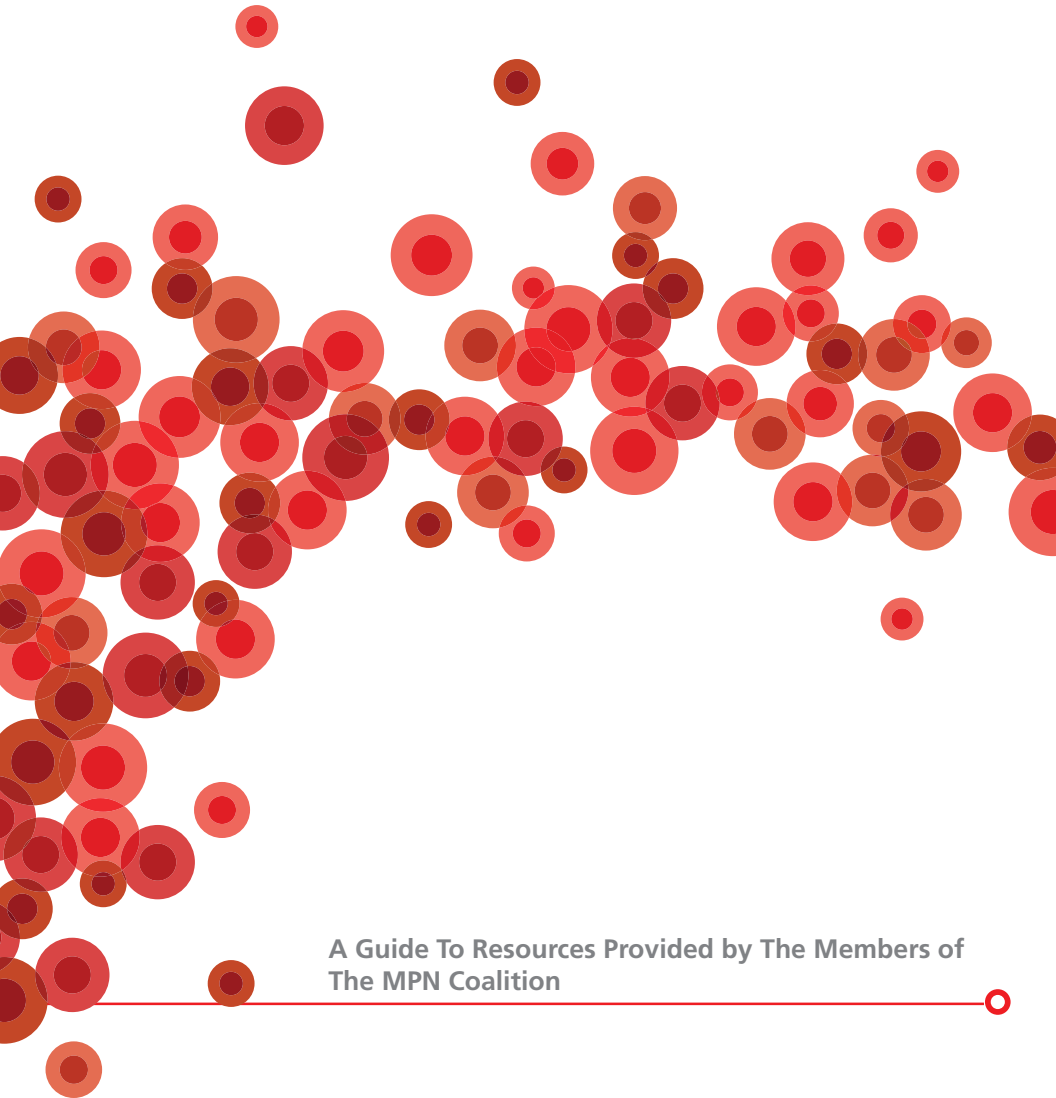


MYELOFIBROSIS

RESOURCES FOR PATIENTS
AND FAMILIES



A Guide To Resources Provided by The Members of
The MPN Coalition



This is a guide to resources provided by members of the MPN Coalition for patients and families affected by myelofibrosis (MF). The Coalition members are patient organizations offering a broad array of services for people affected by the group of rare bone marrow diseases known as myeloproliferative neoplasms (MPNs).

MPNs, including primary myelofibrosis (PMF), polycythemia vera (PV), and essential thrombocythemia (ET), are considered hematological malignancies or blood cancers. However, unlike some other types of malignancies, they are often experienced by patients as long-term chronic diseases. It is not uncommon for patients to live full, active lives with MPNs for many years. Therefore, it is especially important for patients and their families to be aware of resources available to them.

The Importance of Being an Empowered Patient

Having access to information and resources is also important to patients with MPNs because these diseases are rare. In the U.S., any disease affecting fewer than 200,000 Americans is considered rare. There are nearly 7,000 rare diseases affecting almost 30 million Americans.

It is often difficult for patients with rare diseases to find information in patient-friendly language. Also, many people with rare diseases feel isolated because of the lack of general awareness about their medical challenges. In addition, many experience difficulty finding medical professionals with appropriate expertise. For these reasons, it is important for patients and families living with rare diseases to educate themselves about their diseases, available resources and all treatment options.

The members of the MPN Coalition are independent organizations that have come together to increase awareness of these diseases and empower, educate, and support those affected.

The members of the Coalition are:

○ MPN-Specific Organizations:

MPN Education Foundation
MPN Research Foundation

○ Serving the Cancer Community:

CancerCare
Cancer Support Community
The Leukemia & Lymphoma Society

○ Serving the Rare Disease Community:

National Organization for Rare Disorders (NORD)

To learn about the complete range of services provided by these organizations, contact them or visit their websites. This Resource Guide provides a brief overview of services specifically related to myelofibrosis.

RESOURCES PROVIDED BY THE MPN COALITION

The Coalition members as a group have created the following resources:

○ Myelofibrosis Awareness Website

Visit www.myelofibrosisawareness.org for information about events and activities of interest to patients and their families. A mobile version of this site is being created.

○ Symptom Management Calendar

This calendar, available in print and electronic forms, provides a systematic way for patients to track their symptoms on a monthly basis, along with tips and best practices for communicating with the healthcare team. For printed copies, contact any of the organizations in the MPN Coalition. To download an electronic version, go to: www.myelofibrosisawareness.org and click on "Symptoms".

Coalition Services:

| | Support Groups | Clinical Trial Information | Diagnosis/Treatment Information | Information for Physicians | Financial Assistance | Referrals for Additional Resources | Fund Research | Individual Counseling |
|--------------------------|----------------|----------------------------|---------------------------------|----------------------------|----------------------|------------------------------------|---------------|-----------------------|
| CancerCare | ○ | ○ | | | ○ | ○ | | ○ |
| Cancer Support Community | ○ | | ○ | | | ○ | | ○ |
| LLS | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| MPN Research Foundation | ○ | ○ | ○ | ○ | | ○ | ○ | |
| MPN Education Foundation | ○ | ○ | ○ | ○ | | ○ | | ○ |
| NORD | | | ○ | ○ | | ○ | | |

RESOURCES PROVIDED BY MEMBERS OF THE COALITION

MPN EDUCATION FOUNDATION

P.O. Box 4758
Scottsdale, AZ 85261
Antje Hjerpe: antjehjerpe@gmail.com
Robert Niblack: r.niblack@cox.net
www.mpninfo.org



The MPN Education Foundation is a non-profit organization incorporated in 2004 and run by volunteer MPN patients. It hosts patient-doctor conferences to improve patient knowledge about their MPNs and to give patients the opportunity to meet with top MPN specialists. These events take place every two years. For information, go to www.mpninfo.org and click on "Future Events".

The Foundation also hosts MPN-NET, a global online support group for all MPN patients, their loved ones and caregivers. Services provided by MPN-NET include information about MF and other MPNs, current treatment options and clinical trials, interaction with medical experts, physician referral in the U.S. and many other countries, insurance and financial assistance information, emotional support and information about local support groups.

MPN RESEARCH FOUNDATION

180 N. Michigan Avenue, Suite 1870
Chicago, IL 60601
abrazeau@MPNResearchFoundation.org
(312) 683-7429
www.mpnresearchfoundation.org



The MPN Research Foundation is a non-profit organization whose mission is to fund original research into MPNs in pursuit of new treatments and, eventually, a cure for polycythemia vera, essential thrombocythemia and myelofibrosis. In addition, it promotes collaboration in the scientific community to accelerate research, and serves as a powerful advocacy group for patients and their families.

The MPN Research Foundation and Leukemia & Lymphoma Society have partnered to spur innovation in fibrosis research. Read about this at: www.MFChallenge.org.



MF-specific resources on the MPN Research Foundation's website include:

◦ **Myelofibrosis clinical trials:**

www.mpnresearchfoundation.org/Myelofibrosis-Clinical-Trials

◦ **Myelofibrosis overview:**

www.mpnresearchfoundation.org/Primary-Myelofibrosis

CANCERCARE

275 Seventh Avenue, 22nd Floor
New York, NY 10001
info@cancercare.org
(800) 813-4673 (toll-free)
www.cancercare.org



CancerCare is a non-profit organization providing free, professional support services to individuals, families, caregivers, and the bereaved to help them better cope with and manage the emotional and practical challenges arising from cancer.

Services include counseling, financial assistance, practical help and Connect Education Workshops (CEW), a series of free, one-hour live broadcasts that can be accessed online or by telephone. During a CEW, leading experts in oncology provide up-to-date information on various aspects of cancer. These live broadcasts may later be downloaded as podcasts.

◦ **To register for an upcoming CEW or download podcasts,**

go to: www.cancercare.org/connect_workshops

◦ **To find other MF-specific resources,**

enter "myelofibrosis" in the search box on the home page of the CancerCare website

CANCER SUPPORT COMMUNITY

1050 17th Street, NW
Suite 500
Washington, DC 20036
(888) 793-9355 (toll-free)
www.cancersupportcommunity.org



Backed by evidence that the best cancer care includes social and emotional support, the Cancer Support Community offers services free of charge



to men, women and children with any type or stage of cancer and to their loved ones. Services include support groups, educational programs, healthy lifestyle classes, opportunities for social networking and help locating resources.

These free professional services are provided through a network of over 50 local centers and more than 100 satellite locations in the United States, online and over the phone.

For more information, visit: www.cancersupportcommunity.org or call the toll-free hotline at 1-888-793-9355.

○ **To access MF-specific information on the website,**

type “myelofibrosis” in the home page search box. Resources include fact sheets on topics such as: “About Myelofibrosis”, “Coping With Emotions of Myelofibrosis”, “Blood Cancer”, and “Living With Chronic Illness”

○ **A free booklet,**

“Frankly Speaking About Cancer: Spotlight on Myelofibrosis”, can be ordered by visiting: www.orders.cancersupportcommunity.org

○ **To locate a CSC center near you,**

go to the Cancer Support Community home page and click on “Cancer Support”

THE LEUKEMIA & LYMPHOMA SOCIETY

1311 Mamaroneck Avenue, Suite 310
White Plains, NY 10605
infocenter@LLS.org
(800) 955-4572 (toll-free)

www.LLS.org



The Leukemia & Lymphoma Society (LLS) is the world’s largest non-profit health agency dedicated to helping patients with blood cancer and their families. LLS funds blood cancer research around the world and provides free information and support services to patients and their families.

Information specialists can help people with cancer navigate through treatment, financial and social challenges, provide accurate, up-to-date disease and treatment information, and search for clinical trials. Call (800) 955-4572 Monday through Friday, 9 a.m. to 6 p.m. ET. Translation services are available.

Resources provided by LLS include:

- **Myelofibrosis Facts** (disease information in English and Spanish)
for English and Spanish: www.LLS.org/resourcecenter, click on Free Education Materials
- **Myelofibrosis web page**
www.LLS.org/diseaseinformation, click on Myeloproliferative Neoplasms
- **Myelofibrosis webcast:**
“Advances in Blood Cancers: Update on Treatment for Myelofibrosis” www.LLS.org/webcasts

NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

55 Kenosia Avenue
Danbury, CT 06810
orphan@rarediseases.org
(800) 999-NORD (toll-free)
www.rarediseases.org



NORD was established in 1983 as an umbrella organization providing advocacy, education, and awareness on behalf of all patients and families affected by rare diseases. Approximately 200 rare disease organizations are members of NORD.

Services include education, advocacy, research grants, patient assistance programs, and mentoring for patient organizations. NORD is the national sponsor of Rare Disease Day. Visit www.RareDiseaseDay.US for more information. NORD also hosts online global communities with Rare Diseases Europe (EURORDIS) at www.rareconnect.org.

MF resources provided by NORD include:

- **Online Physician's Guide to Myelofibrosis**
www.nordphysicianguides.org/myelofibrosis
- **Information for patients, their families and the public**
on MF and related diseases in the NORD Rare Disease Database at www.rarediseases.org

MPN Support Groups and Related Organizations

