The purpose of this guide is to help you find information and support on myeloproliferative neoplasms. This guide provides links and references to reliable and current information sources for patients, families, and caregivers.

Many of the materials in this guide can be found at the Patient Education Resource Center (PERC) in the University of Michigan Comprehensive Cancer Center, Level B2.

Brochures and Fact Sheets

- Cancer Support Community
  - Myelofibrosis
    Available online at:
  - Understanding Myeloproliferative Neoplasms
    Available online at:
    [http://goo.gl/8zthmP](http://goo.gl/8zthmP)

- CancerCare
  - Caregiving for Your Loved One with Polycythemia Vera
    [http://goo.gl/aUHbwT](http://goo.gl/aUHbwT)
  - Coping with Myelofibrosis
    [http://goo.gl/wiw84g](http://goo.gl/wiw84g)
  - Managing Essential Thrombocythemia
  - Managing Symptoms of Myelofibrosis
    [http://goo.gl/EHg2GW](http://goo.gl/EHg2GW)
  - Managing Symptoms of Polycythemia Vera
    [http://goo.gl/qVLY3D](http://goo.gl/qVLY3D)
  - Polycythemia Vera: Treatment Update
    [http://goo.gl/8Z7TPf](http://goo.gl/8Z7TPf)

  Available online at:
  [http://goo.gl/JnB6Tc](http://goo.gl/JnB6Tc)
- Leukemia & Lymphoma Society
  - Essential Thrombocythemia Facts
  - Myelofibrosis Facts
  - Polycythemia Vera Facts
  - Understanding Lab and Imaging Tests
  
  To access, go to:
  http://lls.org/resource-center/download-or-order-free-publications
  and click on the any of the above titles

- MPN Advocacy & Education International. Essential Thrombocythemia, Myelofibrosis, Polycythemia Vera.
  Also available online at:
  http://goo.gl/35MvWA

  Available online at:
  http://cancer.gov/types/myeloproliferative/patient/chronic-treatment-pdq

### Audiovisual Resources

- MPN Advocacy & Education International. Interview with Dr. Marie Huong Nguyen, University of Michigan, MPC Researcher/Clinician.
  Available at:
  http://mpnadvocacy.com/2016/02/ann-brazeau-interviews-dr-nguyen

- MPN Education Foundation. MPN Video Library.
  Available at:
  http://mpninfo.org/videos

- MPN Research Foundation. Video Patient Stories on Essential Thrombocythemia (ET), Polycythemia Vera (PV) and Myelofibrosis (MF).
  Available at:
  http://mpnresearchfoundation.org/patient-stories

### Web Resources

- Cancer Support Community
  http://cancersupportcommunity.org
  Provides information on myeloproliferative neoplasms as well as resources, tools, and support for coping with cancer.
CancerCare
http://cancercare.org/diagnosis/myeloproliferative_neoplasms
This site provides educational information, including workshops and podcasts, on myeloproliferative neoplasms as well as counseling, support groups, and financial assistance.

Genetic and Rare Diseases (GARD) Information Center
Provides information on ET, PT, and MF. Also gives the option to listen to the information being read aloud.
- Essential Thrombocythemia
  https://rarediseases.info.nih.gov/diseases/6594/essential-thrombocythemia
- Myelofibrosis
  https://rarediseases.info.nih.gov/diseases/8618/myelofibrosis
- Polycythemia Vera
  https://rarediseases.info.nih.gov/diseases/7422/polycythemia-vera

Genetics Home Reference (a service of the U.S. National Library of Medicine)
This site provides information about the effects of genetic variations.
- Essential Thrombocythemia
- Polycythemia Vera
- Primary Myelofibrosis

Leukemia & Lymphoma Society
https://lls.org
This site provides information on all types of blood cancers. There is also information on support and financial resources.

MPN Advocacy & Education International
http://mpnadvoctasy.com
This site provides information on MPNs as well as the latest news on MPN research and clinical trials. This organization also provides a monthly newsletter called the MPN Community Connection which you may either view online or sign up to have emailed to you.

MPN Education Foundation
http://mpninfo.org
This site provides information on MPNs as well as support, research, and clinical trial information.
• National Cancer Institute
  http://cancer.gov
  Provides information on myeloproliferative neoplasms as well as research and clinical trial information, including a searchable database of available NCI-supported clinical trials.

• National Organization for Rare Disorders (NORD)
  This site provides information on rare diseases.
  - Essential Thrombocythemia
    http://rarediseases.org/rare-diseases/essential-thrombocythemia
  - Polycythemia Vera
    http://rarediseases.org/rare-diseases/polycythemia-vera
  - Primary Myelofibrosis
    http://rarediseases.org/rare-diseases/primary-myelofibrosis

University of Michigan Resources

• University of Michigan Comprehensive Cancer Center Blog article in mCancer Talk. Myeloproliferative Neoplasms: A Collection of Rare Blood Cancers.
  http://goo.gl/1WJd3n

• University of Michigan Comprehensive Cancer Center Myeloproliferative Neoplasm (MPN) Clinical Trials
  The University of Michigan Comprehensive Cancer Center MPN and Systemic Mastocytosis Clinic has many trials underway. More information available at: http://mcancer.org/clinical-trials/myeloproliferative-mpn-clinical-trials or by calling 800-865-1125.

Support Groups and Online Communities

• Leukemia & Lymphoma Society Blood Cancer Discussion Boards
  There is an online discussion group for Myelodysplastic Syndromes, Myeloproliferative Neoplasms – i.e. Polycythemia Vera, Essential Thrombocythemia, and Myelofibrosis.
  To join, go to: http://community.lls.org/forum/20-lls-blood-cancer-discussion-boards and select a group from the list above.

• MPD-SUPPORT – Myeloproliferative Diseases Support and Daily Email Digest
  This email list has been around since 1994. Subscribe at: http://sites.google.com/site/mpdsupport

• MPN Advocacy & Education International
  http://mpnadvo.org/7mpnadvocacy.com/support-groups
  Lists MPN support groups, both in the United State and other countries. Also lists other online support groups.
• MPN Education Foundation
  http://mpninfo.org/support
  Lists MPN support groups by state along with contact information. They also provide MPN-NET online support groups with you can subscribe to at:
  http://mpninfo.org/mpn-net-an-online-support-group

• MPN Research Foundation
  http://mpnresearchfoundation.org/Support-Groups
  Provides a number to call for in-person MPN support groups, and also provides information and links to online MPN support groups. They also provide an MPNRF online community, which you can join at:
  http://mpnrfcommunity.org

Disclaimer: This document contains information and/or instructional materials developed by Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

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