

MPN Focus

FALL 2017

Patient Spotlight: Samantha Trahan



By Jeannine Garnett

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Q: HOW DID YOUR JOURNEY BEGIN?

A: I started having typical MPN symptoms at an atypical age of ~ 26. It started with headaches and fatigue, then progressed to vertigo, erythromelalgia and facial numbness. By the time a blood panel was performed, my platelets were hovering at nearly 1 million.

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Q: WHAT IS YOUR DIAGNOSIS?

A: I have polycythemia vera. Thankfully, I am currently stable without medication.

.....
Q: WERE YOU DIAGNOSED CORRECTLY FROM THE START? IF NOT, WHAT HAPPENED?

A: Initially my symptoms were attributed to common post-pregnancy events. After all, who isn't tired after having a baby? Plus, my baby did not sleep well and I had to go back to work; no one was surprised to hear I was having headaches. Within a few months of escalating symptoms, I saw a new doctor who ordered a complete round of blood tests and then promptly referred me to a hematologist. I was diagnosed at that point with essential thrombocythemia. Three years later, I was diagnosed with polycythemia vera. I think the change in diagnosis had more to do with the discovery of the JAK2 mutation and the reclassification of MPN disorders rather than an original misdiagnosis. But who knows - as much as we want it to be, this is not an exact science.

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Q: DID YOU FIND IT DIFFICULT TO COPE WITH YOUR DIAGNOSIS?

A: Yes, very much so at first. I felt broken; I felt betrayed by my own body. At the age of 26, a diagnosis of an incurable life-long disorder was devastating. I also wanted to have another child. After consulting with numerous experts in hematology and high-risk obstetrics, we made the very personal choice not to attempt another pregnancy. I felt robbed.

As I settled into my 30's and now 40's, those feelings passed. My MPN diagnosis is just another part of me. I'm also only 5'2" (almost), lactose intolerant and have crazy curly hair. So, I see my hematologist regularly, wear heeled shoes, avoid dairy and go through a lot of hair products. My MPN diagnosis is just one more thing that I have to deal with; it's no longer something exerting dominance over my life.

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LETTER FROM THE DIRECTOR



With 2017 nearing an end, we reflect on the tremendous progress that has been made. We are grateful to be enrolling patients into clinical trials that provide better options for improving anemia and bone marrow fibrosis, along with the added control of splenomegaly and myeloproliferative neoplasm (MPN) symptoms. We learn from our patients, and by doing so, we are poised to advance our knowledge greatly at the genetic level of MPNs in the very near future. Although we currently offer amongst the best treatments for our MPN patients, with a greater understanding of what drives MPNs, it is our hope that new therapies will become available that can positively change outcomes for our patients.

For the fifth year in a row, we co-hosted a town meeting for MPN patients and their care partners with Patient Power in October.

There was a great turnout of people at the event, together with those that could join us live online. The two main sessions of the 'Making the Right Choices: Understanding Your Options to Get the Best MPN Care' event were videotaped, and can be viewed online at <https://www.patientpower.info/event/mpn-houston-2017>. We were joined by other MPN experts, including Abdulraheem Yacoub, M.D., clinicians, and patient advocates.

This issue highlights all of the clinical trials that are currently available for those with MPN at The University of MD Anderson Cancer Center, and also summarizes what we will learn at the American Society of Hematology 59th Annual Meeting during the MPN Clinical Trial presentations.

Wishing you all the gifts of the season. May it be filled with peace and joy. •

Dr. Srdan Verstovsek, 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 Neoplasia. 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.

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:



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

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Spotlight

Q: IN WHAT WAYS HAS YOUR LIFE CHANGED SINCE BEING DIAGNOSED?

A: I've seen a lot of doctors and been drained of a lot of blood! It's been 16 years since my diagnosis. I have had low points where I struggled with fatigue and pruritis. I've also had long periods of time when I felt perfectly healthy.

Q: WHAT ARE SOME OF THE WAYS YOU HAVE TRAINED YOURSELF TO COPE?

A: Get educated. There's a steep learning curve to understand the MPN disorders. There's no better way than to jump in with both feet – read current articles, join internet forums and local patient groups, ask questions, research clinical trials, talk with your doctor openly and get answers. With a better understanding of MPNs, a patient can become an active team-member with her physician and receive better care overall.

Live a healthy lifestyle. I'm a firm believer in a healthy diet and regular exercise. My body is already working hard to overcome defects in my

I'm a firm believer in a healthy diet and regular exercise.

–Samantha Trahan

bone marrow. I feel the need to treat my body as well as I can to avoid burdening it further. Exercise is also the best mechanism for combating fatigue. I try to walk or participate in a gym class 3 to 5 days every week.

Become involved. I can't fix my own bone marrow. I can, however, help the MPN community at large. By helping, I gain a sense of power over my MPN.

Q: WHAT ARE SOME OF THE DIFFICULTIES YOU FACE?

A: Pruritis is the worst. It attacks viciously and leaves me at times completely unable to function until the episode passes. I tried all the home remedies without success – bathing/shower combinations, water temperature, soaps/lotions, histamine blockers, anxiety drugs, and any other patient-forum suggestion out there. For me, nothing worked until I finally agreed to participate in a clinical trial for a JAK2 inhibitor, which immediately stopped the pruritis.

I also struggle with the – but you don't look sick – attitude from others. It's true that I'm young(ish) and look healthy. I've also been stabbed in the back of the hip three times for bone marrow extractions and the insides of my elbows have been stuck hundreds of times for blood samples. It's necessary sometimes to draw a line with my family, friends and others on what I can and cannot accomplish because of my MPN – even if I don't look sick.

Q: WHAT IS SOMETHING POSITIVE THAT HAS COME FROM YOUR DIAGNOSIS?

A: I'm pleased to increase awareness of MPNs and to raise funds supporting Be the Match. My team (of two, so far) goes on the road to a different city each year for Be the Match 5k events. We've been within the top three highest team or individual fundraisers in Philadelphia, Charlotte and Houston. We're looking forward to Chicago in 2018 and an even bigger fundraising effort! •

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To schedule an appointment call
1-85-LEUKEMIA (toll-free) or 713-563-2000



**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.

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, or to find other clinical trials for MPN, please go to www.clinicaltrials.gov.

Phase 2 study of INCB054828 for Patients Having FGFR1/8p11.2-rearranged Hematologic Malignancies

INCB 54828-203 (clinicaltrials.gov NCT No: NCT03011372)

Principal Investigator: Srdan Verstovsek

Study Description: INCB054828 is an oral inhibitor of FGFR1/2/3 that is administered once daily for patients with myeloid or lymphoid malignancies that have a FGFR1 rearrangement. In patients with a chromosomal abnormality involving chromosome 8 (specifically 8p11.2), through genetic rearrangement, a protein called FGFR1 gets produced that drives the disease process. The goal of this study is to assess the efficacy and safety of INCB054828, a pill, as a single agent therapy in patients that have a 8p11.2 chromosomal abnormality (i.e. FGFR1 rearrangement). Primary outcome will be measured over about 24 months, which includes determining the overall clinical benefit of the drug over time. This study is currently enrolling patients.

Two Phase 1/2 studies of KIT Inhibitors for Patients with Advanced Systemic Mastocytosis

DCC-2618-01-001 (clinicaltrials.gov NCT No: NCT02571036) or BLU-285-2101 (clinicaltrials.gov NCT No: NCT02561988) for DCC-2618 and BLU-285, respectively

Principal Investigator: Srdan Verstovsek

Study Description: In the great majority of cases, advanced systemic mastocytosis is characterized by the presence of an abnormality in a gene called KIT. The KIT D816V mutation makes an abnormal protein that is important for disease existence and progression. There are two novel KIT inhibitors, namely DCC-2618 and BLU-285, which are being evaluated for their safety and tolerability profiles in patients with advanced systemic mastocytosis. Each of these two studies consists of two parts, a dose escalation phase and an expansion phase. Depending on the therapy, these agents are taken orally either on a daily or twice daily basis. The agents have slightly different mechanisms of inhibiting KIT. Blue-825 inhibits KIT if there is a D816V mutation, whereas DCC-2628 acts as a "switch control pocket" inhibitor of KIT. Both studies are currently enrolling patients.

Phase 2 Study of Ruxolitinib Therapy for Patients with Chronic Neutrophilic Leukemia (CNL) or Atypical Chronic Myeloid Leukemia (aCML)

IRB00010262 (clinicaltrials.gov NCT No: NCT02092324)

Principal Investigator: Jorge E. Cortes

Study Description: The goal of this study is to determine the effectiveness of ruxolitinib in CNL or aCML patients. Some of these patients may have CSF3R mutations, which

may be important for the disease process, but others don't. This trial will therefore study the genetic makeup of patients, which will allow doctors to learn more about CNL and aCML to improve on therapies targeting these diseases. Hematologic responses, changes in spleen size and symptom scores, and safety will be assessed. This study is currently enrolling CNL or aCML patients that have platelet counts that are greater than 25,000 per microliter.



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

INCB 18424-272 (clinicaltrials.gov NCT No: NCT03123588)

Principal Investigator: Prithviraj Bose

Study Description: The purpose of this study is evaluate the safety and efficacy of treating hydroxyurea resistant or intolerant ET patients with either ruxolitinib or anagrelide. Patients are to be randomized in a blinded way to one of the therapies for the duration of a year. Both agents will be administered orally twice daily. This study is enrolling ET patients that have platelet and white blood cell counts that are greater than 650 x 10⁹/L and 11 x 10⁹/L, respectively.

Phase 2 Study for the Evaluation of Ruxolitinib and Thalidomide Combination Therapy for Patients With Primary, Post Polycythemia Vera, or Post Essential Thrombocythemia Myelofibrosis (PMF, post-PV MF, or post-ET MF)

16-1498 (clinicaltrials.gov NCT No: NCT03069326)

Principal Investigator: Prithviraj Bose

Study Description: The objective of this study is to determine whether the combination therapy of ruxolitinib and thalidomide is well tolerated and effective for the treatment of patients with PMF, post-PV MF, or post-ET MF. Patients may be treatment-naïve or could have been on ruxolitinib for at least 3 months. If the patient had received ruxolitinib as indicated, then the dose of ruxolitinib had to be stable for at least a month with the patient having a suboptimal response or progressing disease. Ruxolitinib and thalidomide will be given orally on a daily basis in 28-day cycles.



Phase 2 Study of INCB050465 in Combination with Ruxolitinib for MF Patients

INCB 50465-201 (Clinicaltrials.gov NCT No: NCT02718300)

Principal Investigator: Naval Daver

Study Description: The goal of this study is to evaluate the use of a PI3K inhibitor, a pill, which blocks upstream cancer cell signaling of the JAK-STAT pathway, in combination with ruxolitinib. Ruxolitinib targets the JAK-STAT pathway inside a cell, and therefore two proteins responsible for cell multiplication will be targeted together to destroy cancer cells. Patients that have been on ruxolitinib for 6 months or longer that had an insufficient response, meaning that the spleen is 10 cm or larger when palpated, or if the spleen is palpable between 5-10 cm and the patient has active MF-related symptoms, are being enrolled in the study.

Phase 2 Study of Ruxolitinib in Combination with Azacitidine for Patients With MF or Myelodysplastic Syndrome (MDS)/ Myeloproliferative Neoplasms (MPNs)

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

Principal Investigator: Naval Daver

Study Description: The purpose of this study is to determine whether azacitidine in combination with ruxolitinib will help control MF and MDS/MPNs. Azacitidine is a hypomethylating agent, and incorporates itself into DNA and RNA, that helps cell killing of abnormal hematopoietic cells in the bone marrow. In this study, ruxolitinib will be given alone for 3 months, followed by increased doses of azacitidine. This study is enrolling patients that have not been treated before with ruxolitinib or azacitidine.

Phase 2 Study of Sotatercept to Treat Patients with MPN-associated MF and Anemia

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

Principal Investigator: Prithviraj Bose

Study Description: The goal of this clinical research study is to learn if sotatercept can help to control MPN-associated anemia. Sotatercept is a drug that alleviates anemia. During the study, the safety of this drug will also be studied. This study will evaluate the use of sotatercept at low and high doses, and in combination with ruxolitinib, only if those patients had already been on ruxolitinib therapy for at least 6 months with having been on a stable dose for at least the last 2 months. Sotatercept is well tolerated and is given intravenously every 3 weeks. Both transfusion-dependent and –independent patients may enroll.

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

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 to control MF in patients with anemia. Rigosertib is an investigational therapy that works to increase cancer cell killing. 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 Pacritinib in Patients With Thrombocytopenia and PMF, Post-PV MF, or Post-ET MF that Have Previously Been Treated With Ruxolitinib

PAC203 (clinicaltrials.gov NCT No: NCT03165734)

Principal Investigator: Prithviraj Bose

Study Description: The goal of this study is to evaluate three doses of Pacritinib, a JAK2/FLT3 inhibitor, in patients suffering from thrombocytopenia that have either PMF, Post-PV MF, or Post-ET MF that didn't respond or lost a response to ruxolitinib therapy. To enroll patients will need to have platelet counts that are equal to or less than 100 x 10⁹/L, are symptomatic, and have splenomegaly. Patients will either receive 100 mg per day of pacritinib, or take this drug twice per day at either a 100 mg or 200 mg dose.

Phase 1/2 Study of SL-401 in Patients with Advanced, High-Risk MPNs; Namely Systemic Mastocytosis, Advanced Symptomatic Hypereosinophilic Syndrome, MF, or Chronic Myelomonocytic Leukemia

STML-401-0314 (clinicaltrials.gov NCT No: NCT02268253)

Principal Investigator: Naveen Pemmaraju

Study Description: The goal of this study is to assess the safety and efficacy of SL-401 in high-risk MPNs. The SL-401 drug is designed to target a protein that is highly expressed on the cell surface of MPNs, the IL3R, and in doing so causes the cancer cells to die. Patients will receive SL-401 intravenously on a daily basis for the first 3 days of each 28-day cycle. •

MPN Clinical Trial Highlights from the American Society of Hematology 59th Annual Meeting

DEC 9–12, 2017 • ATLANTA, GA



RESULTS OF THE GLOBAL PHASE 2 STUDY OF PEGYLATED INTERFERON ALFA-2A FOR HIGH RISK PATIENTS WITH POLYCYTHEMIA VERA (PV) OR ESSENTIAL THROMBOCYTHEMIA (ET) THAT ARE RESISTANT OR INTOLERANT TO HYDROXYUREA

Presenter: Abdulraheem Yacoub, M.D.

Pegylated interferon alpha-2a, also known as Pegasys (PEG), is a modified version of interferon-alpha that protects it from being

broken down quickly. The primary objective of the study was to determine if PEG is an effective treatment for patients ET and for those with PV. After 12 months of treatment, 43% and 22% of ET and PV patients, respectively, had a complete hematologic response. For those that remained on the study after 24 months, the complete response rate was 47% for ET patients and 42% for PV patients. If ET patients had a CALR mutation, then their response to therapy was better compared to patients with other mutation types. The study also measured safety, and 72% of the patients enrolled in the study remained on treatment for more than 12 months. If patients can manage the side effects associated with the use of PEG, then it was concluded that PEG may be an effective treatment for ET and PV patients.

LONG TERM OUTCOME OF MYELOFIBROSIS (MF) PATIENTS THAT WERE TREATED WITH PEGYLATED INTERFERON ALPHA-2A (PEGASYS)

Presenter: Jean-Christophe Ianotto, M.D.

Chronic phase myelofibrosis is typically defined as a disease with 0-9% blasts (vs. 10-19% blasts in accelerated phase patients that has a much worse prognosis). This study

is the first to report on a “chronic phase with elevated blasts” patient cohort. In MF patients with blasts between 5–9%, disease characteristics were similar to patients in the accelerated phase, and survival was found to be between those patients with chronic phase and low blasts (0-4%) and patients in the accelerated phase. In a large set of patients that were treated with ruxolitinib, and who had blasts between 5–9%, there was a clear survival advantage, being similar to patients with 0-4% blasts. Of the patients that were treated with ruxolitinib, survival was doubled compared with those patients that did not receive ruxolitinib therapy.

PHASE 3 STUDY OF ROPEGINTERFERON ALFA-2B (ROPEG) TREATMENT VERSUS HYDROXYUREA (HU) COMBINED WITH BEST AVAILABLE THERAPY (BAT) IN PV PATIENTS

Presenter: Heinz Gisslinger, M.D.

In this long-term follow-up study of 24 months, it was found that Ropeg, which is another modified version of interferon-alpha, was significantly better than HU/BAT therapy. Patients that were treated with Ropeg once every two weeks (n=88), compared with

those taking HU daily (n=73), achieved a hematological response of 70.5% versus 49.3%, respectively. This study highlighted that it has an excellent safety and tolerability profile, that lasting hematologic responses were seen, that JAK2 mutational burden decreased, and that symptoms improved. Ropog may be a safe and durable treatment option for patients with PV.

NEW MUTATIONS, NAMELY SETBP1 AND NRAS, ARE ASSOCIATED WITH POST-MPN ACUTE MYELOID LEUKEMIA (AML) IN PATIENTS WITHOUT JAK-STAT ACTIVATING MUTATIONS AND THE BCR-ABL TRANSLOCATION

Presenter: Kamal Menghrajani, M.D.

In patients that were in the chronic-phase of MPN, being represented by similar numbers of patients with post-ET, -PV, and -MF AML, it was found that SETBP1 and NRAS mutations occurred only in triple negative (TN) patients. Each mutation was found in 18.8% of post-MPN TN AML patients. Other mutations were noted in different groups of patients, each carrying important information regarding outcomes with various therapies. The researchers concluded that leukemic transformation has a distinct pattern of mutations when compared with patients that present with primary AML.

INTERIM PHASE 2 RESULTS OF AN ORAL SMAC MIMETIC (LCL161) IN PATIENTS THAT HAD AN INTERMEDIATE OR HIGH RISK OF MYELOFIBROSIS (MF)

Presenter: Naveen Pemmaraju, M.D.

LCL161 mimics the biological effects of second mitochondria-derived activator of caspases (SMAC). LCL161 therefore increases cancer cell death with its use as a therapy. This drug was tested in patients that had an intermediate or high risk of MF that couldn't use the drug ruxolitinib. There were three main goals in the study, where efficacy, changes in symptom burden, and non-driver mutations were detected along with the biological assessment of LCL161 function. Overall the study showed that there was a response rate of 30% when provided

as the only therapy, and that the drug may potentially be used as a novel therapy. Fatigue was the most common side effect.

PHASE 1 STUDY OF IDASANUTLIN (RG7388) IN PV AND ET PATIENTS WITH NO P53 MUTATIONS

John Mascarenhas, M.D.

Idasanutlin, is a drug that prevents degradation of the p53 tumor suppressor protein. If p53 is not decreased inside cancer cells by a protein called MDM2, then it destroys cancer cells. Idasanutlin inhibits the negative regulation of p53 by MDM2. The goal of this study was to assess the safety and tolerability of idasanutlin in a dose escalation study in ET or PV patients that were positive for the JAK2V716F mutation. Idasanutlin was found to be well tolerated at a high dose, and therefore a multicenter Phase 2 trial is underway.

FOUR YEAR ANALYSIS COMPARING RUXOLITINIB (RUX) WITH BEST AVAILABLE THERAPY (BAT) IN PATIENTS WITH PV THAT ARE RESISTANT OR INTOLERANT TO HYDROXYUREA

Presenter: Jean-Jacques Kiladjian, M.D., Ph.D.

Ruxolitinib is a drug that suppresses JAK/STAT cancer cell signaling in patients with MF. The 80 week follow-up results of this RESPONSE trial has been published previously, however this analysis was performed at week 208 of therapy. Patients were initially randomized to receive either rux or bat, and at week 208 the overall goal of the study was to evaluate durability of the primary response, clinicohematologic response, and long-term safety. Of 110 patients that were originally placed on rux therapy, 37% remained on therapy at week 208 versus no patients receiving BAT (median, 34 weeks). There were 38% of patients that crossed over from the BAT arm of the study to eventually receive rux that remained on therapy at week 208. A durable response and the overall safety profile remained consistent between week 80 and week 208.

A RETROSPECTIVE STUDY OF CHRONIC PHASE MF PATIENTS WITH BLASTS BETWEEN 5 AND 9 %, AND THE EFFECT OF RUXOLITINIB THERAPY

Presenter: Lucia Masarova, M.D.

Chronic phase myelofibrosis is typically defined as a disease with 0 - 9% blasts (vs 10-19% blasts in accelerated phase that has much worse prognosis). This study is the first to report on "chronic phase with elevated blasts" patient cohort. In MF patients with blasts between 5 – 9%, disease characteristics were found to be similar to patients in accelerated phase, and survival to be in between those of patients with chronic phase and low blasts (0-4%) and accelerated phase. In a large set of patients that were treated with ruxolitinib, and who had blasts between 5 – 9 %, there was a clear survival advantage, similar to those in patients with 0-4% blasts. Of the patients that were treated with ruxolitinib, survival was doubled compared with those patients that did not receive ruxolitinib therapy.

PHASE 2 STUDY RESULT OF SINGLE AGENT SOTATERCEPT (ACE-011) THERAPY AND WHEN USED AS A COMBINATION THERAPY WITH RUXOLITINIB IN PATIENTS WITH MF AND ANEMIA

Presenter: Prithviraj Bose, M.D.

Sotatercept helps to control anemia in MF patients by increasing the numbers of red blood cells. Early results of the Phase 2 study of sotatercept was presented at ASH in 2016, where it was found that this drug was well tolerated. Additionally, the study was opened up to more patients with anemia who had been taking ruxolitinib for 3 months. In patients that had only been taking sotatercept, new results confirm that it is effective at improving anemia in MF. More data needs to be obtained for patients that take both sotatercept and ruxolitinib, however early data suggests that efficacy is also promising when both drugs are taken together. Another study using a similar agent that helps with anemia, namely luspatercept (ACE-536) will soon be enrolling patients. •

MPNFocus

MPN Focus is a periodic newsletter published by The Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasia 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

February 24, 2018 – San Antonio, TX
March 2018 – San Mateo, CA
April 2018 – Nashville, TN
May 31, 2018 – Cleveland, OH
June 2018 – Pittsburgh, PA

For more information visit mpnadvocacy.com or contact **Ann Brazeau** at **517-889-6889** or 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) 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 or email 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).

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), 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.

APFED is a non-profit patient advocacy organization 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.

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



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.

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.



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