

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 these materials are available to purchase through online resources, or to borrow at your public library.

Brochures and Fact Sheets

- Cancer Support Community
 - **Myelofibrosis**
Available online at:
https://www.cancersupportcommunity.org/sites/default/files/uploads/learn-about-cancer/cancer-types/Myelofibrosis/fsac_myelofibrosis.pdf
 - **Understanding Myeloproliferative Neoplasms**
Available online at:
https://www.cancersupportcommunity.org/sites/default/files/uploads/learn-about-cancer/cancer-types/fact-sheet/fsac_myeloproliferative_neoplasms.pdf
- CancerCare
 - **Caregiving for Your Loved One with Polycythemia Vera**
https://media.cancercare.org/publications/original/199-fs_pv_caregiving.pdf
 - **Coping with Myelofibrosis**
https://media.cancercare.org/publications/original/197-fs_mf_coping.pdf
 - **Managing Essential Thrombocythemia**
https://media.cancercare.org/publications/original/223-fs_managing_et.pdf

- **Managing Symptoms of Myelofibrosis**
https://media.cancercare.org/publications/original/203-fs_mf_symptoms.pdf
- **Managing Symptoms of Polycythemia Vera**
https://media.cancercare.org/publications/original/201-fs_pv_symptoms.pdf
- **Polycythemia Vera: Treatment Update**
https://media.cancercare.org/publications/original/191-ccc_poly_vera.pdf
- **Cure Magazine. A Patient's Guide to Myeloproliferative Neoplasms.**
Available online at:
https://s3.amazonaws.com/curetoday/media/u02/data/htdocs/media/downloads/documents/pocketguide_MPN_2013.pdf
- **Leukemia & Lymphoma Society**
 - **Myeloproliferative Neoplasms Myelofibrosis, Polycythemia Vera and Essential Thrombocythemia**
 - **Understanding Lab and Imaging Tests**Click on the above titles at:
<http://lls.org/resource-center/download-or-order-free-publications>
- **MPN Advocacy & Education International. Essential Thrombocythemia, Myelofibrosis, Polycythemia Vera.**
Also available online at:
<http://mpnadvocacy.com/wp-content/uploads/2013/01/MPN-Advocacy-Brochure-2015.pdf>
- **National Cancer Institute. Myeloproliferative Neoplasms Treatment – Patient Version (PDQ).** Available online at:
<https://www.cancer.gov/types/myeloproliferative>

- Myelodysplastic Syndromes Treatment (PDQ®)–Patient Version
<https://www.cancer.gov/types/myeloproliferative/patient/myelodysplastic-treatment-pdq>
- Chronic Myeloproliferative Neoplasms Treatment (PDQ®)–Patient Version
<https://www.cancer.gov/types/myeloproliferative/patient/chronic-treatment-pdq>
- Myelodysplastic/ Myeloproliferative Neoplasms Treatment (PDQ®)–Patient Version
<https://www.cancer.gov/types/myeloproliferative/patient/mds-mpd-treatment-pdq>

Audiovisual Resources

- MPN Education Foundation. **MPN Video Library**.
Available at:
<https://mpninfo.org/category/video-library/>
- 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://cancerca.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**

- <https://ghr.nlm.nih.gov/condition/essential-thrombocythemia>

- **Polycythemia Vera**

- <https://ghr.nlm.nih.gov/condition/polycythemia-vera>

- **Primary Myelofibrosis**

- <https://ghr.nlm.nih.gov/condition/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://mpnadvocacy.com>

This site provides information on MPNs as well as the latest news on MPN research and clinical trials. Also provides a monthly newsletter called the **MPN Community Connection** to view online or via email.

- **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)**

<https://rarediseases.org/>

This site provides information on rare diseases including **Essential Thrombocythemia, Polycythemia Vera, and Primary Myelofibrosis**.

University of Michigan Resources

- University of Michigan Rogel Cancer Center Blog article in mCancer Talk. **Myeloproliferative Neoplasms: A Collection of Rare Blood Cancers.**

<https://uofmhealthblogs.org/cancer/living-with-cancer-2/myeloproliferative-neoplasms/27467/>

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:

<https://communityview.lls.org/>.

- **MPN Advocacy & Education International**

<http://mpnadvocacy.com/>

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.

- **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://mpnrcommunity.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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