

Canadian MPN Patient Advocacy & Education



Welcome to your newsletter!

September, 2017
Volume 1, Issue 1

Hello and welcome to your Canadian MPN patient advocacy & education newsletter!

MPNs (myeloproliferative neoplasms) are made up of a group of chronic blood cancers. In this newsletter we present information mainly pertaining to the most common 3, which include ET (essential thrombocytosis), PV (polycythemia vera), and MF (myelofibrosis).

Much of the maze of MPN information on the internet seems geared to the understanding level of physicians and health care professionals. Since knowledge is power, patients and care-givers need to have access to, and understanding of much of the same information. With a bit of vetting and explanation we hope to help ourselves gain better understanding and management of our MPN journeys. **Each of us is not alone. Together we are strong!**

During our MPN journeys, many of us have come to realize that no one cares as much about our health as we do. This is why we as patients and care-givers need to take control where possible of our situation.

We advocate that patients should keep copies of all of their laboratory test results, and endeavor to be more prepared to discuss any concerns with our doctors.

Although we provide a lot of information regarding MPNs in this newsletter, every patient is different. Please consult your MPN specialist or physician for any medical advice.

Letter from the Chairperson of the Canadian MPN Network Patient Advocacy Group:

“We have a lot of new initiatives that we are undertaking in the next year, and look forward to sharing with you, news and updates on current and new treatments for MPN's.

We now have support groups in Vancouver, Edmonton, Hamilton, Montreal, and soon another in Calgary! The Canadian MPN Network will provide resources to all of our patient support groups in all of their needs.

Please visit our Facebook page, Canadian MPN Network, Patient Advocacy Group or our website at www.canadianmpnnetwork.ca for up to date information on your patient support groups, and news on MPN's in Canada.

Of course, if you would like to contribute something to the Newsletter, we would love to have you write an article, share some news, or pass on helpful hints to other patients and caregivers.

Welcome to your newsletter!

I extend my warmest wishes to each of you!”

Cheryl Petruk,

Chairperson, Canadian MPN Network Patient Advocacy Group.

Printable MPN Guide

Canadian MPN Guide for patients and families

Excellent Comprehensive 60 page printable booklet provided by Princess Margaret Cancer Centre, covering the MPNs, ET, PV, and MF

<http://www.mpncanada.com/site/wp-content/uploads/2017/01/MPNs-a-guide.pdf>

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MPN Videos

2015, 10 minute 15 second video from Dr. Raja Narayan (New York, USA) of Khan Academy, explaining about MPNs- comprehensive technical explanations with diagrams

<https://www.youtube.com/watch?v=eLsegxXzaiE>

2015, 9 minute 36 second video from Dr. Raja Narayan of Khan Academy, explaining about ET- comprehensive technical explanations with diagrams

https://www.youtube.com/watch?v=1POB_czE16k

2015, 10 minute 34 second video from Dr. Raja Narayan of Khan Academy, explaining about PV- comprehensive technical explanations with diagrams

<https://www.youtube.com/watch?v=vOPuAPCioE4>

2015, 7 minute 43 second video from Dr. Raja Narayan of Khan Academy, explaining about MF-comprehensive technical explanations with diagrams

<https://www.youtube.com/watch?v=-YEtWOxweRg>

Understanding Lab Test Results

Webinar Replay: Understanding and Interpreting Complete Blood Count (CBC) Results

2017 Patient Power (1 hour 12 minutes) A very general discussion of routine blood tests including the CBC, differential, LDH, FISH, electrolytes, HGB, HCT, presence of peripheral blood blasts, chromosome ps and qs, among others. (Scroll down to view the video)

<https://www.patientpower.info/video/webinar-replay-understanding-and-interpreting-complete-blood-count-cbc-results>

Other useful lab test related videos can be found at Patient Power- "Ask the Expert" at: (Scroll down to view the videos of choice)

<https://www.patientpower.info/series/ask-the-expert-understanding-lab-tests-and-lab-test-results>

Useful searchable website with lab test explanations- Lab Tests Online

<https://labtestsonline.org/>

Hematology Searchable Glossary of terms

<http://hematologyoutlines.com/glossary.html>

Pseudohyperkalemia in Serum: A New Insight into an Old Phenomenon (about false high serum potassium readings that are associated with high platelet count)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2442023/>

Wonderful MPN Links

*Excellent Canadian resource with all kinds of information and important links

<http://www.mpncanada.com/>

Another great Canadian resource with more patient centred information

<http://canadianmpnnetwork.ca/>

And here is a great American site: MPN Education Foundation

<http://mpninfo.org/>

Facebook MPN Support Groups

Where MPN patients and caregivers share personal experiences & support

New! Canadian MPN Network Patient Advocacy (closed group)-need to cut and paste into web browser and join to view

<https://www.facebook.com/groups/345559142142090/>

MPN Humor –Because we can all use a laugh! This is a 596 member forum (closed group)-need to cut and paste into web browser and join to view

<https://www.facebook.com/groups/171019526688237/>

International Essential Thrombocythemia Support Group. This is a 2289 member forum for those caring for or affected by ET forum (closed group)-need to cut and paste into web browser and join to view

<https://www.facebook.com/groups/456028451193700/>

International Polycythemia Vera Support Group. This is a 4276 member forum for those caring for or affected by PV (closed group)-need to cut and paste into web browser and join to view

<https://www.facebook.com/groups/180180118669211/>

International Myelofibrosis Private Support Group. This is a 3166 member forum for those caring for or affected by MF (closed group)

<https://www.facebook.com/groups/myelofibrosisprivatesupportgroup/>

International MPN Interferon support group. This is a 1922 member forum that is dedicated to MPNs and how interferon relates to their treatment, evolution, and future directions. It is open to anyone taking interferon, considering interferon, family members of those with MPNs who want to discuss interferon for treating any MPN (closed group)

<https://www.facebook.com/groups/163047923897090/>

Expert Updates:

2016 WHO Clinical Molecular and Pathological Criteria for Classification and Staging of Myeloproliferative Neoplasms (MPN) Caused by MPN Driver Mutations in the JAK2, MPL and CALR Genes in the Context of New 2016 WHO Classification: Prognostic and Therapeutic Implications
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5394501/>

2017 New DIPPS plus scoring system to estimate prognosis in post ET and post PV MF patients
<http://www.nature.com/leu/journal/vaop/ncurrent/abs/leu2017169a.html>

Common Symptoms and Escalating symptoms for MPNs marking progression (Illinois, USA)
<http://www.mpnresearchfoundation.org/MPN-Escalating-Symptoms>

2002 Headache in ET
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3469735/>

2017 New shingles vaccine – this one contains no live virus!
<http://www.mdmag.com/medical-news/shingles-vaccine-shingrix-gets-fda-panel-backing>

2016 Dr. Ruben Mesa (Arizona, USA) gives updates from the 2016 American Society of Hematology relevant to the treatment of essential thrombocythemia, polycythemia vera, myelofibrosis and systemic mastocytosis (8 minute 25 second video)
<https://www.youtube.com/watch?v=-gOtxly2mRk&sns=fb>

2017 Dr. Rami Komrokji (Florida, USA) Discusses Latest Developments in MPNs in this printed interview
<http://www.onclive.com/web-exclusives/expert-discusses-latest-developments-in-mpns?p=1>

Stem Cell/Bone Marrow Transplant Information:

2017, this 33 minute video is about the evolving role of transplant in treating MPNs from MPN Education Foundation
<https://www.youtube.com/watch?v=bvhBxInjudU&feature=youtu.be>

Dr. Michael Pulsipher (Los Angeles, USA) 1 hour 3 minute webinar about Donating Bone Marrow or Stem Cells to a Relative is from BMTinfonet.org (excellent resource)
<https://www.youtube.com/watch?v=c6COJq3WmW8&feature=youtu.be>

Joining the Canadian One-Match Stem Cell and Marrow Network is simple. If you're between the ages of 17 and 35 and in good general health, you're eligible to sign up. You can start the registration process
<https://blood.ca/en/onematchhowto>

2002, this Survivors guide (68 pages) to bone marrow/stem cell transplant- What to Expect & How to Get Through It, is through National Bone Marrow Transplant Link, NBMTlink.org which is another valuable resource
<http://www.nbmtlink.org/documents/sg.pdf>

Medication Information:

2011 Dr. Richard Silver (New York, USA) Recombinant interferon- α may retard progression of early primary myelofibrosis: a preliminary report

<http://www.bloodjournal.org/content/117/24/6669?variant=long&sso-checked=true>

2015 Dr. Richard Silver (New York, USA) discusses interferon therapy for MPNs (9 minute 25 second video) (scroll down to view the video)

<https://www.patientpower.info/video/new-horizons-for-interferon-therapy-in-mpns>

2016 Dr. Clair Harrison (London, UK) discusses the use of Ruxolitinub/Jackafi for Myelofibrosis

<http://www.hematologyandoncology.net/archives/november-2016/when-to-initiate-treatment-in-myelofibrosis/>

2016 Some PV and MF patients are finding itch relief from this combo of OTC drugs

<http://www.pvreporter.com/otc-combo-zyrtec-zantac-helping-polycythemia-vera-patients-get-relief-itching/>

2013 Claritin for bone pain- some MPN patients have found 24 hour Claritin helps with their bone pain

<http://myangrycancer.blogspot.ca/2013/02/claritin-is-worth-its-weight-in-gold.html>

UK Comprehensive Guide to Interferon treatment for MPNs. This comes from MPNvoice.org.uk Which is a web site from the United Kingdom that contains a wealth of information including much about many of the commonly prescribed MPN medications

http://www.mpnvoice.org.uk/documents/treatmentleaflets/Drug_Interferon-Alpha_A5_web.pdf

Interesting New Research:

2017 Dr. Hans Hasselbalch (Denmark) Minimal Residual Disease or Cure in MPNs? Rationales and perspectives on Combo Therapy with Interferon-alpha2 and Ruxolitinib

<https://mpncancerconnection.org/2017/06/minimal-residual-disease-or-cure-in-mpns-rationales-and-perspectives-combo-therapy-with-interferon-alpha2-and-ruxolitinib/>

2014 Dr Hans Hasselbalch (Denmark) This review describes the co-morbidities associated with MPNs and the potential impact of early intervention with anti-inflammatory and/or immunomodulatory agents such as JAK-inhibitors, statins, and IFN- α to inhibit cancer progression and reduce MPN-associated co-morbidity impact.

<http://www.tandfonline.com/doi/full/10.1586/17474086.2013.876356>

2017 Dr Srdan Verstovsek (Texas, USA) New clinical studies using various combinations of therapies with Ruxolitinib in treating myelofibrosis are discussed.

<http://www.targetedonc.com/conference/soho-2017/combo-strategies-with-ruxolitinib-explored-in-myelofibrosis-treatment->

Closing With Hope:

*There are so many clinical trials and research studies that are very promising coming up on the horizon, including: CAR-T therapy, CRISPR, Methotrexate, NOX4 enzyme, Metformin, PRM-151, Pacritinib, SL-401, Ropoginterferon, and even Cannabis.

Meet the Chairperson of the Canadian MPN Network:

“My husband was diagnosed with ET in 1992. From 1992 to 2010, we didn’t really pay much attention to the “blood disorder” as we were told that my husband had. In 2010 after having routine blood work, Blasts were found in the blood work. We saw a top MPN Doctor where we live and my Husband was then diagnosed with Myelofibrosis. When we were given the diagnosis, there was not much information about support groups or other people to turn to. We were told that my husband had a rare blood cancer, so I found as much information on the internet and read everything. In 2014, we joined 10 others from across Canada at our first meeting of the Canadian MPN Network, and our group was born! Since then, we have had 2 successful patient conferences, we have been able to support and start local patient support groups in major Canadian cities, with more to be started soon! We have become part of a Global MPN Advocates Network, and we continue to work with our outstanding Canadian MPN Doctors in helping them help our patients! This has become such a rewarding passion for me! The Canadian MPN Network has a lot of new ideas and plans for the upcoming year, to assist patients and their families in navigating their journey with an MPN. We look forward to hearing from you! Please feel free to reach out to us!”

Cheryl A. Petruk

Canadian MPN Network

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Meet the Editor:

Zeta Charania is a retired Medical Laboratory Technologist and an MF patient with the CAL-R mutation. “I had ET for over 30 years that was treated with baby Aspirin. Then about 15 years later I was treated with a varied combination of Aspirin, Hydroxyurea, and Anagrelide. About 3 years ago my ET changed/progressed to MF. At that time my hematologist offered Interferon alpha 2B as a treatment option. I am now in hematological remission.”

Should you have links, information or stories that you think should be shared in our newsletter please send by e-mail to: canadianmpnnetwork@gmail.com Attention Editor: Zeta Charania