

# MPN Focus

SPRING 2018



## Caregiver Spotlight: Bennie Fuelberg

By Jeannine Garnett

**Q: PLEASE COULD YOU TELL ME WHAT MYELOPROLIFERATIVE NEOPLASM YOUR WIFE HAS, WHEN IT WAS DIAGNOSED, AND WHAT HER JOURNEY HAS ENCOMPASSED SINCE THEN?**

**A:** Jeanie has myelofibrosis. She was diagnosed in 1999 with Essential Thrombocythemia when our primary care physician, Dr. Jerry Hood, discovered abnormalities in her blood during an annual physical checkup. He referred her to Dr. Ballijepalli Netaji, a hematologist/oncologist, who then officially diagnosed her and began treating her with hydroxyurea until it was replaced with anagrelide.

Her disease progressed to Polycythemia Vera, and in 2005 it progressed further to Myelofibrosis. While Dr. Netaji continued treating her, he also continually sought out new treatments and new discoveries that might assist her! We went to UT Medical Branch in San Antonio but were told they had no treatments or trials recruiting patients at that time which would benefit Jeanie. Dr. Netaji then researched the Jak2 inhibitor discoveries, and found investigations were being conducted at MD Anderson and other places!

In late 2007, we began visiting with clinic staff at MD Anderson, ultimately

seeking admission to the trials being conducted there, but we were told she was still not a candidate to be included in a trial. Then in December 2009, she was a strong

candidate to be included in a JAK2 inhibitor trial! She was accepted into the trial of a drug called ruxolitinib and her symptoms began to be relieved within a matter of weeks! Days, actually!

**Q: WHAT CHALLENGES DID YOU FACE WHEN YOUR WIFE WAS INITIALLY DIAGNOSED, HOW HAVE THESE CHALLENGES AND VARYING ROLES EVOLVED FOR YOU AND YOUR FAMILY OVER TIME, AND IN WHAT WAYS HAS YOUR LIFE CHANGED WITH YOUR WIFE'S DIAGNOSIS?**

**A:** When her initial diagnosis of ET was received, we went through the stages of grief with a heavy emphasis on denial, but all of these stages were eased by Dr. Netaji's consistent positive attitude and his determination to find the right treatment to prolong and enhance her life! While he never failed to be forthright about her outlook, at each stage he continued to pursue all avenues for new or improved treatments, which helped ease our concerns and grief.

When Jeanie was initially diagnosed, her symptoms and limitations were light and rare with few changes to our lives and activities! She went alone to her doctor visits, in addition to her transfusions and tests, as I was still working full time and she felt able to

do that. While it did consume more of her time, the physical limitations were muted even while the symptoms persisted. Fatigue became the biggest limiting factor but Jeanie fought through as much as she could. As her diseases progressed, our lives changed with me taking on more of the physical tasks in and around the home. We began looking at the tasks and things in our lives more critically since our priorities had changed. At some point in the early years, she was told she had a life expectancy of maybe 10 years! WOW! What a wake up-call! We began planning for her death, even to the point of planning her memorial service and the video she wanted shown. We worked on the video which was primarily about her friends, and especially the kids and students whom she had taught over the years. I took an early retirement so that I could spend more time with her in the last stages of her life and to just be there for her.

As her disease progressed through 2007, 2008, and 2009, we became more housebound and dependent on each other. We are blessed with many really wonderful, close and giving friends who willingly helped, visited, and volunteered their assistance, kindness, and comfort. But at the end of each day, and hopefully at the start of each morning, it was just Jeanie and me. We grew closer and

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## LETTER FROM THE DIRECTOR



As Leo Tolstoy once said, “Spring is the time of plans and projects.” With that in mind, we have actively made plans to start investigating the varying genetic profiles of different MPN patients, with the hope of being able to provide individualized therapies in the near future.

In this issue we highlight the currently available clinical trials for our patients with MPNs, and we also provide some additional information for our patients and their caregivers on resources that are freely available to them here at The University of MD Anderson Cancer Center. I’m proud to be a part of this dynamic and multi-faceted institution of excellence.

I would also like to draw your attention to a couple of other resources available on the internet that may be extremely useful to

you as a guide to help you through your diagnosis and treatment/s. The National Comprehensive Cancer Network has released an updated guide for MPN patients, which can be found at the following URL: <https://www.nccn.org/patients/guidelines/mpn/74/>. It is important that you track your symptoms over time, and therefore you may consider keeping a few copies of the assessment form handy, which can be located online at <https://www.mpnconnect.com/pdf/mpn-assessment-form.pdf>. As you may be aware, we collaborate very closely with community physicians regarding your care. It would be beneficial if you were able to complete the total symptom assessment form regularly, and present them to us and your local doctor.

Wishing you all many blessings. •

*Dr. Srdan Verstovsek, United Energy Resources, Inc. Professor of Medicine in the Department of Leukemia at The University of Texas MD Anderson Cancer Center serves as the Director of the Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasms. Dr. Verstovsek is an internationally recognized physician scientist, who is not only dedicated to understanding the biology of MPNs, but also to developing new therapies for MPNs.*



### MPN RESEARCH: YOU CAN MAKE A DIFFERENCE

Gifts provide critical support needed to conduct innovative MPN research. Our MPN clinical and laboratory research team is dedicated to improving treatment outcomes for patients with MPNs.

To make a donation by mail, please send gifts to The University of Texas MD Anderson Cancer Center and specify “MPN Clinical Research Center” in the memo line using the attached envelope.

## Support for Patients in Texas



Founded by MPN patient and advocate Charlie Nielsen, the South Texas support group meets several times a year to discuss issues associated with living with an MPN.

The North Texas support group is led by Andrea Spica and meets quarterly.

Both groups provide an opportunity to meet and share with others who have a similar diagnosis.

To find out more information or join either group, please contact them either by e-mail or through their Facebook page:



North Texas,  
Dallas/Ft. Worth  
[Andrea926@SBCGlobal.net](mailto:Andrea926@SBCGlobal.net)



South Texas,  
Houston  
[CharlieNielsen@aol.com](mailto:CharlieNielsen@aol.com)



Facebook  
[Facebook.com/groups/  
MPNSupportTX](https://www.facebook.com/groups/MPNSupportTX)

## Spotlight

more attuned to each other. In 2009, as her spleen and liver grew, her physical condition deteriorated. As her stomach, lungs and other organs were squeezed, she became much weaker, so much so that she needed more help physically around the house. During 2009, she could barely walk and rarely left the house. It was at this point that it was more necessary for me to be a true caretaker; trying to do everything I could to make her more comfortable. Watching the one true love of my life fade away in front of me was the hardest thing I could ever imagine! There were tears! BUT DR. NETAJI NEVER GAVE UP, so neither did we!

We were then blessed by Dr. Srdan Verstovsek and his staff and the clinical trials at MD Anderson! After visiting quarterly for two years, when we visited in December of 2009, Dr. Verstovsek told us that Jeanie would be admitted to the blinded clinical trial for the drug known as ruxolitinib that would ultimately be FDA approved! When we started that first day, we were told she would be able to tell in approximately two weeks if she felt different and better, which would indicate whether or not she was on the drug or placebo. We went home after a two day visit hopeful of being given a chance at a longer and better life, however slim that chance might be! True to their predictions, at the end of the second week, her symptoms were easing and she was feeling better!

Both Dr. Netaji and Dr. Verstovsek and their staff were watching her closely. We drove from Austin to Houston for an overnight stay weekly at first, then bi-weekly, then once a month, then once every two months, then every three months, and finally every six months. With each visit the news got better! She obviously endured all the testing, bone marrow biopsies, and other poking and prodding with some tolerance because of the rewards she was receiving from the drug. Then we started having a nurse visit our home weekly to take blood samples

to be sent to the test lab. Obviously, all these things occupied a great deal of our time and effort. We were both focused on her health and recovery almost full time.

Over time as her condition improved, we were able to assume more normal roles and more normal activities. We could have fun and participate in life again, however behind every pleasure, activity, and action there will always be the knowledge that she HAS MYELOFIBROSIS! Even so, every day and activity is better because of how blessed we are to be able to enjoy a near normal life with her again. Dr. Verstovsek told us early on that new discoveries were being made every day that might help Jeanie and other patients. We believe that, and further know that MD Anderson WILL MAKE CANCER HISTORY!

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**Q: WHAT ARE SOME OF THE WAYS YOU HAVE EXPLORED IN ORDER FOR BOTH YOU AND YOUR WIFE TO COPE, AND WHAT STRATEGIES HAVE YOU FOUND HELPFUL FOR YOURSELF WHEN DEALING WITH THE EMOTIONAL, PHYSICAL, SPIRITUAL, SOCIAL, AND FINANCIAL ASPECTS OF YOUR WIFE'S CANCER?**

**A:** Over the last 19 years, the disease has changed our lives a great deal. Obviously, dealing with an endless number of health care visits, treatments, the daily awareness and knowledge of what is happening with her body keeps us focused a lot on that aspect of our lives. It takes time and is our priority!

Finding a balance between helping and hovering has been difficult, but we are settled into good routines and are ready for changes. There was no magic coping lesson that we found, but we kept coming back to the clinic and grew closer in the process! I care about her very much and of course she is my priority, but we both have active lives and try not to let her disease control everything.

The major way we both cope, I think, is through a deep faith and a

continuation of our lives including closeness with our family and many friends! I think we might both go nuts if we just concentrated on that aspect of our lives! We accept the physical limitations of her disease, but also know that since she was first diagnosed with ET in 1999, we have each AGED by almost two decades!

All of our physical problems do not come solely from her disease. Financially, we are fortunate in being able to afford the necessary trips, medicines etc. by prioritizing her care and forgoing things that are not as important! It is a balancing act, but we realize the priority! Obviously, her medical condition has caused us to forego most of the travel we loved, but we try to make our medical visits mini vacations by taking our time to enjoy other sights and attractions that we can.

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**Q: WHAT IS SOMETHING POSITIVE THAT YOU CAN SHARE ABOUT THIS DIFFICULT TIME FOR BOTH YOU AND YOUR FAMILY?**

**A:** The positives are endless! We have seen the very best of the medical community at work! All of our physicians have worked together for her benefit untiringly. The wonderful and positive staff, including all three of our physicians' offices, have made life better! We have met wonderful people who also suffer from a MPN, and we've found support and comfort in their sharing of their stories.

Watching the dedication of all those health professionals to making patients' lives better and longer has been an inspiration for us. When she was first given ruxolitinib, someone told us that the major side effects they had noticed were an increased appetite and a craving for chocolate. Now that was a side effect she could live with! But it has also made us much more aware of our time with our friends, our daughter and her family, and with our three grandchildren!

Most of all, it has made the time we have together more special and made us closer! I appreciate all the things she has done for me in our marriage, and hope I can repay a small portion now. •

# MPN Clinical Trials



Listed below are clinical trials enrolling patients with MPNs at The University of Texas MD Anderson Cancer Center. For more information on these clinical trials, please call the information line toll-free at 1800-392-1611. For additional information on these clinical trials, please go to [www.mdanderson.org/MPNClinicalTrials.com](http://www.mdanderson.org/MPNClinicalTrials.com), or to find other clinical trials for MPN, please go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov).

## Phase 2 Study of INCB054828 for Patients Having a FGFR1/8p11.2-rearranged Hematologic Malignancy

Study #2016-0635 (clinicaltrials.gov NCT No: NCT03011372)

Principal Investigator: Srdan Verstovsek

**Study Description:** The objective of this study is to determine the safety and efficacy of INCB054828, an inhibitor of FGFR1 proteins, as a single agent therapy for patients that have hematologic malignancies with a FGFR1/8p11.2-rearrangement. Overall clinical benefit and primary outcome measures will occur over 24 months.

## Phase 1 Study of BLU-285 for Patients with Advanced Systemic Mastocytosis

Study #2015-0832 (clinicaltrials.gov NCT No: NCT02561988)

Principal Investigator: Srdan Verstovsek

**Study Description:** Most patients with advanced systemic mastocytosis have an abnormality in a gene called KIT. BLU-285, otherwise known as Avapritinib, will be assessed for safety and tolerability. The study consists of a dose escalation phase, which will then be followed by an expansion phase. This agent will be taken orally either once a day.

## Phase 2 Study of Ruxolitinib Versus Anagrelide in ET Patients Who are Resistant to, or Intolerant of, Hydroxyurea (RESET-272)

Study #2017-0111 (clinicaltrials.gov NCT No: NCT03123588)

Principal Investigator: Prithviraj Bose

**Study Description:** This study will compare the use of ruxolitinib or anagrelide treatment in those ET patients that are resistant or intolerant of hydroxyurea. ET patients with platelet counts greater than 650 x 10<sup>9</sup>/L, and white blood cell counts that are greater than 11 x 10<sup>9</sup>/L are eligible to receive either agent orally twice per day.



## Phase 2 Study of Ruxolitinib and Thalidomide Combination Treatment for Patients With PMF, post-PV MF, or post-ET MF

Study #2017-0512 (clinicaltrials.gov NCT No: NCT03069326)

Principal Investigator: Prithviraj Bose

**Study Description:** The objective of this study is to determine the efficacy and tolerability of ruxolitinib and thalidomide combination therapy. Patients who have

never received ruxolitinib, or those that have been on treatment for at least 3 months and on a stable dose for a month who haven't had a sufficient response are eligible to enroll. Both oral agents will be administered daily.

## Phase 2 Study of INCB050465 when Combined with Ruxolitinib Therapy for Patients with MF

Study #2016-0233 (Clinicaltrials.gov NCT No: NCT02718300)

Principal Investigator: Navel Daver

**Study Description:** The goal of this study is to assess whether the addition of a PI3K inhibitor, INCB050465, to a stable regimen of ruxolitinib for patients that have had an insufficient response to ruxolitinib therapy as a single agent, will enhance the killing of cancer cells. These two agents work to suppress the same cancer cell signaling whether pathway but target different proteins. The first part of the study will increase the dose of INCB050465 in combination with ruxolitinib, and the second part will compare two doses of the PI3K inhibitor whilst on ruxolitinib therapy.

## Phase 2 Study of Ruxolitinib when Combined with Azacytidine for MPN patients having MF or Myelodysplastic Syndrome (MDS)

Study #2012-0737 (clinicaltrials.gov NCT No: NCT01787487)

**Principal Investigator:** Naval Daver

**Study Description:** This study will determine if azacytidine when used in combination with ruxolitinib will aide in controlling MF and MDS. Azacytidine works by inhibiting proteins that prevent the proper functioning of tumor-fighting proteins. Patients will take ruxolitinib for 3 months followed by increasing the dosages of azacytidine. Patients that have previously been treated with ruxolitinib are not eligible for participation. This study is only available at MD Anderson.

### Phase 2 Study of Sotatercept for Patients with MF and Anemia

**Study #2012-0534** (clinicaltrials.gov NCT No: NCT01712308)

**Principal Investigator:** Srdan Verstovsek

**Study Description:** The goal of this study is to determine whether sotatercept is safe and may control MF and anemia. If a patient has been on a stable dose of ruxolitinib for half a year and the dose has been the same for the preceding two months, then the patient will also be eligible to enroll. Administration of sotatercept is given intravenously every 3 weeks at low or high doses to transfusion-dependent or transfusion-independent patients. This clinical trial is enrolling patients at MD Anderson only.

### Phase 2 Study of the Efficacy and Safety of Oral Rigosertib in Patients with MF and Anemia

**Study #2014-0546** (clinicaltrials.gov NCT No: NCT02730884)

**Principal Investigator:** Jorge Cortes

**Study Description:** The goal of this clinical research study is to learn if rigosertib can help control MF in patients with anemia. Rigosertib is an investigational therapy that works by increasing the killing of cancer cells. The safety of this drug, spleen volume, anemia responses, and symptom responses will be evaluated. Both transfusion-dependent and –independent patients with MF and anemia may enroll.

### Phase 2 Study of Luspatercept for Patients with MF and Anemia

**Study #2017-0504** (clinicaltrials.gov NCT No: NCT03194542)

**Principal Investigator:** Prithviraj Bose

**Study Description:** The purpose of this study is to learn whether luspatercept can help control MF and anemia in transfusion-dependent and –independent patients. Luspatercept works by promoting the maturation of all nucleated red blood cells. Those that have been on a stable dose of ruxolitinib for at least 112 days may also enroll in the study. The safety and efficacy of luspatercept will be monitored.



### Phase 2 Study of LCL-161 in PMF, Post-PV MF, or Post-ET MF Patients

**Study #2013-0612** (clinicaltrials.gov NCT No: NCT02098161)

**Principal Investigator:** Naveen Pemmaraju

**Study Description:** The goal of this study is to determine whether removing the brakes on cancer cell killing through the inhibition of IAP by LCL-161 will help control MF. It has been reported that anemia, splenomegaly, and MF symptom improvements may occur when on therapy. The study will also assess safety.

### Phase 2 Study of Pacritinib in PMF, Post-PV MF, or Post-ET MF Patients Having Thrombocytopenia that have Previously Received Ruxolitinib

**Study #2017-0320** (clinicaltrials.gov NCT No: NCT03165734)

**Principal Investigator:** Prithviraj Bose

**Study Description:** This study will evaluate three doses (100 mg per day, or 100/200 mg twice daily) of Pacritinib, an inhibitor of JAK2/FLT3, in PMF, Post-PV MF, or Post-ET MF patients with thrombocytopenia that didn't respond to ruxolitinib treatment. To be

eligible, patients must be symptomatic with splenomegaly and their platelet counts need to be  $\leq 100 \times 10^9/L$ .

### Phase 1/2 Study of SL-401 in Patients with Advanced, High-Risk, MPNs

**Study #2014-0976** (clinicaltrials.gov NCT No: NCT02268253)

**Principal Investigator:** Naveen Pemmaraju

**Study Description:** The purpose of this study is to evaluate the safety and efficacy profile of SL-401 in high-risk MPNs, namely systemic mastocytosis, advanced symptomatic hypereosinophilic syndrome, MF, or chronic myelomonocytic leukemia. SL-401 inhibits IL3R, a cell surface protein that is highly expressed on the cells surface in MPNs, thereby resulting in the death of cancer cells. SL-401 will be administered intravenously on the first 3 days of each 28-day cycle.

### Phase 1b Study of PU-H71 in Combination with Ruxolitinib in MF, Post-PV MF, or Post-ET MF Patients

**Study #2017-0750** (clinicaltrials.gov NCT No: NCT03373877)

**Principal Investigator:** Naveen Pemmaraju,

**Study Description:** The goal of this study is to evaluate the safety, tolerability, and efficacy of a heat shock protein 90 inhibitor, namely PU-H71, with concomitant ruxolitinib therapy. There are two parts to the study with the first being to determine the recommended dose of PU-H71, which will then be confirmed in more patients.

### Phase 4 Observational Study of Patients with MF or ET

**Study #2016-0874**

**Principal Investigator:** Srdan Verstovsek

**Study Description:** The main goal of this study is to monitor MF and ET patients through questionnaires. In addition, a patient may elect to participate in any of three substudies. •

A diagnosis of cancer can be a very lonely and tumultuous time for both the patient and for those that care for the patient. myCancerConnection, a program of Volunteer Services and Merchandising, is a free University of Texas MD Anderson Cancer Center (UTMDACC) cancer support community of trained survivor and caregiver volunteers dedicated to providing you with one-on-one support during each step of your cancer journey.

Susan French, Associate Vice President, Volunteer Services and Merchandising, and her staff manage the recruitment, placement and training of all of our dedicated volunteers supported by net proceeds from the department's retail operations and philanthropic donors. Each day there are well over a hundred, trained onsite blue-jacketed volunteers providing compassionate support to our patients and their loved ones. Volunteer positions are carefully designed to meet the needs of patients and caregivers, and

volunteers are placed in positions based on their prior experience, skills, and where their interests lie. MyCancerConnection survivor and caregiver volunteers, on and offsite, provide one-on-one support. Connection is what it's all about. By personally matching you with a volunteer, which is based on diagnosis, treatment modality, and experience, they'll be able to provide you with the hope, support, and understanding that you need. This can occur in person at the UTMDACC, or conveniently by telephone.

Wally Dawid is one of our leukemia survivor volunteers. He has volunteered onsite and with myCancerConnection for nearly three years now, and has logged more than 1100 volunteer hours. Between 9 a.m. and 1 p.m. on Tuesday mornings he volunteers in the Leukemia Clinic, and then on Thursday mornings he opens up the Hospitality Center in the Mays Building, where you'd be able to get free coffee, tea, crackers, and cookies, before he ends his shift at 2 p.m. in the Stem Cell Transplant



Wally Dawid, Cancer Survivor & myCancerConnection Volunteer

Department as an inpatient volunteer. Both the Leukemia Center and the Stem Cell Transplant Department saved Wally's life in 2014, and having had that experience he humbly said **"I've been blessed with such perfect, wonderful healing, and in my opinion the gift is too big to keep and not to share it. I can't keep it in, I just want to do something bigger than me, and MD Anderson is. So that's my incentive."** He undoubtedly takes tremendous pride in the knowledge that he's continually making a difference in the lives of so many patients and their families.

myCancerConnection is multifaceted and also includes programs geared to help pediatric, young adults (18-39), and adult patients and their caregivers throughout the various stages of cancer and survivorship.

- If you and/or your family are at the UTMDACC on the 2nd, 3rd, and 4th Tuesdays of the month, you're welcome to attend a free

# Social Work Support

luncheon seminar called partners in knowledge and news in cancer (PIKNIC). Here, you'll be able to learn from experts on a variety of topics. These lunch-n-learn sessions span important topics such as how to handle fatigue to the management of your insurance, and to learning about scientific terms such as 'targeted therapy'. PIKNIC is for an hour beginning at noon in the Mays clinic on the aforementioned days.

- Please feel free to stop by one of our Hospitality Centers at any time, such as the one that Wally David volunteers at. There are two convenient locations in the Mays Clinic and in the Main Building.
- A great myCancerConnection resource for young adult cancer survivors is a program known as Cancer180. Groups meet socially and discuss issues such as career continuation, fertility, insufficient insurance, and what long-term survivorship may look like. Importantly, on June 9th, 2018, myCancerConnection will sponsor a young adult survivor conference in the CPB building. The Leukemia and Lymphoma Society partnered with myCancerConnection for this upcoming event.
- myCancerConnection will be hosting MD Anderson's Annual Cancer Survivorship Conference in September, 2018. This fun-filled event includes not only informative break-out sessions and panelist discussions, but also wellness classes and ample time to network with others. •

*For additional information on this wonderful program, please click on "Request Support" at the following URL [www.mdanderson.org/mycancerconnection](http://www.mdanderson.org/mycancerconnection). If you're interested in providing one-on-one support through myCancerConnection at the UTMDACC, please call 1-844-359-2857 to find out more about this survivor and caregiver volunteer opportunity. Though a link within the aforementioned URL, you'll be able to view all upcoming myCancerConnection's events and activities and the specific topics that will be discussed.*



**A** cancer diagnosis can result in increased distress for patients and their caregivers. It's important for you to know that you have support here at the University of MD Anderson Cancer Center. The Department of Social Work is a resource that can help you with a variety of things including counseling, linking you with resources, and advance care planning.

The Department of Social Work has approximately seventy licensed master's level social workers who are assigned to outpatient clinics and inpatient floors, and they highly encourage patients and caregivers to utilize their services.

No matter how big or how small the problems are that you're facing, it's always worth asking for help. You are not alone, and don't have to cope with these problems alone. Social work services are available at no cost,

no matter how much or how little you need them.

You may want to speak with a social work counselor if you have concerns or questions about:

- Counseling
  - Adjustment to diagnosis or treatment
  - Life changes
  - Grief and loss
  - Safety
  - Intimacy and sexuality
  - Relationships with partners, family, friends, etc.
  - Your child or children coping
  - Caregiver coping
- Advance care planning
  - Transitions in care
  - Values and goals of care
  - Medical power of attorney
  - Living will
- Resource linkage
  - Financial stress
  - Housing and transportation
  - Disability

*If you're interested in speaking with a social worker, there are a number of ways you can contact one. For more information visit [www.mdanderson.org/socialwork](http://www.mdanderson.org/socialwork) or call 713-792-6195. You can also stop by their office in the Main Building (2nd floor, near elevator D, Room B2.4650), or simply ask someone on your care team to make a referral for you.*

# MPNFocus

MPN Focus is a periodic newsletter published by The Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasms at MD Anderson Cancer Center to provide members of the MPN community with information on current research and treatments.

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## Resources FOR PATIENTS



**2017 Patient Education Symposia** hosted by  
MPN Advocacy & Education International

**May 31st, 2018** – Cleveland, OH

**June 7th, 2018** – Pittsburgh, PA

**September 28th, 2018** – Women & MPN  
Conference, Chicago, IL

**September 29th, 2018** – Pediatric/Young Adult  
Conference, Chicago, IL

**November 8th, 2018** – San Mateo, CA

For more information visit [mpnadvocacy.com](http://mpnadvocacy.com)  
or contact **Ann Brazeau** at **517-889-6889**  
or [abrazeau@mpnadvocacy.com](mailto:abrazeau@mpnadvocacy.com).

Founded by Ann Brazeau, former vice president  
of development at **MPN Research Foundation**,  
**MPN Advocacy & Education International**  
provides educational programs, materials, and  
resources for patients, caregivers, physicians,  
and entire healthcare teams to improve their  
understanding of MF, PV, and ET.



**MPNforum Monthly**—  
the MPN community's  
hometown paper — is a  
not for profit online  
magazine founded by MPN patient Zhenya Senyak.  
MPNforum monthly ([mpnforum.com](http://mpnforum.com)) publishes  
stories, features and columns that impact the lives of  
patients suffering from an MPN.

Founded in 1994 by patient advocate, Robert  
Tollen, the **MPDSupport.org** website and email  
list has offered interesting information on MPNs.  
Anyone is welcome to subscribe and all archives  
are available. Robert, who was diagnosed with

PV in 1990 has also created a closed Facebook  
group with more than 1500 members. For  
more information or to join the list serve go to  
[mpnsupport.org](http://mpnsupport.org) or email [listserv@listserv.icors.org](mailto:listserv@listserv.icors.org)  
with "subscribe mpdsupport" in the body of the  
email. To join the Facebook group go to [facebook.com/groups/375525335856981](https://www.facebook.com/groups/375525335856981).

**MPN Education Foundation** Formed in 2004, the  
**MPN Education Foundation** aims to  
bring information,  
reassurance and support  
to MPN patients and  
their loved ones all over the world via a website  
([mpninfo.org](http://mpninfo.org)), by convening a patient conference  
every 2 years, and via the email-based support  
group MPN-NET.

**MPN-NET** is an email-based support group formed  
in 1994 by patient Joyce Niblack. In May of 1996  
the group became a member of the Association of  
Cancer Online Resources, distributing email via a  
listserv platform. Although MPN-NET remains a  
US-centric organization, the group has nearly 2900  
members from around the globe. All discussions  
since its inception in May 1996 are archived and  
available to all members. You can subscribe to MPN-  
NET on Foundation's homepage at [mpninfo.org](http://mpninfo.org).

**Apfed** **APFED is a non-profit  
patient advocacy  
organization**  
American Partnership  
for Eosinophilic Disorders  
established to assist and  
support patients and  
their families coping with eosinophil associated  
diseases (EADs), including eosinophil-associated  
gastrointestinal disorders, hypereosinophilic  
syndrome, and Churg-Strauss Syndrome. For more  
information go to [apfed.org](http://apfed.org).

**The Mastocytosis Society, Inc.** is a non-profit  
organization dedicated to supporting patients

with mastocytosis and mast  
cell activation disorders, as well  
as their families, caregivers and  
physicians through research,  
education and advocacy.  
[tmsforacure.org](http://tmsforacure.org)



**PV Reporter.com** is a  
comprehensive, easy-to-  
navigate, patient-focused  
website for MPNs developed  
by David Wallace, "an aspiring  
web designer, publisher, writer,  
patient advocate," who was diagnosed with  
polycythemia vera in 2009. [PV Reporter.com](http://PVReporter.com)  
was created to provide "easy access" to  
pertinent information on PV, ET, and MF.  
For more information visit [pvreporter.com](http://pvreporter.com).



**MPN Cancer Connection**, also founded by  
David Wallace, is a non-profit "patient-focused"  
organization that helps educate and empower  
MPN patients by providing the necessary  
resources and funding for PV Reporter.  
For more information or to subscribe to their  
newsletter visit [mpncancerconnection.org](http://mpncancerconnection.org).



Founded by patients for  
patients, the  
**MPN Research  
Foundation** is a  
catalyst for research funding in pursuit of new  
treatments — and eventually a cure — for MPNs. To  
date, they have funded more than \$11 million in  
MPN research. They are also dedicated to  
helping patients change their prognosis by  
serving as a valuable source of education and  
resources in the MPN community.  
[mpnresearchfoundation.org](http://mpnresearchfoundation.org)