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
  - 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)

- **Cure Magazine. A Patient's Guide to Myeloproliferative Neoplasms.**
  - 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 any of the above titles

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

National Cancer Institute. Chronic Myeloproliferative Neoplasms Treatment –
Patient Version (PDQ).
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](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**
  - **Myelofibrosis**
  - **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](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](http://mpnadvocacy.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](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.
    o Essential Thrombocytethemia  
      http://rarediseases.org/rare-diseases/essential-thrombocytethemia
    o Polycythemia Vera  
      http://rarediseases.org/rare-diseases/polycythemia-vera
    o 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 Thrombocytethemia, 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://mpnadvocacy.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](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](http://mpninfo.org/mpn-net-an-online-support-group)

• **MPN Research Foundation**
  [http://mpnresearchfoundation.org/Support-Groups](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](http://mpnrfcommunity.org)