Patient Spotlight: Anna Silver

Q: WHAT WAS YOUR ORIGINAL DIAGNOSIS, AND HOW DID YOUR MPN JOURNEY BEGIN?
A: I started itching while living in Florida. At that time my dermatologist said that I had dry skin. We moved back to Texas some time later and I continued to itch. Nothing helped, over the counter or prescription medication didn’t help relieve any of the intense itching, which led me on a quest to figure out what was happening to my body. I saw a number of various specialty doctors, until finally I saw an oncologist who did a bone marrow test and told me that I had polycythemia vera (PV). It was a relief knowing what my diagnosis was, but nevertheless the severe itching progressively worsened. I then asked my local oncologist if I could go to MD Anderson Cancer Center’s leukemia clinic. He referred me to Dr. Verstovsek who confirmed my PV diagnosis.

Q: SINCE YOUR ORIGINAL DIAGNOSIS, HOW HAS YOUR DIAGNOSIS CHANGED?
A: I completed a blinded clinical trial at MD Anderson Cancer Center under Dr. Verstovsek’s protocol, and immediately thereafter started taking Jakafi, a JAK1/2 inhibitor otherwise known as ruxolitinib, which dramatically changed my life – NO MORE ITCHING! It was a tremendous relief.

Q: WHAT CHALLENGES DID YOU FACE WITH YOUR ORIGINAL DIAGNOSIS, AND WHAT DIFFICULTIES DO YOU FACE NOW THAT YOUR DISEASE HAS PROGRESSED?
A: There are many challenges that you face with this disease. My thoughts have ranged from thinking how long could I keep it under control, to what if Jakafi stops working for me, to wondering if I could continue affording such a costly medication. I worry quite a lot now about those and other challenges since my disease has progressed to myelofibrosis (MF). I often think about what other steps that I can take to keep me healthy in mind and body. It saddens me that I’m constantly tired. I haven’t found any support groups where I’d be able to discuss my concerns, which is likely because I’m a private person or that I’ve been in denial about the progression of my disease.

Until my spleen started enlarging I was still fairly confident and optimistic, however now I’m constantly thinking about what will happen next and how long I have before my MF gets worse. Hopefully the new clinical trial that I’m embarking on will be fruitful.

[continued on page 3]
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.

This issue highlights selected presentations from the annual American Society of Hematology meeting, which was held at the beginning of December 2018 in San Diego, California. Included in this issue is also a brief summary of the clinical trials that are currently available to those with different myeloproliferative neoplasm (MPNs), within our Leukemia Department at The University of MD Anderson Cancer Center. Knowledge is power, and it means a great deal to me that we are able to help you better understand new developments in the MPN field.

With 2018 behind us, we reflect on the significant progress that has been made, and the path forward into 2019. We are grateful to be able to work together with our patients that participate in ongoing clinical trials, that may provide better options to patients with myelofibrosis, for example, those with significant anemia, thrombocytopenia, enlarged spleen and liver and/or MPN related symptoms, not controlled well with standard therapies. We learn from our patients and by doing so not only improve their own outcome, but benefit future patients at large. It is our hope that new approved therapies will become approved soon, that can positively change outcomes for MPN patients around the globe.

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.

GREETINGS TO ALL!

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:
Q: HOW HAVE YOU MANAGED TO COPE WITH YOUR MPN JOURNEY THUS FAR?
A: My family is very supportive, and my daughter tries to come to all of my oncologist visits so that she knows exactly what is happening to me.

My family is very supportive, and my daughter tries to come to all of my oncologist visits.

– Anna Silver

I haven’t thought of this disease as life-threatening until recently, and the gravity of that weighs heavily on my mind. I do my very best not to complain too much, which is helpful not only to myself but also to my family.

Additionally, I often receive physical therapy for another medical problem. Interestingly, it has helped a great deal in managing my MPN too. Also, I have started doing as much walking as I’m able to, which has provided me with more energy for other activities.

Q: WHAT ARE SOME OF THE POSITIVE ASPECTS OF YOUR DIAGNOSES THAT YOU MAY LIKE TO SHARE WITH US?
A: One of the biggest positive aspects for me is that I have a great doctor, who understands my needs and takes the time to listen. Not only is he fantastic, but he has terrific staff too. On a more personal level, I’m not sure that there are any positive aspects excepting for the fact that I don’t itch anymore.

I have a great doctor, who understands my needs and takes the time to listen.

– Anna Silver

 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 RESEARCH: YOU CAN MAKE A DIFFERENCE

Follow us on Facebook and Twitter

Facebook.com/MDAndersonLeukemia
@LeukemiaMDA
Follow #MPNSM for current news and events

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

From ASH 2018 a series of interviews featuring our MDACC faculty can be found online. Some examples include through Patient Power: A panel of experts discussing interferon at ASH 2018 https://www.patientpower.info/video/updates-from-ash-the-latest-on-interferon-therapy-in-mpns

Looking for innovative ways to find out information on the MPN research field? You may want to check out Twitter and follow the conversation at #MPNSM = Myeloproliferative Neoplasms on Social Media.

Co-founded by our own Dr Pemmaraju, this forum has provided a platform for stakeholders from all across the healthcare spectrum to learn about and contribute to discussions about the field of MPN.

For a primer on the topic, check out this video interview from ASH 2018 Meeting, done with Dr. Pemmaraju and Ann Brasou from MPN Advocacy & Education Intl': https://vimeo.com/304442189

Spotlight

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

Winter 2019
Phase 2 study of INCB054828 for Patients Having Myeloid/Lymphoid Hematologic Malignancy with FGFR1 rearrangement (8p11 chromosomal abnormality)
Protocol # 2016-0635 (clinicaltrials.gov NCT No: NCT03011372)
Principal Investigator: Srdan Verstovsek

Study Description: Pemigatinib is an oral inhibitor of FGFR1 enzyme. In patients with a chromosomal abnormality involving chromosome 8 (specifically 8p11), through genetic rearrangement, a protein called FGFR1 gets abnormally fused to another protein and drives the disease process. Early results of this study are extremely encouraging, with majority of patient achieving complete remission.

Two Phase 1-2 studies of KITD816V Inhibitors for Patients with Advanced Systemic Mastocytosis
Protocol # 2015-0621 (clinicaltrials.gov NCT No: NCT02571036) or Protocol # 2015-0832 (clinicaltrials.gov NCT No: NCT02561988) for DCC-2618 and BLU-285, respectively
Principal Investigator for DCC-2618 study: Filip Janku
Principal Investigator for BLU-285 study: Prithviraj Bose

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 persistence and progression. There are two novel KIT inhibitors which are being evaluated for their safety and tolerability profiles in patients with advanced systemic mastocytosis.

Phase 2 Study of Ruxolitinib Versus Anagrelide in Patients with Essential Thrombocythemia (ET) Who are Resistant to or Intolerant of Hydroxyurea (RESET-272)
Protocol # 2017-0111 (clinicaltrials.gov NCT No: NCT03123588)
Principal Investigator: Prithviraj Bose

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 multicenter study is enrolling ET patients that have platelet and white blood cell counts that are above normal.

An Open-Label, Phase 1/2, Dose-Escalation/Dose-Expansion Safety Study of INCB059872 in Subjects With Advanced Malignancies
Protocol # 2016-0556 (clinicaltrials.gov NCT No: NCT02712905)
Principal Investigator: Gautam Borthakur

The purpose of this multi-center study is to evaluate the safety and tolerability of INCB059872, a pill that inhibits an enzyme called LSD1, which makes modifications to DNA that regulate gene expression. Patients with myelofibrosis are eligible to participate if they have failed or are not candidates for standard, approved treatments like ruxolitinib.

Phase 2 Study of INCB050465 in Combination with Ruxolitinib for Myelofibrosis (MF) Patients
Protocol # 2016-0233 (clinicaltrials.gov NCT No: NCT02718300)
Principal Investigator: Naval Daver

The goal of this study is to evaluate the use of a PI3K inhibitor, a pill, which blocks cancer cell signaling, in combination with ruxolitinib. Ruxolitinib targets the JAK-STAT pathway inside a cell, and therefore two proteins responsible for cell growth, survival and multiplication will be targeted together to destroy cancer cells. Patients that have been on ruxolitinib for 6 months or longer with a stable dose for at least the preceding 8 weeks are being enrolled in the study.
Phase 2 Study of Sotatercept to Treat Patients with MPN-associated MF and Anemia

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

Principal Investigator: Prithviraj Bose

The goal of this clinical research study is to learn if sotatercept can help to improve MPN-associated anemia, both alone and in combination with ruxolitinib. The latter patients must have already been on ruxolitinib therapy for at least 6 months with a stable dose for at least the preceding 2 months. Sotatercept is given subcutaneously every 3 weeks.

Phase 2 Study Evaluating the Tolerability and Efficacy of Navitoclax in Combination with Ruxolitinib for the Treatment of MF

Protocol # 2017-0495 (clinicaltrials.gov NCT No: NCT03222609)

Principal Investigator: Naveen Pemmaraju

Study Description: The goal of this study is to determine an optimum dosage of navitoclax (BCL-2 inhibitor) that should be used in combination with a stable dose of ruxolitinib. Navitoclax will be taken orally once daily and ruxolitinib twice daily. At the time of starting the study, participants should have been taking a stable dose of ruxolitinib for at least eight weeks.

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

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

Principal Investigator: Jorge Cortes

The goal of this clinical research study is to learn if rigosertib can help improve anemia in patients with MF. Rigosertib is an investigational therapy that blocks two different enzymes (PI3K and PLK) that are important for cancer cell growth, survival and multiplication. Both transfusion-dependent and–independent patients with MF and anemia may enroll.

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

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

Principal Investigator: Naveen Pemmaraju

The objective of this study is to determine whether LCL-161, a SMAC mimetic, also known as an IAP inhibitor, will help control MF. Preliminary data suggests that there are improvements in anemia, splenomegaly, and MF symptoms when on treatment. The study therefore also assesses safety. To be eligible, there are no minimum blood counts that are required.

Phase 1B Study of Ruxolitinib in Combination With PU-H71 for the Treatment of MF

Protocol # 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, the first being to determine the recommended dose of PU-H71, which will then be confirmed in more patients.

Phase 2 SL-401 in Advanced, High Risk Myeloproliferative Neoplasms

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

Principal Investigator: Naveen Pemmaraju

Study Description: SL-401, or tagraxofusp, is an IL3-Receptor antagonist, or CD123 inhibitor. The goal of this study is to evaluate the safety and efficacy of this novel approach in patients with relapsed and refractory myelofibrosis. Importantly, this drug is given intravenously, and does require inpatient hospitalization for 3 days per month for most patients.

Phase 2 Study of CPI-0610 Either Taken With or Without Ruxolitinib in Patients with MF

Protocol # 2018-0202 (clinicaltrials.gov NCT No: NCT02158858)

Principal Investigator: Prithviraj Bose

Study Description: CPI-0610 is a pill that interferes with the action of bromodomain proteins, proteins that have wide-ranging effects in determining which proteins and how much a cell makes. Inhibiting bromodomain proteins can reduce the levels of many proteins that are important for the survival and multiplication of cancer cells. Furthermore, there is evidence that drugs like CPI-0610 and ruxolitinib work even better together than each drug alone. The study is open and enrolling patients.
Phase 2 Study of Ruxolitinib in Patients with Chronic Neutrophilic Leukemia or Atypical Chronic Myeloid Leukemia
Presenter: Kim-Hien Dao

CNL and atypical CML are rare subtypes of MPN with no standard treatments. Activating mutations in the receptor (CSF3R) for G-CSF, a substance that stimulates white blood cell production, occur frequently in these diseases, and activate the JAK-STAT signaling pathway inside cells, making a case for studying ruxolitinib (JAK inhibitor). In this study, 20 patients each with CNL and atypical CML received ruxolitinib and many had very good clinical improvement, particularly those with CSF3R mutation.

Avapritinib, a Potent and Selective Inhibitor of KIT D816V, Improves Symptoms of Advanced Systemic Mastocytosis (AdvSM): Analyses of Patient Reported Outcomes (PROs) from the Phase 1 (EXPLORER) Study Using the (AdvSM) Symptom Assessment Form (AdvSM-SAF), a New PRO Questionnaire for (AdvSM)
Presenter: Jason Gotlib

Systemic mastocytosis is a rare cancer of mast cells. Advanced forms of systemic mastocytosis (AdvSM) are associated with poor survival, from a few months to few years. Avapritinib is a highly selective and potent inhibitor of the mutant KIT protein, thought to drive the disease in the vast majority of cases. In this ongoing study great majority of patients responded and improved quality of life.

A Phase 2 Study of the Safety and Efficacy of INCB050465, a Selective PI3K Inhibitor, in Combination with Ruxolitinib in Patients with Myelofibrosis
Presenter: Naval Daver

Many ongoing “add on” clinical trials in myelofibrosis are studying the addition of a variety of new drugs to ruxolitinib in patients who have had an insufficient response to the same or are losing response to ruxolitinib, in efforts to improve or restore responsiveness to ruxolitinib. Parsaclisib (formerly INCB050465) is an inhibitor of PI3K, an enzyme important for the growth, survival and multiplication of cancer cells. Around 60% of patients had some reduction in spleen volume and symptoms after combination therapy.

Safety and Efficacy of Combined Ruxolitinib and Thalidomide in Patients with Myelofibrosis: Initial Results of a Phase II Study
Presenter: Raajit Rampal

In this study being conducted at MD Anderson and Memorial Sloan Kettering, a low dose of an old drug, thalidomide, which has modest efficacy on its own in patients with myelofibrosis, is added in patients on ruxolitinib. While the results presented were only on 10 patients who had been on the study long enough to be evaluated for response, a striking improvement in platelet count was seen in 6 (60%).

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addition of thalidomide could prove valuable in clinical practice as a strategy to improve platelet counts in patients with myelofibrosis so as to allow optimization of the dose of ruxolitinib, important for spleen response which, in turn, is linked to survival in myelofibrosis.
Results of the Myeloproliferative Neoplasms - Research Consortium (MPN-RC) 112 Randomized Trial of Pegylated Interferon Alfa-2a (PEG) Versus Hydroxyurea (HU) Therapy for the Treatment of High Risk Polycythemia Vera (PV) and High Risk Essential Thrombocythemia (ET)

**Presenter: John Mascarenhas**

Hydroxyurea is the most widely used initial therapy for patients with PV or ET at high risk for having a blood clot. However, interferons, although not approved in the US for treatment of MPN, are clearly effective as well. Hydroxyurea and pegylated interferon alfa were compared head to head in 168 previously untreated patients with high risk PV or ET. This final, 24-month analysis showed no significant differences between the two treatments in terms of blood count normalization, spleen size reduction or appearance of the bone marrow under the microscope. Both hydroxyurea and pegylated interferon alfa are reasonable options for the initial treatment of high risk patients with PV/ET.

Evidence for Superior Efficacy and Disease Modification after Three Years of Prospective Randomized Controlled Treatment of Polycythemia Vera Patients with Ropeginterferon Alfa-2b Vs. HU/BAT

**Presenter: Heinz Gisslinger**

Ropeginterferon-alfa-2b (ropeg) is a novel, long-acting interferon formulation that can be administered every 2 weeks instead of weekly. This drug is expected to be approved in Europe soon. In the registrational PROUD/CONTI-PV trial, patients with “early” high-risk PV were randomly assigned to receive either hydroxyurea or ropeg. Non-inferiority of ropeg to hydroxyurea was demonstrated after 12 months of treatment. After three years of treatment, however, patients receiving ropeginterferon alfa had significantly higher rates of blood count control, spleen size reduction and symptom improvement, as well as greater declines in the proportions of cells carrying the JAK2 V617F and other gene mutations.

Imetelstat Is Effective Treatment for Patients with Intermediate-2 or High-Risk Myelofibrosis Who Have Relapsed on or Are Refractory to Janus Kinase Inhibitor Therapy: Results of a Phase 2 Randomized Study of Two Dose Levels

**Presenter: John Mascarenhas**

Imetelstat, given intravenously every 3 weeks, blocks the activity of telomerase, an enzyme important for maintaining the structural integrity of chromosomes in normal and malignant cells. Patients had to have failed a JAK inhibitor and have an enlarged spleen and active symptoms of myelofibrosis. A third of patients experienced meaningful spleen shrinkage and symptom reduction at week 24. Bone marrow fibrosis improved in 18%. Median survival was 30 months in this poor prognosis group.

A third of patients experienced meaningful spleen shrinkage and symptom reduction at week 24.

PRM-151 in Myelofibrosis: Efficacy and Safety in an Open Label Extension Study

**Presenter: Srdan Verstovsek**

PRM-151, a novel anti-fibrotic drug is, in fact, a recombinant form of a naturally occurring substance, pentraxin-2, that is involved in repair at sites of tissue injury. The outcomes of 18 patients with myelofibrosis, 9 receiving PRM-151 (IV every 4 weeks) alone and 9 in combination with ruxolitinib, were reported. Approximately half the patients had objective improvements in bone marrow fibrosis, and PRM-151 was extremely well tolerated. Spleen and symptom benefits were observed even in patients who received PRM-151 alone. Patients were on the study for a median duration of 31 months.

LCL161, an Oral Smac Mimetic/IAP Antagonist for Patients with Myelofibrosis (MF): Novel Translational Findings Among Long-Term Responders in a Phase 2 Clinical Trial

**Presenter: Naveen Pemmaraju**

Developing drugs that target pathways other than the JAK-STAT signaling pathway in myelofibrosis is important for patients that either fail ruxolitinib or are not good candidates for it. LCL-161 is a weekly pill that works by pushing cancer cells “over the edge”, thereby facilitating their natural death, a process called apoptosis. Among 44 patients treated in an ongoing study at MD Anderson, the overall response rate was 32%, and responses in different disease parameters (spleen, symptoms, anemia) were seen.

Interim Results from Fight-203, a Phase 2, Open-Label, Multicenter Study Evaluating the Efficacy and Safety of Pemigatinib (INCB054828) in Patients with Myeloid/Lymphoid Neoplasms with Rearrangement of Fibroblast Growth Factor Receptor 1 (FGFR1)

**Presenter: John Mascarenhas**

Interim data from Fight-203 in patients with intermediate-2 or high-risk myelofibrosis showed an overall response rate of 80%, and pemigatinib was generally well tolerated.

No therapy exists for FGFR1-rearranged malignancies, which generally run an aggressive course. This is a multi-center, multi-national study of pemigatinib, a new, selective and potent, oral inhibitor of FGFR1. The overall response rate among the 10 patients reported was 80%, and pemigatinib was generally well tolerated.

A rare group of molecularly defined blood and marrow cancers often associated with increased blood eosinophil numbers is termed “myeloid/lymphoid neoplasms with rearranged PDFGRA, PDFGRB, FGFR1 or with PCM1-JAK2”. Interim data from Fight-203, a Phase 2, Open-Label, Multicenter Study Evaluating the Efficacy and Safety of Pemigatinib (INCB054828) in Patients with Myeloid/Lymphoid Neoplasms with Rearrangement of Fibroblast Growth Factor Receptor 1 (FGFR1)

**Presenter: Srdan Verstovsek**

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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.

Editor: Srdan Verstovsek, M.D., Ph.D.
For questions, comments or to subscribe, please contact Dr. Verstovsek at sverstov@mdanderson.org

Resources FOR PATIENTS

MPN Advocacy & Education International

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. Information on 2019 Patient Education Symposia hosted by MPN Advocacy & Education International can be found at http://mpnadvocacy.com/events.

For more information visit mpnadvocacy.com or contact Ann Brazeau at 517-889-6889 or abrazeau@mpnadvocacy.com.

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 mpdsupport.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/375525335858981.

MPN Education Foundation

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 2,900 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.

11th Joyce Niblack Memorial Conference on MPNs will be held March 2-3, 2019 in Scottsdale, AZ.

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.

MPN Cancer Connection

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.

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 was created to provide “easy access” to pertinent information on PV, ET, and MF. For more information visit pvreporter.com.

MPN Research Foundation, 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 numerous laboratory and clinical projects related to 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. Visit mpnresearchfoundation.org.

American Partnership for Eosinophilic Disorders (APEFED)

APEFED was created by convening a patient conference every 2 years, and via the email-based support group MPN-NET.

Resources FOR PATIENTS

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