



## Myeloproliferative Neoplasms (MPN) Information, Research, & Patient Support Resources

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**MPN Research Foundation**  
<http://www.mpnresearchfoundation.org/>

The MPN Research Foundation was founded by patients, for patients with a single goal: to stimulate original research in pursuit of new treatments -- and eventually a cure -- for polycythemia vera, essential thrombocythemia and myelofibrosis, known collectively as myeloproliferative neoplasms (MPN). It funds basic science research that holds promise for further knowledge in MPN functioning. It also has a lot of educational information for patients and their loved ones.



**MPN Education Foundation**  
[www.mpninfo.org](http://www.mpninfo.org)

The Foundation promotes collaboration in the scientific community to accelerate research, and serves as a powerful advocacy group for patients and families. Hold a bi-ennial MPN Patient Conference with Mayo Clinic Scottsdale in February (next one: 2017). This volunteer run organization also hosts and administers MPN-NET, a global online support and education list for patients, families, researchers and physicians.

**MPN-NET:** <http://listserv.acor.org> subscribe (it's free!) with email to [listserv@listserv.acor.org](mailto:listserv@listserv.acor.org)

Discussions include patient experiences, psychosocial issues, new research, clinical trials, and discussions of current treatment practices and alternatives. The principal focus is expected to be information and reassurance for patients and loved ones.

**MPNforum Magazine** <http://www.mpnforum.com>

MPNforum Magazine and its companion MPN Quarterly Journal are open source publications managed and staffed by patients and caregivers with the volunteer participation of scientists, hematologists, and healthcare providers. No subscription is required, but subscribers (no fee, just sign up with email address) get special bulletins, early notice of publication, plus the option to join the private MPNforum Facebook discussion group).



**MPN Advocacy and Education International**  
[www.mpnadvocacy.com](http://www.mpnadvocacy.com)

The organization focuses on providing educational programs for patients and physicians to improve the lives of those affected by MPNs. The website lists many resources and they post articles of interest to patients.

**MPDchat** (google groups): <http://groups.google.co.uk/group/mpdchat?hl=en-GB>  
Online support/chat group operated by a care giver of a long-time MPN patient.  
Patients can post questions and share MPN experiences with one another.



**Leukemia & Lymphoma Society**  
[www.lls.org](http://www.lls.org)

LLS is the largest voluntary health agency dedicated to blood cancer and funds lifesaving blood cancer research around the world. The ***First Connection*** program facilitates peer support by matching patients with cancer survivors trained in peer support.



**NORD - National Organization for Rare Disorders**  
[www.rarediseases.org](http://www.rarediseases.org)

The National Organization for Rare Disorders is committed to the identification, treatment and cure of rare disorders through education, advocacy, research and patient services.



**CancerCare Inc.**  
[www.cancercare.org](http://www.cancercare.org)

Cancer Care provides free professional support services for coping and managing the emotional and practical challenges arising from cancer.



**Cancer Support Community**  
[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

CSC is an international non-profit organization dedicated to providing support, education and hope to people affected by cancer. They have offices in several cities, each with local services for patients and care givers.

**MPD-RC The MPD Research Consortium** [www.mpd-rc.org](http://www.mpd-rc.org)

A National Cancer Institute supported project involving 50 International MPN Centers in the United States, Canada, Europe and Israel. It is a resource for both patients and physicians focusing on advancing the science and therapy of myeloproliferative neoplasms.

**Cancer Research & Treatment Fund (CRT)** [www.crt.org](http://www.crt.org)

CRT funds clinical research on MPN and related blood cancers, primarily through Weill Cornell Medical College. Founded by Dr. Richard T. Silver in 1948, CRT has invested more than \$10 million in clinical research.

## Local Support & Social Media

Thanks to technology, no one has to go through the MPN experience alone. MPN patients and their care givers are some of the nicest people around. They provide encouragement and insights with each other in many ways. Some special friendships have formed as a result of the MPN diagnoses.

Support is generally in three ways and many people participate in several:

1. **In-person Support Groups**
2. **Online Support Groups**
3. **Peer to Peer Support**

### **In-person Support Groups**

There are local/statewide support groups in many states across the country. The most up-to-date contact info is on the [MPN Research Foundation](#) Support Group page.

#### **MPN Atlanta Support Group**

Coordinator: Bonnie Evans [kbemje@bellsouth.net](mailto:kbemje@bellsouth.net)

Bonnie's helper: Marina Peed [marinapeed@gmail.com](mailto:marinapeed@gmail.com)

This group meets quarterly, usually somewhere in metro Atlanta. There is also a private Facebook group, MPN Atlanta Support Group. If you would like to join, simply request and tell us a bit about yourself.

### **Online Support Groups**

A couple were listed earlier:

**MPN-NET:** <http://listserv.acor.org> subscribe (it's free!) with email to [listserv@listserv.acor.org](mailto:listserv@listserv.acor.org)

**MPDchat** (google groups): <http://groups.google.co.uk/group/mpdchat?hl=en-GB>

### **Facebook Groups & Pages**

There are numerous groups on Facebook. Some are "open" and others are "closed" (you request access and be approved by an administrator).

Each group has its own culture and groundrules. They are administered by patients or care givers of MPN patients. They tend to have a certain topical focus, and many of us participate in several groups.

Most groups are "closed" to protect the discussions from showing up on newsfeeds, getting personal information shared with marketers, etc.

A Friendly Note about Facebook and Social Media:

Some people have created a Facebook account with a pseudonym for the purpose of maintaining some privacy. Some people have done so for more nefarious purposes (collecting patient data without consent, selling, spam). So if you do so and request to

join a group, consider informing the administrator so they will favorably consider your request.

### **Peer to Peer Support**

**LLS's First Connection:** <http://www.lls.org/support/peer-to-peer-support>

The Patti Robinson Kaufmann First Connection Program connects patients to volunteers who have experienced the same illness. First Connection volunteers must be trained and vetted by LLS to listen and know about resources that can benefit the patient. Their online chats and discussion boards are not very active on MPNs, perhaps because of the other groups mentioned here.

**Imerman Angels:** <http://www.imermanangels.org>

Offers peer support from people who have gone through this already – both patients and caregivers. They match by disease, age, gender, to strengthen the relationship. They have “mentor angels” who provide support in the United States and 60 other countries.

## **For Really Thick Reading... Published Scientific Studies**

PubMed: [www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)

PubMed is the US National Library of Medicine, operated by the National Institutes of Health. You can create a free account and search for articles, save favorites, and print out information.

Blood: [www.bloodjournal.org](http://www.bloodjournal.org)

Published by the American Society of Hematology, Blood Journal posts many scientific articles on blood cancers and diseases.

Fortunately, we have some incredibly bright and dedicated patients and volunteers who keep apprised of the latest reports and share highlights at the MPNforum magazine and journal and the MPN-NET. Information on both of these are listed on the first page.

### **Final thoughts:**

1. Be optimistic! There are more significant discoveries about the pathogenesis of MPNs and trials with more treatments than ever before.
2. Stem cell transplantation continues to improve as a treatment and cure.
3. What you may have read five years ago is old news.
4. Learn the latest and make sure you see a MPN specialist once a year to keep your health on track.