MPN FOCUS

The Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasia Newsletter

THE UNIVERSITY OF TEXAS MD Anderson Cancer Center
Making Cancer History®

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Hanns A. Pielenz: A Myelofibrosis Patient and Businessman with a Vision to Cure Myelofibrosis

Hanns A. Pielenz first encountered MD Anderson on June 14th, 2011 when he visited for his initial appointment with Dr. Srdan Verstovsek. It was at this first appointment that his diagnosis of myelofibrosis (MF) was confirmed, initiating a journey that culminated in what is now to be called The Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasia. In that initial meeting, after finding out the details of the disease and the long term prognosis, rather than turn inward with his thoughts as most would, he looked Dr. Verstovsek straight in the eye and asked what resources were needed to change the course of the disease. As Dr. Verstovsek said, "you may imagine how shocking that was, right there in the examining room." That was the first of many discussions between Hanns and Dr. Verstovsek about MF and the tools needed to beat the disease. Hanns felt strongly that if medical and financial resources were coordinated and aggregated and business skills were applied to the process, one might develop a disease modifying treatment that would change the destiny of future patients. For him, in this as in everything, time was of the essence!

For those who knew him well, this was vintage Hanns Pielenz–identify a problem, organize resources, and forge on. Hanns was a native of Bönnigheim, Germany and attended schools in Switzerland and Germany. After the death of his older brother in 1960, he was asked to join the family's textile business and assumed the title of CEO in 1968. From that time until his retirement in 2005, revenues of Amann & Sons grew 8% compounded annually and the regional yarn company that had been in his family since 1854 established a global presence in the textile industry. The company was the third-largest manufacturer of sewing yarns in the world with manufacturing facilities around the globe. In recognition of his contribution to the industry, in 2009 Hanns was named the first recipient of the Otto Mecheels Medal for his leadership and contribution to the development of textiles in Germany.

Transforming a small business that had been in his family for 150 years into a multinational player was not sufficient achievement for Hanns though. He invested in and became the chairman of a refrigerated warehouse company based in Atlanta, Georgia and was chairman from 1981 until it was sold in 1998. In 2000, he formed a family office in Atlanta, HAP Investment Group, LLC, to invest in opportunistic real estate transactions, purchase minority stakes in operating companies and fund start-up ventures as an angel investor, lending both financial support and his skills as a visionary business leader. In this role, he served on the board of directors of numerous companies.

After his retirement from Amann in 2005, Hanns spent the bulk of his time in Vero Beach, Florida with his wife Christa. He was an avid golfer and a dedicated hunter. He was involved in the community of Vero Beach and sat on the boards of the hospital, the art museum, and wherever he felt his talent could make a difference. He spent the late summer and early fall at his home in Michigan where he loved nothing better than long walks in the woods with his wife of 45 years. Hanns and Christa had two daughters and four grandchildren that he loved dearly and he delighted in their achievements and in time spent with each of them. Hanns was loved by all that knew him for his quick mind and his wicked sense of humor but also for his incredibly strong sense of self.

Clinical Research Center for Myeloproliferative Neoplasia to be renamed the Hanns A. Pielenz Clinical Research Center for MPN

One of his greatest passions, aside from family, was business. Business for him was an art form–one that he perfected over the years. It was his illness and his passion for business that ended up changing the landscape of MF. Although he did not have a scientific background, he got a sufficient education from Dr. Verstovsek to understand the underlying pathology of the disease and roughly the disease components that were needed to change the course. He was aware that with only 16,000 cases in the US, this is not a high priority disease among the larger pharmaceutical companies. He also realized that efforts were

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fragmented in the world of MPN research such that even the scarce resources available were not being used very efficiently. Given this, he made donations to The Clinical Research Center for Myeloproliferative Neoplasia to allow it to better coordinate collaboration among experts in the field, to provide funds for more research, and to encourage proactive communication and education of doctors and patients. In the two years since his diagnosis, the visibility of MD Anderson's MPN program and collaboration among doctors has grown exponentially. Hanns participated in the Jakafi trial with Dr. Verstovsek and was poised to take part in another clinical trial later this year. Unfortunately, the MF progressed quickly this spring and after a lengthy stay at MD Anderson, he went home to Florida to rebuild his strength. However, his compromised immune system was too weak and he passed away at his home in Vero Beach, Florida, surrounded by his wife and daughters on June 13th of this year, ironically, almost exactly 2 years after his initial meeting with his doctor and dear friend, Dr. Serge Verstovsek.

Even death could not fully extinguish the indomitable spirit of Hanns Pielenz. All who knew him delighted in his quick humor, his keen intellect, and his unfailing confidence. His support of research in the MPN field and continued encouragement of the coordination of resources will continue to be a focus for his family and his Atlanta office. While finding a cure was not in the cards for him, it was his fervent hope that the mission he began would be completed by those whose passion he fueled and whose coffers he filled to fund the fight. In naming the MPN Research Center after Hanns, it will be a constant reminder to all that one man–with financial means, an indomitable spirit, courage beyond compare and unbridled passion could in two short years change the course of the disease. One of Hanns' favorite sayings was "do not look out the rear view mirror or you will wreck the car." He was focused on the future and his spirit will infuse each and every member of the research staff as they seek to find a cure.

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Nancy Thomason, Chief Financial Officer at HAP Investment Group, LLC, knew Mr. Pielenz for 30 years and worked for him the last 15 years. When he was diagnosed with myelofibrosis, she spent months researching the disease to find the perfect doctor for him, which ended up being Dr. Verstovsek.

Letter from the Director

Dr. Srdan Verstovsek, *Professor of Medicine in the Department of Leukemia at MD Anderson, serves as Director of the Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasia. Dr. Verstovsek is an internationally recognized physician scientist dedicated to understanding the biology of and developing new therapies for MPNs.*

In 2011, the Department of Leukemia at MD Anderson Cancer Center established the Clinical Research Center for Myeloproliferative Neoplasia (MPN) as a distinct operational unit within the Leukemia Department and Leukemia Outpatient Center, thanks in large part to the generosity of my patient Hanns A. Pielenz. Mr. Pielenz was an extraordinary man who shared my vision for creating a coordinated effort to enhance research in MPNs, develop new therapies, and educate patients and caregivers about these rare diseases. Unfortunately, we were not able to find a cure in time for Hanns, but his wife has generously decided to continue to support the mission and vision of the Center. Therefore, I am very proud to announce that we have renamed the center the Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasia to honor Hanns and his legacy.

The mission of the Center is to identify and develop treatment strategies to effectively treat MPNs, prolong patients' lives, and ultimately cure them of the disease. The overarching goal of the Center is to develop a comprehensive approach to understanding the biology of MPNs through translational research, leading to new and effective therapies for MPNs, and to educate patients, families, and healthcare providers about the latest treatment and research strategies. Because MPNs are rare disorders, studying these diseases has been difficult, with few resources targeting research and little public awareness about MPNs. However, great strides have been made in this regard over the last several years. MD Anderson has become the largest single center in the world for MPN patient referral and research. We see more than 250 new patients with MPN annually, more than any other clinical center in the world, and are engaged continuously in clinical research (conduct of clinical studies) to try to find effective therapies for these diseases.

The Center provides the clinical infrastructure for the conduct of clinical research in MPN and a centralized tissue bank for the collection of patient samples for translational research, as well as a database for clinical and pathology information. In addition, one of the goals of the Center is to disseminate information about MPNs to educate patients, families, and healthcare providers about the latest treatment and research strategies. This newsletter is one step towards that goal.

It is crucial that we identify treatment strategies to effectively treat MPN to prolong patients' lives and ultimately cure the disease. The development of novel therapies for patients with MPN has been historically hampered by limited understanding of the abnormal processes and molecular causes of these diseases. However, recent findings have greatly enhanced our understanding of MPNs. The most important recent finding in the MPN field was the discovery of the Janus kinase 2 (JAK2) gene mutation in MPNs. Discovery of this mutation led to the rapid development of JAK inhibitors, which have significantly changed the treatment landscape for MPNs. However, the JAK2 gene is not the whole story and there is much more to learn.

Many clinical studies with novel medications are underway. Over the last 5 years more than 30 clinical studies specifically for MPN have been conducted at MD Anderson, with many more to come. The trials currently enrolling patients are listed inside. The goal of this periodic newsletter is to update the MPN community (patients, caregivers, and healthcare providers) on the latest research findings and information about novel therapies for MPN, as well as provide education and hope to patients and their families.

Support for Patients in Texas

When first diagnosed with myelofibrosis (MF) by a local hematologist, I was referred to a transplant center. Since we knew nothing about this disease, my wife and I were initially quite overwhelmed by the news. We nervously scoured the internet for information in an attempt to understand what we were dealing with.

While waiting for the appointment with the transplant doctor, we found an online MPN support group that referred us to Dr. Verstovsek at MD Anderson. We also learned from that same online support group of a patient/doctor conference held in Arizona every 2 years. The timing was perfect–we were able to attend only weeks after receiving my diagnosis and before seeing Dr. Verstovsek.

We learned so much from the doctors at the conference, including Dr. Verstovsek. It was a great way to quickly come up to speed on MPNs and treatment options, as well as the latest research. But what also had a great impact on us, was meeting other patients living with MF. They helped us navigate those initial steps into the MPN Journey. It was really a breakthrough moment for us that helped change our mood from one of doom and gloom to one of optimism.

After attending the conference, we were interested in finding some way to connect with other MPN patients in our local area on a more frequent basis and started looking for a local support group. It was with some surprise we discovered that while there were many MPN patient groups in the US, there was none in all of Texas. With the help of the MPN Research Foundation, I listed my name on their website and offered to start a support group in the Houston area. Slowly, people contacted me from various parts of Texas. Curiously, most patients were from the Dallas-Fort Worth area and only a few from the Houston area. I had mentioned the Arizona conference to a number of people and arranged to meet Karen Stern and her husband Mike while there. At the conference, we met more patients and their loved ones from Texas, and decided there were enough people to have two support groups: one in the Dallas-Fort Worth area and one in the Houston area.

South Texas MPN Support Meeting 21-Sep-13, Dripping Springs, TX

There are approximately 30 patients/significant others in each group. Meetings are held quarterly, generally in someone's home or at a local restaurant, and are fairly informal in nature. We also arrange to meet individually when possible and keep in touch by phone, e-mail, and Facebook

To find out more information or join our group, please contact us either by e-mail or through our Facebook page:
North Texas, Dallas/Ft. Worth – Karen-Stern@sbcglobal.net
South Texas, Houston – CharlieNielsen@aol.com
Facebook: https://www.facebook.com/groups/MPNSupportTX/

Charles Nielsen is a patient being treated by Dr. Verstovsek for myelofibrosis. Charles and his wife live in the Houston, TX area.

MPN Clinical Trials

Listed below are all open clinical trials enrolling patients with MPNs as of October 31, 2013. For more information on these clinical trials, call the information line toll-free at **1-800-392-1611** or the Leukemia New Patient Referral Line at **713-85-LEUKEMIA**

Evaluation of Ruxolitinib and Azacytidine Combination as a Therapy for Patients with Myelofibrosis and Myelodysplastic Syndrome/ Myeloproliferative Neoplasm

2012-0737 (NCT No: NCT01787487)

Principal Investigator: Naval Daver
Treatment Agent: Ruxolitinib and azacytidine

Study Description: This goal of this Phase 2 research study is learn if the combination of ruxolitinib and azacytidine can help to control disease in patients with myelofibrosis (MF) and myelodysplastic syndrome (MDS)/ MPN. Ruxolitinib is designed to block some of the proteins in the blood that may cause MF symptoms. Azacytidine is a drug that has been used to treat myelodysplastic syndromes (MDS). Combination of these agents, which have different targets, may improve the overall effectiveness of each drug. Ruxolitinib is a pill that will be taken twice per day for the first 3 months, after which time low-dose azacytidine will be added. Azacytidine will be given intravenously daily for the first 5 days of each 28-day cycle. This trial is accepting patients with MF or MDS.

A Phase-2, Prospective, Open-Label Study to Determine the Safety and Efficacy of Sotatercept (ACE-011) in Subjects with Myeloproliferative Neoplasm-Associated Myelofibrosis and Anemia 2012-0534 (NCT No: NCT01712308)

Principal Investigator: Srdan Verstovsek
Treatment Agent: Sotatercept (ACE-011)

Study Description: Sotatercept (ACE-011) is a biological therapeutic (a treatment that uses your immune system to fight disease) that blocks signaling by activin A. Studies suggest that sotatercept may increase the growth and development of red blood cells by blocking activin signaling. The goal of this clinical research study is to learn if sotatercept can help to control MPN-associated myelofibrosis (MF) and anemia. The safety of this drug will also be studied. Patients will be given subcutaneous injections once every 3 weeks in continuous 21-day cycles for at least 6 months. This study is accepting patients with primary or secondary MF and significant anemia.

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MPN Clinical Trials continued from page 3

An Open-Label, Multiple Simon 2-Stage Study of INCB039110 Administered Orally to Subjects with Primary Myelofibrosis, Post-Polycythemia Vera Myelofibrosis or Post-Essential Thrombocythemia Myelofibrosis 2012-0035 (NCT No: NCT01633372)

Principal Investigator: Srdan Verstovsek
Treatment Agent: INCB039110

Study Description: Anemia and thrombocytopenia are common side effects associated with inhibiting the JAK2 pathway. INCB039110 has been designed to inhibit JAK1 more than JAK2. This aim of this strategy is to reduce side effects, such as anemia and thrombocytopenia, while maintaining effects on myelofibrosis (MF) symptoms and spleen size. The goal of this clinical research study is to study the effects of INCB039110 on spleen size and/or disease symptoms. Researchers also want to learn about any side effects that might occur during or after receiving the drug. This study is open and enrolling patients with primary or secondary MF. INCB039110 is a pill that will be taken two times per day. This study is accepting patients who have primary or secondary MF.

Polycythemia Vera Symptom Study Evaluating Ruxolitinib Versus Hydroxyurea in a Randomized, Multicenter, Double-Blind, Double-Dummy, Phase 3 Efficacy and Safety Study of Patient Reported Outcomes 2012-0492 (NCT No: NCT01632904)

Principal Investigator: Srdan Verstovsek
Treatment Agent: Hydroxyurea; Ruxolitinib

Study Description: The goal of this clinical research study is to compare the effects of ruxolitinib against those of hydroxyurea in patients with polycythemia vera (PV). The safety of these drugs will also be studied. Ruxolitinib is designed to block some of the proteins in the blood that may cause MF symptoms. This may cause the cancer cells to die. Hydroxyurea is designed to block cancer cells from dividing. This may cause the cancer cells to die. In this study, both drugs are being compared to placebos. A placebo is not a drug. It looks like the study drug but is not designed to treat any disease or illness. It is designed to be compared with a study drug to learn if the study drug has any real effect. This study is accepting patients with PV who are currently taking hydroxyurea but are still having symptoms.

A Phase 2 Study to Evaluate the Efficacy and Safety of GS-6624 in Adult Patients with Primary, Post-Polycythemia Vera or Post-Essential Thrombocythemia Myelofibrosis 2011-0016 (NCT No: NCT01369498)

Principal Investigator: Srdan Verstovsek
Treatment Agent: AB0024 (GS-6624)

Study Description: The goal of this clinical research study is to study the effectiveness and safety of GS-6624 in combination with ruxolitinib in patients with myelofibrosis (MF) . GS-6624 is a drug that is designed to bind to and block the activity of a protein called LOXL2, which may be involved in the development of bone marrow fibrosis. Ruxolitinib is designed to block some of the proteins in the blood that may cause MF symptoms. Patients being treated with ruxolitinib will be receive GS-6624 by intravenous infusion every two weeks for a total of at least 6 infusions. This study is accepting patients who have primary or secondary MF.

A Phase 1/2, Open-label, Dose-escalation, Multi-center Study to Assess the Safety, Tolerability, Pharmacokinetics, and Pharmacodynamics of Orally Administered NS-018 in Patients with Primary Myelofibrosis, Post-Polycythemia Vera Myelofibrosis, or Post-Essential Thrombocythemia Myelofibrosis 2011-0090 (NCT No: NCT01423851)

Principal Investigator: Srdan Verstovsek
Treatment Agent: NS-018

Study Description: The goal of this clinical research study is to find the highest tolerable dose of NS-018 that can be given to patients with myelofibrosis. The safety and efficacy of this drug will also be studied. NS-018 is a drug that blocks the JAK2 protein, which is involved in the growth and survival of cancer cells. NS-018 is a pill that will be taken once or twice a day. This study is accepting patients who have primary or secondary myelofibrosis (MF).

A Phase 2, Open-Label, Prospective Study of PRM-151 in Subjects with Primary Myelofibrosis, Post-Polycythemia Vera Myelofibrosis, or Post-Essential Thrombocythemia Myelofibrosis 2013-0051

Principal Investigator: Srdan Verstovsek
Treatment Agent: PRM-151

Study Description: The goal of this clinical research study is to learn if PRM-151 can help to control myelofibrosis (MF). Two different dosing schedules will be compared. The safety of this drug will also be studied. PRM-151 is designed to be active at places in the body where there is tissue damage, which may help to control tissue scarring (such as bone marrow fibrosis). Some participants will also receive ruxolitinib. Ruxolitinib is designed to block some of the proteins in the blood that may cause MF symptoms. PRM-151 will be given intravenously for at least 6 months. This study is accepting patients with primary or secondary MF.

Eltrombopag for the Management of Thrombocytopenia Associated with Tyrosine Kinase Therapy in Patients with Chronic Myeloid Leukemia and Myelofibrosis 2011-0319 (NCT No: NCT01428635)

Principal Investigator: Gautam Borthakur
Treatment Agent: Eltrombopag

Study Description: The goal of this clinical research study is learn if eltrombopag can help control or prevent low platelet counts in patients receiving treatment for chronic myeloid leukemia or myelofibrosis (MF). Ruxolitinib, a treatment for MF, can cause low platelet counts. Eltrombopag is a protein that binds a molecule on blood cells that controls the production of platelets. Patients will continue taking ruxolitinib as prescribed, but will also take eltrombopag as a pill once per day. This study is currently accepting patients with primary or secondary MF.

A 24-Week with Possible Extension, Prospective, Multicentre, Randomized, Double Blind, Placebo-Controlled, 2-Parallel Group with a Randomization 1:1, Phase III Study to Compare Efficacy and Safety of Masitinib at 6 mg/kg/day to Placebo in Treatment of Patients with Smouldering Systemic, Indolent Systemic or Cutaneous Mastocytosis with Handicap 2008-0275

Principal Investigator: Srdan Verstovsek
Treatment Agent: Masitinib

Study Description: The goal of this clinical research study is to compare the benefits of treatment with masitinib to no treatment in patients with mastocytosis with handicap. Masitinib is a drug that inhibits a protein called KIT that is often mutated in patients with mastocytosis. Masitinib may be effective in reducing the number of mast cells in patients with mastocytosis. Patients will take masitinib as a pill twice per day for at least 24 weeks. This study is currently accepting patients with mastocytosis who have defined handicaps.

JAK Inhibitors and the JAK2^{V617F} Mutation: What's the Connection?

The JAK2^{V617F} mutation is the most prevalent gene mutation among patients with myeloproliferative neoplasms (MPNs), and its discovery led to the development of JAK inhibitors, which have transformed the treatment landscape for myelofibrosis (MF). While 95% of patients with polycythemia vera (PV) harbor the JAK2^{V617F} mutation, only 50-60% of patients with essential thrombocythemia (ET) and MF have the mutation. More importantly, results from clinical trials of ruxolitinib (Jakafi) and other JAK inhibitors, show that patients have significant improvements in symptoms and quality of life regardless of whether they have this mutation or not. So, what exactly is the connection between the JAK^{V617F} mutation and JAK inhibitors?

First a bit about the role of JAK signaling in MPNs:

Under normal conditions, JAKs (short for Janus kinases; there are 4 members of the JAK family of proteins: JAK1, JAK2, JAK3, and TYK2) play important roles in the development of blood cells and regulation of the immune system. JAKs are molecules inside the cell that interact with structures called receptors that are present on the surface of blood and immune system cells. Receptors protrude through the cell membrane. On the outside of the cell they are a docking site for different proteins called cytokines and growth factors. When cytokines (e.g., interleukins and interferons) or growth factors (e.g., erythropoietin, a growth factor for red blood cells, and thrombopoietin, a growth factor for platelets) bind to the receptors, the JAK molecules are activated. Once activated, STAT (signal transducers and activators of transcription) molecules are recruited to the receptor, where they can be activated by JAKs. STAT molecules then travel to the nucleus (a structure in the center of the cell containing chromosomes that carry genes), where they are responsible for turning on genes (transcription) involved in many basic cellular functions, including cell growth and survival **(Figure 1)**.

Unchecked activation of the JAK-STAT pathway results in uncontrolled cell growth and survival, which can lead to pathological states such as MPN **(Figure 2)**. This increased activation (dysregulation) of the JAK-STAT pathway can occur through activating mutations in the JAK2 gene (i.e., JAK2^{V617F}), exaggerated expression of cytokines that activate JAK proteins, or through other mutations that disrupt the function of molecules that turn off the JAK-STAT pathway. Increasing evidence suggests that dysregulated JAK-STAT signaling plays a central role in the development of MPNs, but there are likely mutations in other genes, which have not yet been discovered, that are also contributing to the development of MPNs.

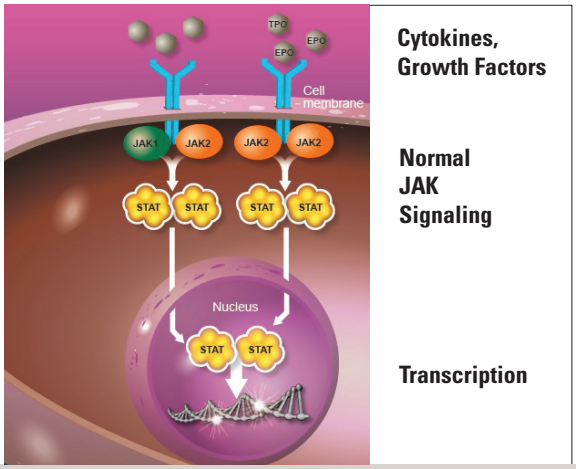

Figure1. The JAK-STAT signaling pathway. Normal JAK-STAT signaling is mediated by cytokines and growth factors, including erythropoietin (EPO) and thrombopoietin (TPO), which are essential for normal blood cell formation. The receptors are show in blue and the cytokines/growth factors in grey.

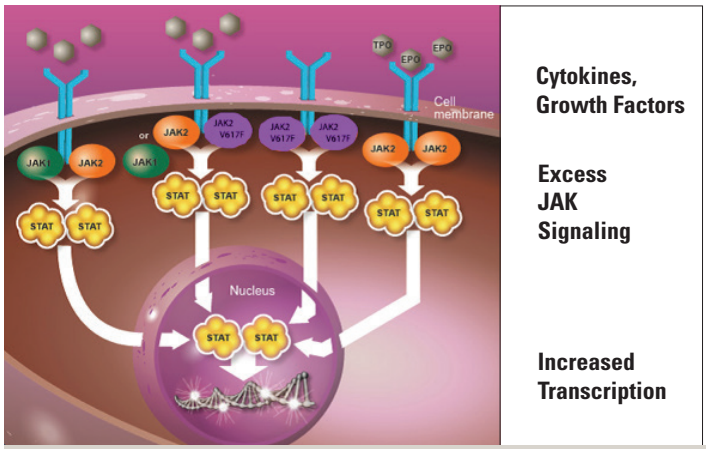

Figure 2. Dysregulated JAK-STAT signaling. Increased levels of cytokines and the JAK2^{V617F} mutation lead to persistent activation of the JAK-STAT pathway. Increased JAK signaling results in a pro-inflammatory state caused by overproduction of cytokines, which is thought to cause many of the symptoms experienced by patients with MF, including fatigue, night sweats, itching and bone pain.

How do JAK inhibitors work?

Clinical studies of ruxolitinib (Jakafi) and other JAK inhibitors have shown that they significantly improve many of the worst symptoms of MF, such as fatigue, night sweats, itching and bone pain, reduce splenomegaly, and improve quality of life. Importantly, these beneficial effects are seen regardless of whether the patient harbors the JAK2^{V617F} mutation. This is thought to be caused by the inhibitory effects of ruxolitinib on JAK proteins, specifically JAK1 and JAK2, which reduces the production of pro-inflammatory cytokines and controls cell growth and survival. While the JAK2^{V617F} mutation results in persistent activation of the JAK-STAT pathway, it is currently understood that in the addition to the uncontrolled cell growth and survival, an exaggerated production of cytokines mediated by JAK proteins is another important feature of MF that is thought to cause many of the associated symptoms, including fever, night sweats, pruritus, and weight loss. In fact, studies have shown an association between reductions in cytokine levels in patients on ruxolitinib therapy and improvements in their symptoms.

Is testing for the presence of the JAK2^{V617F} mutation necessary?

While the discovery of the JAK2^{V617F} mutation was an important turning point in the treatment of MF as well as our understanding of MPNs, its presence is not important for deciding whether a patient will derive benefit from a JAK inhibitor. However, testing for the mutation can help physicians make a proper diagnosis, which is critical for determining the optimal treatment plan. For example, since 95% of patients with PV have the mutation, its presence along with an increased red blood cell mass (erythrocytosis) or abnormally high hemoglobin and low EPO is highly suggestive of PV. For those with ET and MF, where the JAK2 mutation is only present in 50-60% of patients, the JAK2^{V617F} mutation is not a major diagnostic characteristic. For ET and MF, JAK2 mutation testing is only another piece of the puzzle that still needs to be associated with clinical, biologic, and pathologic data to allow proper diagnosis.

Much has been learned about the molecular biology of MPNs since the discovery of the JAK2^{V617F} mutation in 2005, but the precise causative factor remains an enigma. Current and future studies are aimed at unraveling the complexity of these neoplasms and identifying new targets for therapy. However, the take-home message is that JAK inhibitors are a promising treatment option for all patients with symptomatic MF, either those with symptomatic splenomegaly or MF-related systemic symptoms, regardless of whether they have the JAK2^{V617F} mutation.

How to find out more about your diagnosis and get support

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. The Foundation organizes a biyearly conference in conjunction with the Mayo Clinic at Scottsdale, Arizona, which brings together over 200 patients and a dozen or more medical professionals who are experts in MPNs and allied fields. Run over 2 days, with many presentations and discussion forums, it provides a unique opportunity for patients to interact with the experts. The Foundation's website provides valuable resources, including FAQs on the three main MPN variants, links to other allied sites, and a list of clinical trials on MPNs.

MPN-NET is an email-based support group formed in 1994 by patient Joyce Niblack. 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. Discussions center on the patient experience of MPNs — support and information on diagnosis, treatments, and all the issues and problems associated with those. In addition, there is much discussion on new research trends and potential new drugs, as well as on the emotional support that is desperately needed by many patients, particularly when first diagnosed with an MPN. You can subscribe to MPN-NET on the Foundation's homepage at **www.mpninfo.org**.

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

MPN AEI is dedicated to making a difference in the lives of those affected by myeloproliferative neoplasms (MPNs) and strives to grow awareness and advocate on behalf of the MPN community. MPN AEI fosters collaboration with all entities who make a contribution to the MPN community through research, drug development, education, and support. They bring the most up to date information about MPN research, treatment options, and clinical trials, and available support that will empower and guide those who are affected by an MPN through the course of their care or the care of loved ones. Our expert speakers are leaders in the field. Dr. Ruben Mesa, Mayo Clinic, Scottsdale, Arizona, is our scientific advisor and frequent speaker at educational symposia.

Visit **www.mpnadvocacy.com** to learn more about upcoming events and available resources.

Founded by Zhenya Senyak and MPN patients, MPNforum is a not for profit patient and caregiver online magazine that publishes stories, features, and by-lined columns that impact the lives of patients suffering from a myeloproliferative neoplasia (MPN). MPNforum independently reports on events, people, and scientific research affecting the MPN community. MPNforum Magazine publishes the The Senyak Report, the Forum's monthly newsletter, as well as other publications including MPNclinic, an online resource where patients can have their questions answered by MPN physicians, and the MPNforum Quarterly Journal of Myeloproliferative Science and Therapy (MQJ; **www.mpnjournal.org**). The MQJ was created to serve physicians and patients who are interested in understanding MPN causes, diagnosis, and treatment. The journal presents interviews and discussions with hematologists and scientists, and summarizes recent research findings published in journals and presented at conferences. MPNforum also created and sponsors The Fatigue Project, a research effort conducted with the Mayo Clinic-Scottsdale team under the direction of Dr. Ruben Mesa to discover successful interventions to relieve MPN-related fatigue (MRF).

MPNforum Magazine is freely available on the internet, without a subscription; however, subscribers get special bulletins, early notice of publication, and the option to join the private MPNforum Facebook discussion group. MPNforum is entirely managed and staffed by patients and caregivers with the participation of volunteer scientists, hematologists, and clinical investigators. You can read all of the content, including archived material at **mpnforum.com**.

Patient Power is a patient education organization dedicated to connecting you to the knowledge of a community of experts to empower you–or a loved one–to live well with cancer. From cutting-edge research and treatment news to coping with cancer in your everyday life, our community-based health centers cover the topics most important to you. Through our video interviews, in-person events and online features, we provide you with the tools and resources you need to better manage your cancer and live with hope. Patient Power is on the forefront of developing research and we bring you treatment news as it happens. We interview the top researchers in their field, on location at medical conferences, and help you to understand what ongoing studies and research could mean for you or your loved one. You'll learn from patients like you as they share their stories, insights and inspirational tips for coping with cancer. And through our patient interviews and featured blogs, you'll hear how to be your own advocate to ensure that you live, and feel, the very best that you can. We also want to hear directly from patients and caregivers! Visit us online at **PatientPower.info** to share your story through video, e-mail or via our social media channels. Your insights and advice will help patients like you. And be sure to join our community so that you can be alerted when we post new information.

MPN Research Foundation's mission is to promote, fund, and support the most innovative and effective research into the causes, treatments, and potentially the cure for ET, PV, and MF. Since 2000, the MPN Research Foundation has provided nearly $9 million in research funding.

Our newsletter – MPN Update – and email alerts keep the MPN community informed about research news and any upcoming events, from fundraisers and support group meetings to scientific gatherings. Anyone can sign up for free at **www.mpnresearchfoundation.org**.

Founded by patients for patients, the Foundation has had a remarkable track record of success in allocating their limited funds to achieve the highest impact for people with PV, ET, and MF. According to Weill Cornell's Chairman of Medicine and the head of our Scientific Advisory Board Dr. Andrew Schafer, "the Foundation has provided key support for virtually every major advance that has been made in MPN research since 2000."

NIH funding gets harder to come by every single year. But our grants have created the foundation on which researchers have gone on for advanced funding from the NIH to take their projects to the next level. Our funding has also helped launch the research careers of productive investigators in the field, as well as incentivizing already successful scientists in related areas to turn their attention to curing the MPNs.

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. We have a dedicated Medical Advisory Board of experts in mast cell disorders from all over the world. Our Research Committee conducts its own research, as well as helping the Board to select recipients for the Research Grants we offer.

We offer educational material free of charge upon request, including DVDs, brochures, patient emergency cards and cards describing the disease process for family members and friends. For our patient members, we offer care coordination to facilitate access to experts in mast cell disorders. This is especially critical for patients with the more aggressive variants and myeloproliferative disorders, as there is a limited number of treatment centers with physicians familiar with aggressive mastocytosis.

Our quarterly newsletter, The Mastocytosis Chronicles, is mailed to all members. Membership in TMS is only $35.00 per year. If you are unable to afford that because of financial difficulty, please contact the membership chair about a free, one year confidential angel fund membership paid for by generous donations. For more information visit our website at **www.tmsforacure.org**.

To join a support group in your area: **supportgroups@tmsforacure.org**
To find a physician: **chairman@tmsforacure.org** or **education@tmsforacure.org** • Phone: 508-842-3080 or 952-905-6778
To request free educational materials or to become a member: **membership@tmsforacure.org**
For any other communication: **tmsbod@tmsforacure.org**

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MPN FOCUS
The Hanns A. Pielenz Clinical Research Center for Myeloproliferative Neoplasia Newsletter

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 available at MD Anderson:

- **Cancer survivor message board:** http://www.mdanderson.org/patient-and-cancer-information/guide-to-md-anderson/patient-and-family-support/anderson-network/cancer-survivor-message-board/index.html
- **Anderson Network:** http://www.mdanderson.org/patient-and-cancer-information/guide-to-md-anderson/patient-and-family-support/anderson-network/index.html
- **Cancer-Related Fatigue Clinic:** http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/specialty-and-treatment-centers/internal-medicine-center/fatigue-clinic/index.html
- **Cancer Pain Management Center:** http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/specialty-and-treatment-centers/pain-management/index.html
- **Cancerwise blog:** http://www2.mdanderson.org/cancerwise/
- **Cancer Newsline (podcast):** http://www.mdanderson.org/newsroom/cancer-newsline/index.html
- **CancerFrontline:** http://www2.mdanderson.org/cancerfrontline/
- **Focused on Health:** http://www.mdanderson.org/publications/focused-on-health/index.html

How to find out more about your diagnosis and get support

continued from page 7

Apfed
American Partnership for Eosinophilic Disorders

Founded in 2001, the American Partnership for Eosinophilic Disorders (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.

APFED was founded by a group of dedicated mothers of young children living with these diseases who saw the need for support and reliable information and to spread awareness of EADs. These pioneers had lived through similar experiences – years of misdiagnosis, struggling to find answers, and leaning on each other for support.

APFED organizes regional educational meetings and a large annual conference that is attended by patients and caregivers in the U.S. and abroad, featuring seminars given by specialists in the field. Educational materials that the organization produces are comprehensive, credible, and user-friendly, and include booklets, brochures, fact sheets, webinars, web chats, and recorded presentation materials. APFED members receive a quarterly subscription to the EOSolutions newsletter, and the public is invited to stay up-to-date on current news and events by subscribing to APFED's free monthly email.

To learn more about eosinophil associated diseases and APFED, and to access free educational resources, visit **www.apfed.org**.

To Schedule an Appointment

Call **1-85-LEUKEMIA** (toll-free) or **713-563-2000**

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Leukemia Department at MD Anderson

The Leukemia Department at MD Anderson is the largest leukemia program in the world, with a large team of world-renowned and highly experienced physicians focused on the treatment of Leukemia. We currently have more than 150 active clinical trials for leukemia, many of which are not available elsewhere. To find out more information please visit our website at **http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/care-centers/leukemia/index.html**

Leukemia Insights: Leukemia Insights is a quarterly newsletter for physicians and other health professionals. Insights has the latest leukemia news, research and results from ongoing clinical trials, and available leukemia programs at MD Anderson. **http://www.mdanderson.org/publications/leukemia-insights/index.html**