using current resources (ie) could we hire a contracted social media manager?
- MPN patients and their care partners must continue to make their voices heard among other, more well-known cancers. Despite the current lack of awareness of MPNs, it is important that we continue to attend events such as the Health E-Matters conference.
- We need to consider how we might extend our reach to minorities and marginalized communities with MPN diagnoses. This starts with understanding our own power and privilege.
- There is power in STORIES; both patient and caregiver/care partner.

Thank you very much for the opportunity to attend the Health E-Matters conference. It was a very valuable experience overall, and I hope I have provided some useful information that will help the CMPNN in our work moving forward.

Kristen Hummel – CMPNN Board Director
Group Coordinator – Barrie Ontario MPN Support Group





Cheryl Petruk - Executive Director CMNPRF

The MPN Genie Quality of Life (QoL) Tracking Tool is an invaluable resource for individuals living with myeloproliferative neoplasms (MPNs). This tool provides patients with the ability to monitor their symptoms and overall health on a regular basis, allowing them to take a proactive approach to their care. The MPN Genie QoL Tracking Tool is an essential tool for patients living with MPNs, as it provides them with the information they need to make informed decisions about their health communicate this information with their MPN Hematologist and their general practitioner. Research Data is an important part of helping patients. Through gathered research data, Researchers are able to look at real world evidence from patient reported outcomes to help with new treatment opportunities.

The MPN Genie QoL Tracking Tool is designed to help patients track their symptoms over time. Patients can enter information about their symptoms, including MPN 10 prognostic scoring indicators, pain, fatigue, and other symptoms, and the tool will generate a report that can be shared with their healthcare provider. This report provides a comprehensive overview of the patient's health, allowing them to make informed decisions about their care. Additionally, the tool can be used to track the patient's response to treatments, allowing them to adjust their care accordingly.

Overall, the MPN Genie QoL Tracking Tool is an invaluable resource for individuals living with MPNs. It provides patients with the information they need to make informed decisions about their care, and it helps

them to track their response to treatments. This tool is essential for helping patients to maintain a high quality of life, and it is highly recommended for anyone living with MPNs.

Patient reported outcomes (PROs) are an invaluable tool for both patients and their physicians. They provide an opportunity for patients to share their experiences and perspectives on their health and treatment, and they provide physicians with a more comprehensive understanding of their patients' health. Furthermore, PROs are an important resource for the research community, as they can help to provide insights into how treatments are impacting patient health and wellbeing. For patients, PROs offer a platform to share their unique experiences and perspectives on their health and treatment. This information can be used to inform the treatment plan, and to ensure that the patient is receiving the best care possible. Furthermore, PROs can help to ensure that the patient's voice is heard and that their needs are taken into consideration.

For physicians, PROs can provide invaluable insights into the patient's health and wellbeing. By understanding the patient's experiences and perspectives, physicians can develop more effective treatments and ensure that the patient is receiving the best care possible. Furthermore, PROs can help to identify potential areas of improvement in the patient's care and can be used to ensure that the patient is receiving the best possible care.

Finally, PROs are an important resource for the research community. By collecting and analyzing patient-reported outcomes, researchers can gain valuable insights into how treatments are impacting patient health and wellbeing. This information can be used to develop more effective treatments, and to ensure that patients are receiving the best possible care. Overall, patient reported outcomes are an invaluable tool for both patients and their physicians, as well as for the research community. They provide an opportunity for patients to share their experiences and perspectives on their health and treatment, and they provide physicians with a more comprehensive understanding of their patients' health.

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MPN Horizons 2022 – Learn, Share, Grow

November 18th – 22nd, 2022
Netanya, Israel

Patti Saluk – CMPNN Board Member
Group Coordinator – Northern Alberta MPN Support Group

I had the privilege of attending the MPN Horizons Conference last November and as this was my first time at a conference of this type, I was not sure what to expect, especially since I had never been to Israel. This conference was exceptionally organized and set the bar high for any others.

I flew from Edmonton to Toronto and was the guest of Dov and Marilyn Lidor, two wonderful people from our CMPN Network. Just being able to see them and network during my overnight stay was not only extremely valuable in exchanging all kinds of information, but it was great to meet each other in person, something we have all missed in the past few years.

The Conference was broken up into two main areas: Advocacy Sessions (of which there were 5) and Medical Sessions (of which there were 4). Each day began early and alternated between these sessions. Each session discussed at least three topics with world renown speakers giving 20–23-minute presentations. A 30-minute Q/A session followed each.

The Advocacy Sessions included World Regional Meeting reports, best practice from MPN communities, challenges with living with a chronic disease, patient organization's collaboration with pharma, and from theory to reality. Ruth Fein, Werner Zinkand and Cheryl Petruk were just a few of the speakers. What stood out to me in these sessions was first how each area of the world has a different approach to MPNs for various reasons. A number of countries have patient registries which tell them how much MPNs are growing or becoming diagnosed. Sweden registers 300–400 people/year with an MPN and has specialists to recognize this whereas in South America it is very difficult to find the patients and there is no access to doctors with MPN specialization or MPN treatment. My question here was "how can the CMPNN educate doctors of MPNs"?

There were a number of people, including doctors and pharma reps that wanted to see how the MPN Genie really worked. Cheryl's presentation was good and insightful but seeing it on my phone was eye-opening and there was interest in gaining access.

One of the pharma representatives who presented did admit, as did the other reps in the audience, that they go where the numbers are. If a country has few MPN numbers, they won't necessarily make their drug treatments available. Sad, but so true. The best statement I think was "pharma needs patients and patients need pharma". We are a long way from making drug treatments available to everyone in the world.

An interesting presentation from the UK was about how they have community led fundraising due to a number of issues. They have done a variant on a "walk to support" as well as a community-led recipe book that was developed with more than just recipes.

There were four Medical Sessions with a total of 12 topics presented: challenges still existing in MPNs, novel therapies in MPNs, effective complimentary therapies for MPNs and personalized medicine in MPNs. Drs Mesa, Pemmaraju, Ellis, Hobbs, and Cook were just a sample of excellent well-known speakers.

These sessions were very informative and of course contained lots of medical terminology but to their credit, presenters made it fairly easy to understand. A few things stood out to me. Dr. Pemmaraju mentioned that since Covid, new MPNs exist and that there are a number of other non-driver mutations other than JAK2 and CALR/MPL. According to Dr. Ellis there is currently no 'mutation-directed therapy' but there is hope that this will change with RAS inhibitors, pathway inhibitors, specific JAKm inhibitors, and CALR directed immunotherapy.

It was interesting to hear from Dr. Gabriela Hobbs, that a scale of symptoms needs to be made available for patients which made me think of our MPN Genie! Another interesting point from her was that a number of her patients see a dermatologist because of rashes or skin lesions.

What is being done now and in the works for MPNS is remarkable. The wonderful news that was presented is that there are numerous phase 3 trials for MF going on and many for phase 1 and 2 for MF.

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Dr. Nathalie Cook from Australia, who is a PV patient herself, gave a fantastic presentation on Nutrition. A multitude of information included reasons why one should follow a Mediterranean diet to put mushrooms in sunlight and they produce vitamin D. Eating 6 prunes/day if your system can handle it will reduce inflammation and the risk of osteoporosis.

A comment made by a number of speakers, including Dr. Pemmaraju, is that we need to get rid of 'prehistoric' methods such as phlebotomies and bone marrow biopsies. There is science now being used such as ultrasound sonography and computers to flatten body part pictures to get much more accurate views of cells. They are able to now train the computer to recognize cells and thus see possible progressions – another WOW. The stopping point for it being used more is simply money – the cost is enormous but hopefully as it gets more widespread, the benefits will be seen and then used.

The conference was excellent in so many ways. The location, hotel, food, tours and dinners were fantastic. Besides all the great information taken in during the day, one of the best times was spent on a coach bus going to planned dinners and tours each night. The people I met were fantastic and we all established friendships that will last a lifetime.

The next Horizons Conference is October 13-15, 2023, location TBA. I urge any of you wanting to get involved in and learning more about your MPN, join a committee and become part of the Canadian MPN Board. Opportunities such as this conference could be there for you!

Patricia Saluk – Board Member
Group Coordinator, Northern Alberta MPN Support Group – Advocacy/Education/Patient Support

Message from Board Chair – Doug Chisholm

As I sit in Scottsdale, AZ at the Joyce Niblack Physician-Patient Conference, I am freshly excited about the tremendous progress being made in our MPN journeys. When I was first diagnosed in 1990 it was a “disease” (MPD) rather than a “cancer” (MPN); very little was known about any variations; and my Bone Marrow

Biopsy was taken from my sternum. Fast forward to today and the pipeline is full of new, targeted medications and the current understanding of the Molecular Biology of our MPNs is being taken to levels that boggle my mind. If there was ever a time in the last 30 years to have to journey with an MPN it has never looked as hopeful as it does today. As I write this, the first monoclonal antibody for the targeted treatment of CALR in MPNs has had the medical community excited for the last two months!

Our Canadian MPN Network Board of Directors, and the regional MPN Support Groups, are all putting our foot on the gas to grow quickly with our medical partners. Our goals are to educate you with up-to-date, factual & relevant information; to advocate for new medical approvals and therapies in Canada; and to support our Patients and Care Partners in their MPN journeys. To this end, our Board is planning our first Strategic Planning Session in late May to identify priorities & focus for our organization, and to attach the necessary donated funds to each in order to make them happen.

We haven't been dormant through the pandemic. It has become obvious during this large US Conference I'm attending that we are building a “best practices” organization here in Canada. One that our American friends are more than a bit envious of. Rather than having unconnected MPN Support Groups spread around the US, each doing their own thing in their own cities (if there is one), our Canadian organization was founded in 2014 as a “network” of connected, consistent and focused regional MPN Support Groups that work passionately together under the umbrella of our Canadian MPN Network Board of Directors. Our momentum grows every month and we actively support each other to bring our Patients & Care Partners our best efforts. Our Canadian Board works hard to provide funding, establish consistent service levels across Canada and share ideas that our Group Coordinators can take back to their Support Groups ... to you.

I hope you can join us for our Free online National MPN Conference on February 25th.

Doug Chisholm – CMPNN Board Chair

Report from Joyce Niblack Memorial Patient Conference

February 18th - 19th, 2023
Phoenix, Arizona

John Clark/Doug Chisholm/ Patti Saluk - CMPNN Board Members

13th Joyce Niblack Memorial Conference on Myeloproliferative Neoplasms

A few of us (Doug Chisholm, John Clark and Patti Saluk) made the trek to Phoenix in late February to represent the Canadian MPN Network at the Joyce Niblack Memorial Patient Conference. This is the oldest MPN conference, held every two years, bringing patients from both the U.S. and Canada together to hear from world renowned MPN specialists.

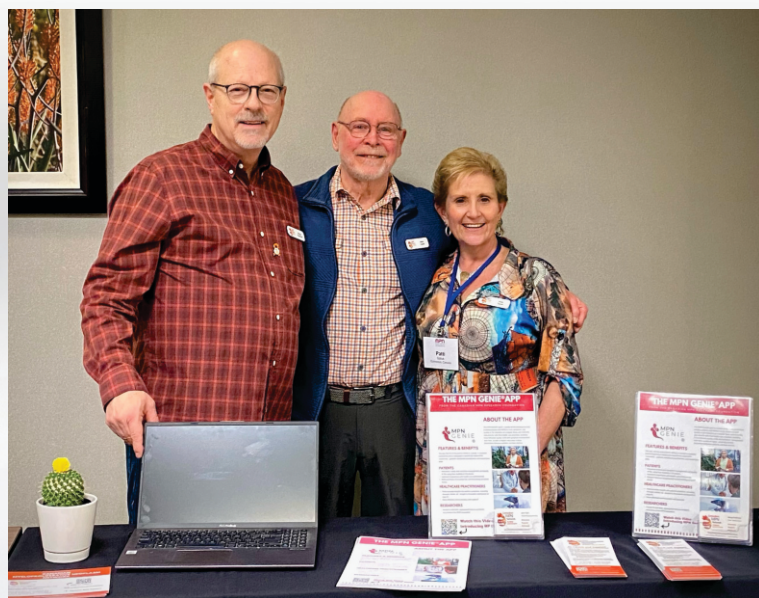
Although learning about new and novel treatments from these experts was interesting, our main mission there was to make fellow Canadians and American friends aware of our national Canadian MPN Network and the Canadian Canadian MPN Research Foundation's MPN Genie quality of life app. We did this by hosting a well attended "Meet and Greet" information session.

It was gratifying to meet Canadians who were unaware of the CMPN Network and connect them to their closest regional support group. One takeaway from the session was how fortunate we are to have both the CMPN Network and regional support groups in Canada. Many of our American friends expressed the wish they had the same - hopefully finding out about what we are doing here will inspire them to do something similar.

There was also a great deal of interest in the Canadian Research Foundation's MPN Genie app. Coincidentally, it was made available in the U.S. the same day as our session and we expect many Americans will soon join Canadian MPN patients by downloading it to their phones, too!

We would like to thank both our Canadian MPN Network and the Canadian MPN Research Foundation for their support in making this all possible.

John Clark - Board member
Group Coordinator - MPN Ontario Support Group



Doug Chisholm, John Clark, Patti Saluk



MPN Genie - (continued from page 3)

It is essential for Myeloproliferative Neoplasm (MPN) blood cancer researchers to understand the patient reported outcomes in order to gain a comprehensive understanding of the disease. Patient reported outcomes provide invaluable insight into the patient experience, which is essential for the development of effective treatments and interventions.

By understanding the patient reported outcomes, researchers can gain a better understanding of the disease, its progression, and the impact it has on the patient's quality of life. Furthermore, patient reported outcomes can provide valuable information on the effectiveness of treatments and interventions, allowing researchers to make informed decisions about the best course of action for their patients. Ultimately, patient reported outcomes are essential for MPN blood cancer researchers to gain a comprehensive understanding of the disease and its impact on patients.

Canadian MPN Network Patient Support Groups

Doug Chisholm (Western Canada)

John Clark (Eastern Canada)

MPN Saskatchewan – Alison Sander

No news from Saskatchewan of note. We had one new member join.

MPN Northern Alberta – Patti Saluk

The Northern Alberta MPN Support Group had its first in-person meeting Saturday, January 21st at Wellspring Alberta – Edmonton. The group met for 3 hours and still had lots to talk about! 10 people attended the informal chat and get-to-know each other. The group will continue to meet at Wellspring every 5–6 months. They are interested in having speakers especially in dealing with chronic pain. As well, the group has grown to 18 people.

MPN Southern Alberta – Doug Chisholm

The Southern Alberta MPN Support Group had a good online Meeting last Saturday, January 28 with Dr. Michelle Geddes. There were about 21 group members in attendance. We welcomed several new members and have added another one since our Meeting. They mostly come from [physician referrals. We heard from Jolaine about her Sole2Soul hike, and Cheryl presented the "MPN Genie". We also reviewed our recent Survey findings.

MPN Vancouver – Mark Williams

Held a support group zoom call last weekend which went very well. One of our main BC members just had a SCT and he discussed much of his experience – he's out of the hospital now but still staying close to our transplant hospital (only Vancouver General Hospital does SCT in BC) until he gets the approval to head home (he's at day 95 or so now). He lives in the Victoria area.

MPN Barrie Ontario – Kristen Hummel/Cindy Buckle

The Barrie Ontario MPN Patient Support Group continues to be active via email and sharing of resources. Coordinators send detailed newsletters bi-monthly, full of information and events of interest to MPN patients and caregivers. The pandemic put a damper on attracting members to online or in-person support group meetings. However, with COVID restrictions now lifted and pandemic concerns waning, our group will attempt to "relaunch" and organize a group meeting in the spring.

MPN Ontario – John Clark

We held an informal online meeting using Zoom on Saturday, January 28th with approximately 30 in attendance, including several new members. This was the first time we've held an informal meeting without a presenter and when people didn't need to register. In addition to new member introductions and announcements, most of the time was given over to members asking and answering questions, sharing experiences and connecting with one another. All in all, a successful meeting. The MPN Ontario Facebook (open to all residents of Ontario) now has 128 members. Our next meeting will be in March/April with Dr. Brian Leber giving his annual MPN update and answering patient question – no date yet set.

MPN Manitoba – Jean Read

Reached out to an MPN patient who needs support. Distributed a supply of the MPN palm cards to a health centre that has older members. Cancer Care MB continues to include a listing for MB MPN in their monthly newsletter, I have put some new notices up on the MB Facebook page.

MPN Atlantic – Stephen Evans/Rosanne Briand

Four new members since December 2022. Planning on having our second MPN Atlantic Support Group meeting in April. Constantly updating MPN Atlantic Facebook page. Would like to have a face-to-face meeting but because we encompass the four Maritime provinces, we'll probably have another Zoom meeting.

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 CMPNN website soon. Winners will be announced at our September conference.



Canadian MPN Network Patient Support Groups – Contact Info

Doug Chisholm (Western Canada) – John Clark (Eastern Canada)



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
B.C.	vancouver@canadianMPNnetwork.ca	Mark Williams
Alberta	southernalberta@canadianMPNnetwork.ca northernalberta@canadianMPNnetwork.ca	Doug Chisholm Patti Saluk
Saskatchewan	www.facebook.com/groups/176201377568815	Alison Sander
Manitoba	manitoba@canadianMPNnetwork.ca	Jean Read
Ontario	mpnontario@canadianMPNnetwork.ca barrie@canadianMPNnetwork.ca ottawa@canadianMPNnetwork.ca	John Clark/Marie Grenier-Davis/Joanne McKinley Kristen Hummel/Cindy Buckle Phil Arner
Quebec	quebec@canadianMPNnetwork.ca	Augusto Latge/Catherine Picard
Atlantic	atlantic@canadianMPNnetwork.ca	Stephen Evans/Rosanne Briand

Upcoming Meetings - MPN Ontario - Saturday, April 22nd at 10am