

ESSENTIAL THROMBOCYTHEMIA

MYELOFIBROSIS

POLYCYTHEMIA VERA



 **MPN** | ADVOCACY & EDUCATION
INTERNATIONAL

mpnadvocacy.com

About Us

MPN Advocacy and Education International provides educational programs, materials, and resources for patients, caregivers, physicians, and entire healthcare teams to improve their understanding of myelofibrosis, polycythemia vera, and essential thrombocythemia.

Dedicated

MPN Advocacy and Education International is dedicated to making a difference in the lives of those affected by myeloproliferative neoplasms (MPNs) and strives to grow awareness and advocate on behalf of the MPN community. MPN Advocacy and Education International fosters collaboration with all entities who make a contribution to the MPN community through research, drug development, education, and support.

Most up-to-date information

MPN Advocacy and Education International brings you the most up-to-date information about MPN research, treatment options, clinical trials, and available support that will empower and guide you through the course of your care or the care of loved ones.

Experts in the field of MPN

Our speakers are experts in the field of MPN treatment and research, and many are directly involved in clinical trial studies. Dr. Ruben Mesa is our scientific advisor and frequent speaker at our educational symposia.



Dr. Ruben Mesa, MD
*The Mayo Clinic,
Scottsdale, Arizona*



Letter from the CEO



Ann Brazeau, CEO

Dear MPN Community Friend,

We are thrilled to be able to host educational symposia across the country and abroad with the most knowledgeable researchers and clinicians in the field of MPNs. Patients, caregivers, and healthcare teams benefit greatly from these programs. There are so many patients who cannot possibly get a second opinion from a specialist at the Mayo Clinic or MD Anderson, or anywhere that would require time off of work, additional care for children; or, perhaps, their health prohibits travel to such places. MPN Advocacy and Education International's goal is to bring the experts to you. We research locations and venues that provide easy access, comfortable spaces, and healthy menus. Our speakers are not only great MPN researchers and clinicians, but gracious men and women who are always willing to present at these events to share information and to hear your stories.

They listen, offer sound advice and direction, and, many times, follow up with the patients and caregivers in attendance. Additionally, we include speakers who address the psychosocial issues patients and caregivers face and we highlight patient stories. You will learn how drugs are developed and understand the FDA approval process. MPN Advocacy and Education International is here to provide education, advocacy, support, resources, and a listening ear. If we can't provide what you need, we can direct you to the appropriate organization or person who can. Let us know how we can better serve you.

Warm regards,

Ann Brazeau, CEO

MPN Advocacy and Education
International

abrazeau@mpnadvocacy.com

www.mpnadvocacy.com

Overview of Myeloproliferative Neoplasms

NOTE: For a glossary of terms used in this booklet that may be unfamiliar to you, please see page 11.

Myelofibrosis (MF)

Myelofibrosis occurs in about 1.5 out of every 100,000 people in the United States annually. Men, women and children can all be affected and more people are being diagnosed at an earlier age.

Myelofibrosis is a type of chronic blood cancer that can occur on its own or as the result of another bone marrow disorder. It is called primary myelofibrosis when it occurs on its own and secondary myelofibrosis when it converts from another disorder.

In primary myelofibrosis, a genetic mutation in the blood-forming stem cell disrupts the body's production of normal blood cells, including the red blood cells, white blood cells, and platelets. The abnormal cells begin to take over the normal cells causing a disruption in the function that those cells serve. Extensive scarring in the bone marrow occurs known as fibrosis. Myelofibrosis is often diagnosed by an enlarged spleen and abnormal blood test results.





Polycythemia Vera (PV)

Polycythemia vera is one of the myeloproliferative disorders in which the bone marrow makes too many red blood cells. It may also result in the production of too many other types of blood cells, such as white blood cells and platelets. Red blood cells carry oxygen to the body. White blood cells fight infection. Platelets are involved in clotting the blood in response to an injury. Polycythemia vera slows your blood flow which can increase the risk of developing clots that can sometimes cause strokes. Up to 95 percent of PV patients have the JAK2 gene mutation, which plays a significant role in the production of red blood cells, white blood cells and platelets. The discovery of this mutation has been instrumental in the development of new drugs that are currently in clinical trials. One JAK2 inhibitor (JAKAFI) was approved in 2011 for myelofibrosis and is currently being tested in PV patients. With proper care, treatments, and all around good healthy choices, many PV patients are able to live long and productive lives.

Essential Thrombocythemia (ET)

Essential thrombocythemia causes the body to produce too many blood platelets—thrombocytes. The disease is predominant among women. The most common complications of ET are abnormal clotting or bleeding. The bone marrow makes too many platelet-forming cells or megakaryocytes, which release platelets into your blood. Approximately 50 percent of patients with ET have the JAK2 gene mutation. Other gene mutations are linked to ET and other myeloproliferative neoplasms.

Mutations in the JAK2, MPL, and THPO genes that are associated with essential thrombocythemia lead to overactivation of the JAK/STAT pathway. This activation leads to an overproduction of megakaryocytes which results in an increased number of platelets.

Coping with Myeloproliferative Neoplasms



If you've been diagnosed with myelofibrosis, polycythemia vera, or essential thrombocythemia, it's important to have a primary care physician, hematologist, and healthcare team that you feel comfortable with and at ease asking any question important to you. An empathetic, knowledgeable group can make your journey less trying. It's okay to get a second opinion if you choose. Learn as much as you can. The more knowledgeable you are about your MPN the more empowered you will be in making decisions with your family, caregivers and physician(s).

Educate yourself and others

Educate yourself, caregiver, and family members. Learn everything you need to know about your diagnosis. Attend educational symposia and hear from the experts in the field of MPNs. View webcasts after events if you are unable to attend. Visit the numerous sites that focus on MPNs and read as much as possible. Ask questions. Remember to take notes during your appointments or have someone else take notes. If you don't understand what your doctor is saying, ask for explanations. Know who to call if you need medical attention outside of a scheduled doctor appointment. Be sure to keep your medical records in order. Coordinate your care by making your physician(s) and health care team your partners in care.

Carry an ID Card & avoid possible complications

If you are having elective surgery, make sure you meet with your entire healthcare team to discuss your MPN and whether you may require special needs. Carry an ID card that requests a call to your hematologist immediately if you are in an emergency situation that may require medical care or surgeries. List your MPN on that card with your physician's name and phone number.

Join a support group

There are many support groups across the country and abroad. Support group meetings are a safe place to hear from other patients and caregivers who share similar experiences, issues, and concerns. It is also a place where you will hear updates on research, clinical trials and treatment options

Be an advocate for your care

Decide what you do at home to monitor your symptoms and track changes to your health. Get plenty of rest, Exercise, meditate and replace negative thoughts with positive thoughts. Eat properly and quit bad habits like smoking. Continue to do things you enjoy to take your mind off your illness, read, golf, swim, and volunteer. Use all resources available to connect with others, like social media, Know you are not alone.

MPN PATIENT & CAREGIVER SUPPORT GROUP GUIDE

United States

Arizona

Phoenix

Contact: Kathy VanMeter
kathyvanmeter@cox.net or by
phone at 623-326-2456

California

Los Angeles

Contact: Ron Anderson
randerson@activetech.com

San Diego

Contact: Antje Hjerpe
jahjerpe@sbcglobal.net

San Francisco – Bay Area

Contact: Susan
Susanklepper@hotmail.com

Coachella Valley

Contact: Linda
suttonprescott@aol.com

Colorado

Denver

Contact: Mabel
mabel.d.peters@kp.org or 303-764-8523

District of Columbia

Contact: David
55saveslives@gmail.com

Georgia

Atlanta

Contact: Bonnie Evans
kbemje@bellsouth.net or 404-771-0010

Idaho

Boise

Contact: Susan Hill
jacksue@cableone.net

Indiana

Bloomington

Contact: Ellen
hankandellen@bluemarble.net

Illinois

Chicago

Contact: Raquel
nunez@MPNResearchFoundation.org
or 312-683-7243

Kentucky

Contact: Susan at smkennedy0@gmail.com

Massachusetts and greater New England

Contact: Colleen Curley
massmpn@gmail.com

Michigan

Lansing

Contact: Ann Brazeau
abrazeau@mpnadvocacy.com or
517-899-6889

Nevada

Contact Cristina
corozco11@cox.net

New Mexico

Albuquerque

Contact: abq_mpn@yahoo.com

New York

New York City

Contact: Susan Protter
sapla@aol.com or 212-580-0115

North Carolina

Contact: Janice
jcreed@roadrunner.com

Ohio

Akron / Cleveland

Contact: Jay Schmitt
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Columbus

Contact: Judy at judyMPN@yahoo.com

Cincinnati, SW Ohio, NE Kentucky, & SE Indiana

Contact: Rebecca
Lubitz rebeccalub@aol.com or
513-793-3179

Pennsylvania

Philadelphia

Contact: Marie
mtomp57083@comcast.net

Pittsburgh

Contact: Jean
mpn.pgh.sup@gmail.com or
724.831.0368

Puerto Rico

San Juan

Contact: Maribel & Michael Rey,
P.O. Box 364885, San Juan, PR 00936
maribel.rey@gmail.com

South Carolina

Contact: Janice
jcreed@roadrunner.com

Charleston

Contact: Leslie
lesliedispensaperlman@yahoo.com

Texas

Dallas – Fort Worth

Contact: Karen Stern at karen-stern@
sbcglobal.net or 214-395-2541

Houston

Contact: Charlie Nielsen
charlienielsen@aol.com

Utah

Salt Lake City

Contact: Rynda
ryndabrown2006@yahoo.com

Washington

Seattle

Contact: Seattle MPD Yahoo Group

Wisconsin

Racine (Includes SE Wisconsin and
NE Illinois)

Contact: Karen Luba
klipluba@yahoo.com or 262.552.7047

MPN PATIENT & CAREGIVER SUPPORT GROUP GUIDE

Outside the U.S.

Australia

Contact: Ken Young
kyoung@yarranet.net.au

Canada

Saskatoon, Saskatchewan

Contact: Gordon Walz
g.walz@sasktel.net

Edmonton, Alberta

Contact: Cheryl
cap@interbaun.com or 780-940-6569

Hamilton, Ontario (Including Toronto, S. Ontario, Western New York)

Contact: mpnontario@gmail.com or
call John at 905-892-8238 or Donna at
905-389-1278

Vancouver, BC

Contact: Lisa
mpdvancouver@gmail.com

France

A support group is forming. Visit
www.mpd.tel for more details.

Germany

Contact:
MPD-Netzwerk@yahoogroups.de

Japan

Contact: Kaori Taki
patchleo.jp@yahoo.co.jp

Japan (English speaking)

Contact: Ira Wolf
irawolf@aol.com

The Netherlands

Contact: MPD Stichting
info@mpd-stichting.nl or 088-0074-300

Spain

Contact: Peter
MPDSpainPacientes@gmail.com

United Kingdom

Upcoming meetings and forum:
mpdvoice.org.uk/get-involved/
upcoming-events/

London

Contact: info@mpdvoice.org.uk

Scotland

Contact: info@mpdvoice.org.uk

Online Support Groups

MPD Chat

MPN-Net

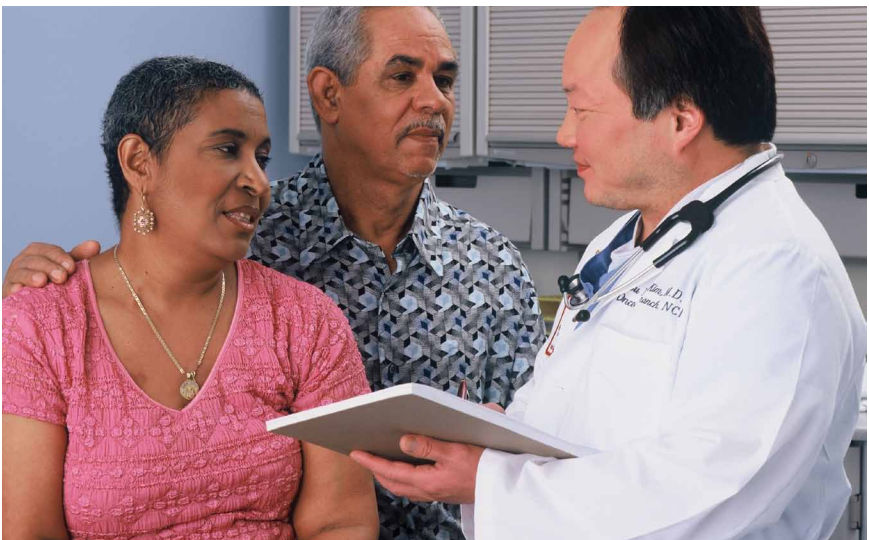
Facebook Myelofibrosis Support

Myeloproliferative Disease Support and

Free Daily Email Digest

A list of MPN cancer centers can be found at mpnadvocacy.com.

MPN Advocacy and Education International is building a comprehensive list of cancer centers as possible options for MPN patients. If you would like to recommend a physician and/or center to add to this list, please let us know. Simply call 517-899-6899 or e-mail abrazeau@mpnadvocacy.com



Do you need help paying for MPN treatment?



As more drugs for MPN patients are approved, options for treatments and greater access should improve. Improving access is an ongoing issue in most disease groups and particularly in rare diseases.

Advocacy groups like MPN Advocacy and Education International have become a powerful and sought-after voice by some biotech and pharmaceutical companies. They want to know how to better serve patients. Access and cost are the topics most discussed and will be until better healthcare programs are implemented in the US. In the meantime, no patient should go without a treatment that could improve their quality of life or save their life.

Cancer Care, Inc.

cancercare.org
800-813-4673

Chronic Disease Fund

cdfund.org
877-968-7233

Incyte Corporation

Prescription Assistance Program for Jakafi
jakafi.com/IncyteCARES

Leukemia and Lymphoma Society

LLS Co-pay Assistance
877-557-2672

Partnership for Prescription Assistance

pparx.com
888-477-2669

Patient Access Network Foundation

(PAN Foundation)
panfoundation.org
202-347-9272

Patient Services, Inc.

patientservicesinc.org
800-366-7741

New Initiative Offered



Over the years, the landscape in the MPN community has changed tremendously. The former demographics are no longer the norm. A new profile is emerging as younger patients are being diagnosed and new issues are being recognized by the MPN medical community who see women experiencing additional challenges who have myelofibrosis, essential thrombocythemia, and polycythemia vera.

MPN Advocacy and Education International encouraged further exploration into these specific issues women face with the help of Dr. Laura Michaelis, MD. Dr. Michaelis has partnered with MPN Advocacy and Education International to provide a unique program, Women and MPN, which will include an annual, two day event with MPN experts, breakout sessions addressing specific needs of women with chronic diseases, and a host of other educational and living well programs.

Dr. Laura Michaelis, MD



Laura C. Michaelis is an Associate Professor of Medicine at the Medical College of Wisconsin/ Froedtert Hospital and has been active in the research and clinical care of patients with

Myeloproliferative Neoplasms for more than a decade. She has a particular interest in the unique ways these diseases impact woman and their unique manifestations in patients of different genders and across the age spectrum. She has spoken nationally on these topics and is a regular participant in patient education forums on acute and chronic leukemias. Dr. Michaelis was elected by the American Society of Hematology to serve on their national advocacy board and will be working to advance the interests of patients with

hematologic malignancies through this legislative effort.

More and more is being understood about the ways that these diseases, including polycythemia vera, essential thrombocythemia and myelofibrosis, play out across the spectrum of age and gender. Certainly, the life events of women, including experiences of fertility and menopause, can pose unique challenges in treatment choices. The higher risk for clotting that younger women face can often mean earlier diagnosis and longer exposure to complicated therapies. Whether or not these conditions are experienced differently in women or whether or not there are differences in treatment response are outstanding questions that scientists and researchers continue to address.

Glossary of Terms

Allogenic: Describes tissues or cells that are genetically different and immunologically incompatible; cell types that have a specific immune response.

Anemia: When the number of red blood cells is below normal, it can result in fatigue, weakness, and shortness of breath.

Bone Marrow: The soft, fatty, vascular tissue inside bones that produces blood cells.

Bone Marrow Biopsy: A procedure used to remove soft tissue, called marrow, from inside the bone.

Bone Marrow Transplant (BMT): A procedure to replace damaged or destroyed bone marrow with healthy bone marrow stem cells.

Blood Cancer: The rapidly multiplying cancerous cells are found attacking the different aspects of the circulatory system. Blood, the lymphatic system and bone marrow can be the focus of attack.

Calreticulin (CALR): is a protein that in humans is encoded CALR gene. It is a multifunctional protein that binds Ca^{2+} (a second messenger in signal reduction) ions rendering it inactive.

Complete Blood Count/CBC: A blood test that measures the concentration of white blood cells, red blood cells, and platelets in the blood.

Chemotherapy: A cancer treatment that can be given orally and/or intravenously using chemical agents or drugs that are selectively destructive to specific cancer cells.

Donor: Some MPN patients choose to have bone marrow transplants. Donors who are considered a perfect match are the optimal candidates and are often a family member. Many donors are unknown to the recipient although some do connect after successful transplants.

Essential Thrombocythemia: is an uncommon disorder in which your body produces too many blood platelets (thrombocytes). It's also known as primary thrombocythemia.

Fatigue: A condition marked by extreme tiredness and inability to function normally due to a lack of energy.

Fibrosis: Thickening and scarring of connective tissue.

Genes: The basic building blocks of heredity that are present in all cells.

Hemoglobin: The part of the red blood cell that carries oxygen.

Hematologist: A doctor who specializes in blood cancers.

Hematopoietic Stem Cell: A cell that develops into any type of specialized blood cell.

Hepatomegaly: Enlargement of the liver.

JAK 2 (JAK2v617F): The genetic mutation found in approximately 50 percent of myelofibrosis patients, 95 percent of polycythemia vera patients, and approximately 50 percent of essential thrombocythemia patients.

MRI Scan: A scan that uses magnets and radio frequency waves to produce images inside the body.

Myeloproliferative Neoplasms: Diseases of the blood and bone marrow, in which the body makes too many blood cells. The three main types of MPNs are: polycythemia vera (PV), essential thrombocythemia (ET), and myelofibrosis.

Neoplasm: An abnormal mass of tissue that results when cells divide more than they should or do not die when they should.

Neutropenia: A significant decrease in the number of white blood cells.

Night Sweats: Episodes of excessive sweating while sleeping.

Petechiae: Flat, red, pinpoint spots under the skin caused by bleeding.

Platelets: Small cell fragments that help blood clot.

Polycythemia Vera: A bone marrow disease that leads to an increase in the number of blood cells.

Pruritus: Severe itching associated with a number of disorders including cancer.

Radiation Therapy: A type of treatment that uses high energy to kill cancer cells.

Red Blood Cells (RBCs): Cells that carry oxygen through the body.

Spleen: An organ located on the left side of the abdomen that is part of the lymphatic system. The spleen makes lymphocytes, filters the blood, stores blood cells, and destroys old blood cells.

Splenectomy: Surgical removal of part or the entirety of the spleen.

Splenomegaly: Enlargement of the spleen.

Stem Cell: A cell that can become a more mature type of blood cell.

Stroke: Rapid loss of brain function due to a disturbance of blood flow to the brain such as a blockage or hemorrhage.

Transplant: Bone marrow transplant or stem cell transplant.

Transfusion: A procedure in which a person is given an infusion of blood intravenously.

Ultrasound: High frequency sound waves used to look at organs and structures inside the body.

White Blood Cells (WBCs): Blood cells that help fight infection.

*For current treatment options visit our online resource:
www.mpnadvocacy.com/resource*

Organizational Partners

MPN Research Foundation
Leukemia Lymphoma Society
CancerNet
MPN Education Foundation
Patient Access Network Foundation (PAN Foundation)
Patient Services, Inc.
Cancer Care, Inc.
Partnership for Prescription Assistance
Cancer Support Community
National Organization for Rare Disorders (NORD)

Industry Partners

Incyte Corporation
Geron Corporation
Janssen Research and Development
CTI BioPharma
Promedior



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