Spring/May 2016

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

MPN Focus

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

But You Don't Look Sick…

My name is Emily, and I have essential thrombocythemia (ET). I was diagnosed at the age of 18. At 18 I was a typical college freshman; happily and healthily being the semi-irresponsible person I was supposed to be at that stage of my life. That spring I started getting lots of headaches, and had HUGE bruises on my forearms. I went to my GP and after a brief side-trip to misdiagnosis-land, it was determined that I should see a specialist. I started seeing a hematologist (who had never seen an MPN patient before…), and after a quick and painful bone marrow biopsy (sans anesthetic, I might add), followed by a not so quick, almost as painful waiting period, found out that I have essential thrombocythemia. Big long words with no meaning (to my 18-year-old mind). A quick trip to Google later and I was slightly more well-informed. Being 18, I didn't take it terribly seriously and didn't want to feel labeled. So, what's the logical thing to do? Ignore it and hope it'll go away. Kind of like "if I can't see you, you can't see me," the typical three-year-old's hide-and-seek theory, applied to medicine. Unfortunately, that doesn't actually work.

I was first prescribed Anagrelide and was on anywhere from 0.5mg/day to 7.0mg/day. I had lots of side effects: headaches, heart palpitations, dizziness etc. If it could be found on the label as a possible side effect, I probably had it. I am lucky to be in the 50% of the population that do not tolerate it well. So in addition to not wanting to recognize this issue in the first place, I was able to almost get away with not taking my meds by emphasizing how bad the side effects were.

After a while of not taking my meds on time, or sometimes even not at all, and having LOTS of complications, I came to realize that I was being pretty silly. Shortly thereafter, I got a new doctor who, thankfully, is an MPN specialist, was reassessed, and given new prescriptions and started taking my meds…almost regularly even!

[continued on page 2]

See Inside:

Letter from the Director

We continue to make progress in understanding and treating MPNs. Ruxolitinib has been added to the treatment armamentarium for patients with polycythemia vera who are intolerant or resistant to hydroxyurea. Importantly, strides are also being made in developing new treatments for patients with the more rare MPNs, such as mastocytosis and chronic neutrophilic leukemia. While rare and, in many cases, relatively benign diseases, both can follow a more aggressive course, so it is important to know the symptoms and be monitored by your doctor. We provide an overview of the signs and symptoms of mastocytosis and current treatment options on pages 6-7. As an important goal of our Clinical Research Center is to provide additional therapeutic options for our patients, we now have 2 clinical trials open at MD Anderson Cancer Center for patients with aggressive systemic mastocytosis (BLU-285 and brentunximab vedotin) and chronic neutrophilic leukemia (ruxolitinib). Additional details of these clinical trials can be found on page 5.

As always, we continue to pursue our clinical and laboratory research with the goal of bringing new and better treatment options to our patients.

Dr. Srdan Verstovsek, Professor of Medicine in the Department of Leukemia at MD Anderson Cancer Center 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.

[continued from page 1]

But You Don't Look Sick…

I still had complications from time to time, resulting in pheresis and increases in the dosages of my meds, but instead of being apathetic and letting "whatever happens happen," I became an active patient. Managing my health is not only the responsibility of my doctors it is also mine. I came to realize that I could be a partner in my own health, rather than a passive victim of my condition.

I am now very involved in my treatment to the point where my doctors potentially dread seeing me, and my now infamous binder. The binder goes with me to all of my doctor's appointments–Hem/Onc, GP, dentist–it doesn't matter. The binder goes with. It has every piece of my medical info I can get my hands on plus questions I may have, articles I've run across that I want my doctor to look at, etc. I have accepted that this is part of my life. I have setbacks occasionally, but mostly I just roll with it.

When this started, I was so afraid that I'd be labeled as "the sick girl," that I made myself sicker. It took me a while to figure it out...but I finally realized that these diseases are only a small part of us. They do not define us as people. What defines us is how we handle the setbacks that may come along with it. With that being said, let's address this "labeling" issue. While none of us wants to be treated as if we are some fragile piece of glass, we also don't want our illnesses to be discounted, simply for not being outwardly visible.

MPNs are "Invisible Illnesses." There really are not many outward signs that show we're sick, but boy do we feel it. I don't know about the rest of you, but no matter how I look, sometimes I feel like I've been run over by a truck.

However well-intended the phrase may be, saying "but you don't LOOK sick…" to a sick person is pretty insulting. The implication being that we are faking it or that it's not real. We don't look sick? Well…what does sick look like pray tell? Should we all be emaciated, bruised, or limping? What does it take to be acceptably sick? This may surprise some…but not all sick people look alike. Shocking, I'm sure (insert snarky eye roll here).

We all have good days and bad, but for the Invisibly Ill, the bad days often outnumber the good. Most of us, though, are obliged to put on the happy face and get on with things. If we didn't, we wouldn't be able get much done. I often feel like I am two completely different people; the one on the outside who looks just fine and deceives everyone around her, and the one on the inside who is exhausted, battered and miserable.

I learned to put on the happy face real quick when I got my first "Grown-Up Job." I started at my office as the receptionist, so putting on the perky, bubbly personality, however fake it may have been, became a part of my daily life. Fatigued, sick, headache? Didn't matter. That smile was plastered on. Inside I might have been cursing the phone for ringing, but I'd still thank you for calling and inquire how I could help. If you didn't know I was sick…you would not guess by looking at me. There are days though when I just can't fake it anymore, my fatigue catches up with me and knocks me out. On those days, I tend to hear that dreaded "but you don't LOOK sick…" Also on those days my sarcastic side will often think (or sometimes say, depending on the audience) "And you don't LOOK like a jerk…but I guess appearances can be deceiving, can't they?"

Please believe me, I am neither wanting nor expecting sympathy. Understanding and acceptance would be wonderful though. Yes, it's true that we don't fit the picture in most people's heads of what "sick" should look like, but trust me, while these illnesses may be invisible, we and our pain certainly are not.

The best advice I can offer to other patients, is to learn as much as they can about their disease. Don't let anyone, whether medical professional, friend, or family member discount your feelings or thoughts. YOU are the patient. You are the only one who can feel what you're feeling. You must make yourselves heard and understood.

Lina is the creator and author of the blog The Life of a Vaguely Neurotic MPN Patient, where she shares her experiences, thoughts and feelings about her life with an MPN. She was first diagnosed in late 2005, and has been pushing her mantra, "You are your own best advocate!" ever since. She hails from St. Louis, Missouri, where she lives with her husband, "M," and their two dogs Tesla and Pascal, who serve as her furry writing buddies. You can read her blog at www.linampn.com and follow her on Twitter @linaMPN, as well as Facebook, SnapChat, Tumblr, Skype, and Instagram.

A 30-minute survey for patients with myeloproliferative neoplasms (MPNs).

A research study (sponsored by Incyte Corporation) is being conducted to learn more about the impact of MPNs on patients' lives.

Incyte is seeking patients aged 18 to 70 with MF, PV or ET to participate in a one-time, 30-minute online survey about how your condition has affected your work, finances, and quality of life. If you are eligible and complete the survey, you will be compensated. For more information, please visit: https://www.surveymonkey.com/r/NQNSY5C

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.

Their last meeting was held on March 19, 2016. They had a guest speaker, Ms. Ricki Hasou, Sr. Managed Care Specialist from MD Anderson Cancer Center. She discussed navigating the world of health insurance, including health insurance options, how to choose an insurance plan and what can be done when you run into issues with your insurance. She also provided information on important insurance resources and reference material.

According to Charlie, "insurance has become a complicated topic and we see too many instances where our friends run into insurance issues. But, Ms. Hasou did a great job explaining what patients can do when they do run into issues and also what can be done up front when choosing insurance plans, to avoid coverage issues."

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

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

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

North Texas, Dallas/Ft. Worth – andrea926@scglobal.net

South Texas, Houston – CharlieNielsen@aol.com

Facebook: https://www.facebook.com/groups/MPNSupportTX/

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 all open clinical trials enrolling patients with MPNs at MD Anderson Cancer Center as of April 15, 2016. For more information on these clinical trials, call the information line toll-free at 1-800-392-1611 or contact Dr. Verstovsek at sverstov@mdanderson.org. For information on other clinical trials in MPN go to www.clinicaltrials.gov.

Phase 2 Study of PRM-151 (anti-fibrotic agent) in Patients with Myelofibrosis

2013-0051 (NCT No: NCT01981850)

Principal Investigator: Srdan Verstovsek
Study Description: The goal of this study is to determine whether PRM-151 can reduce bone marrow fibrosis in patients with myelofibrosis. Three different dose levels will be compared. The safety of this drug will also be studied. PRM-151 is designed to help control tissue scarring (such as bone marrow fibrosis). Only patients who have anemia or low platelets and for whom ruxolitinib has not been effective are eligible. PRM-151 will be given intravenously monthly for at least 9 months. After the first week study visits will be monthly. This study is currently enrolling patients.

Phase 2 Translational Biology Study of Momelotinib in Patients with Myelofibrosis and Transfusion-Dependent Anemia

2015-0557 (NCT No. 02515630)

Principal Investigator: Srdan Verstovsek
Study Description: The goal of this study is to determine the efficacy of momelotinib in improving transfusion-dependent anemia in patients with myelofibrosis. This study will also assess changes in certain biomarker levels while on treatment. Momelotinib is an oral JAK inhibitor that may improve the signs and symptoms of myelofibrosis in patients with anemia. Patients who have received transfusions of 4 or more units of red blood cells in the past 8 weeks are eligible to enroll. Patients will receive momelotinib for at least 6 months. Study visits will be every 2 weeks for the first month and then monthly thereafter. This study is open for enrollment.

Phase 2 Study of Nivolumab in Patients with Myelofibrosis

2014-0962 (NCT No: NCT02421354)

Principal Investigator: Srdan Verstovsek
Study Description: The goal of this study is to determine the effectiveness of nivolumab in patients with myelofibrosis. The safety of this drug will also be tested. Nivolumab is a treatment that uses your immune system to treat disease. Patients will receive nivolumab intravenously every 2 weeks for at least 8 doses and then every 3 months thereafter.

Phase 2 Study of Ruxolitinib and Pracinostat in Patients with Myelofibrosis

2014-0445 (clinicaltrails.gov NCT No: NCT02267278)

Principal Investigator: Srdan Verstovsek
Study Description: The goal of this study is to determine the effectiveness of the combination of ruxolitinib and pracinostat in patients with MF. The safety of this drug combination will also be studied. Pracinostat is a histone deacetylase inhibitor. Patients will receive ruxolitinib orally as a single agent for the first 3 months, after which point oral pracinostat will be added. This study is accepting patients with MF who have not been previously treated with a JAK inhibitor. Study visits will be monthly for the first 6 months and then every 3 months thereafter.

Phase 2 Prospective, Open-Label Study of Sotatercept (ACE-011) in Patients with Myelofibrosis and Significant Anemia

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

Principal Investigator: Srdan Verstovsek
Study Description: The goal of this study is to learn if sotatercept can help to control MF and anemia. The safety of this drug will also be studied. Sotatercept (ACE-011) may increase the growth and development of red blood cells. Patients will be given subcutaneous injections once every 3 weeks for at least 6 months. This study is accepting patients with myelofibrosis and significant anemia.

Phase 2 Study of LCL-161 in Patients with Myelofibrosis

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

Principal Investigator: Naveen Pemmaraju
Study Description: The goal of this clinical research study is to learn if LCL-161 can help to control myelofibrosis. The safety of this drug will also be studied. LCL-161 is an oral drug that activates a signaling pathway that promotes cancer cell death. Patients will receive LCL-161 orally every 7 days. Study visits will be monthly for the first 4 months and then every 3 months thereafter.

Phase 1 Study of BLU-285 in Patients with Advanced Systemic Mastocytosis or Relapsed or Refractory Myeloid Malignancies

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

Principal Investigator: Srdan Verstovsek
Study Description: The goal of this study is to determine the highest tolerable dose of BLU-285 that can be given to patients with advanced systemic mastocytosis or relapsed/refractory myeloid malignancies. The safety and efficacy of this drug will also be studied. BLU-285 is an oral drug that is designed to block the activity of the mutated form of the KIT receptor tyrosine kinase (KITD816V), which is present in patients with systemic mastocytosis. Patients will receive BLU-285 orally once daily. This study is currently enrolling patients with advanced systemic mastocytosis, mast cell leukemia or another myeloid malignancy that has relapsed or not treatable by standard treatments.

Phase 2 Study of Ruxolitinib and 5-Azacytidine (hypomethylating agent) in Patients with Myelodysplastic Syndrome/Myeloproliferative Neoplasm or Myelofibrosis

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

Principal Investigator: Naval Daver
Study Description: This goal of this study is to learn if the combination of ruxolitinib and azacytidine can help to control disease in patients with myelodysplastic syndrome (MDS)/MPN or myelofibrosis. The combination of ruxolitinib and azacytidine may improve the overall effectiveness of each drug. Ruxolitinib will be taken orally 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. Study visits will be monthly for the first seven months and then every 3 months thereafter.

Phase 1/2 Study of SL-401 in Patients with Advanced, High-Risk MPNs, Including Myelofibrosis, Chronic Myelomonocytic Leukemia, and Hypereosinophilic Syndrome/Chronic Eosinophilic Leukemia

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

Principal Investigator: Naveen Pemmaraju
Study Description: The goal of this study is to study the safety and efficacy of SL401 in patients with high-risk MPNs. SL401 is a biological agent that binds to cells that cause MPNs. Patients with symptomatic myelofibrosis who are not candidates for, are intolerant of or have failed therapy with ruxolitinib are eligible. Patients with chronic myelomonocytic leukemia (CMML) or primary eosinophilic disorders who are not candidates for therapy with imatinib are also eligible. SL401 will be given intravenously daily for the first 3 days of each 28-day cycle.

Phase 2 Study of Brentuximab Vedotin (SGN-35) in Patients with CD30-Positive Aggressive Systemic Mastocytosis with or without an Associated Hematological Clonal Non-Mast Cell Lineage Disease

2012-0734 (clinicaltrials.gov NCT No: NCT01807598)

Principal Investigator: Srdan Verstovsek
Study Description: The purpose of this study is to determine if the drug brentuximab vedotin (Adcetris) can help control systemic mastocytosis. Brentuximab vedotin is a biological therapeutic designed to bind to a certain protein (CD30) on cancer cells and kill them. Patients will receive brentuximab vedotin intravenously once every 21 days for up to 8 cycles. Study visits will be every 3 weeks for the first 8 cycles and then every 6 weeks thereafter.

Prospective Evaluation of Ruxolitinib Efficacy for Chronic Neutrophilic Leukemia/Atypical Chronic Myeloid Leukemia Patients with Mutation of CSF3R

2014-0764 (clinicaltrials.gov NCT No: NCT02092324)

Principal Investigator: Jorge Cortes
Study Description: The goal of this study is to learn about the effects ruxolitinib has on patients with chronic neutrophilic leukemia or atypical chronic myeloid leukemia. The safety of this drug will also be studied. Ruxolitinib is drug that blocks the activity of JAK2 tyrosine kinase, an enzyme in bone marrow cells that drives their growth. Patients will receive ruxolitinib orally twice daily for 24 months. Study visits will be weekly for the first month and then every 2 weeks thereafter.

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http://www.facebook.com/MDAndersonLeukemia

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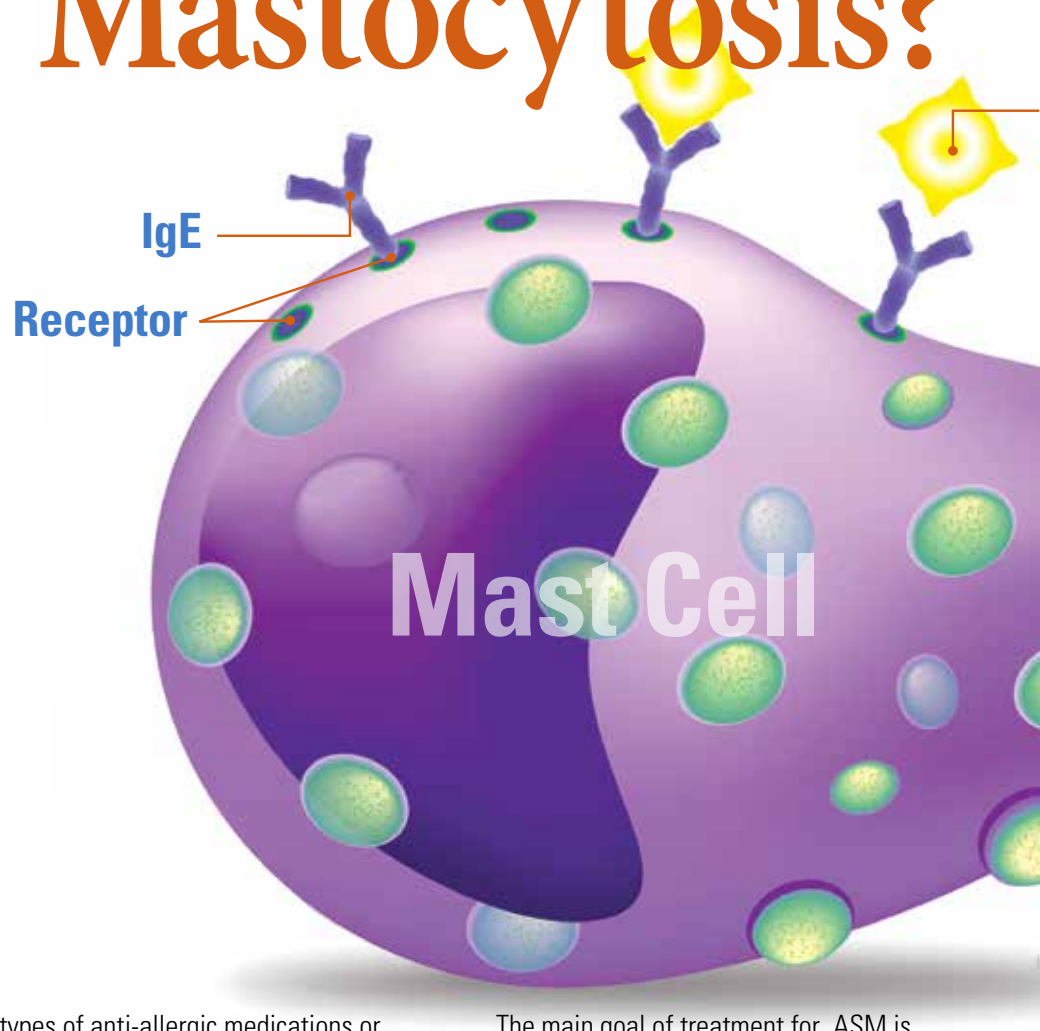
To Schedule an Appointment

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

What is Mastocytosis?

Mastocytosis is a disorder in which the body makes too many mast cells. Mast cells are a type of white blood cell that release chemicals called mediators that activate the body's response to allergens or pathogens. There are two categories of mastocytosis: cutaneous (skin) mastocytosis (CM) and systemic mastocytosis (SM). CM is a relatively benign disease characterized by patches of itchy, red/brown skin lesions (urticaria pigmentosa). It's diagnosed most often in children and often resolves on its own as the child reaches adolescence. In adults, mastocytosis is most often systemic (i.e., affecting one or more internal organs and the bone marrow); however, the skin can also be involved. SM can be classified as indolent or aggressive.



Indolent SM is the most common form of mastocytosis. It does not affect organ function, but may cause many symptoms and poor quality of life. It does not affect life expectancy since, in general, it does not change to an aggressive form.

Symptoms may include

- **skin swelling**
- **hives**
- **lowered blood pressure**
- **shortness of breath**
- **itching**
- **nausea and vomiting**
- **diarrhea**
- **fainting**
- **headache**
- **flushing**
- **musculoskeletal pain**

Most cases can be treated with antihistamines and patients are recommended to avoid dietary and environmental triggers. Prednisone, other types of anti-allergic medications or cromolyn sodium (a mast cell stabilizer) may be helpful in controlling symptoms.

Aggressive SM (ASM) is characterized by the infiltration of internal organs by mast cells resulting in organ dysfunction which may significantly affect patients' life expectancy.

Symptoms of ASM often include

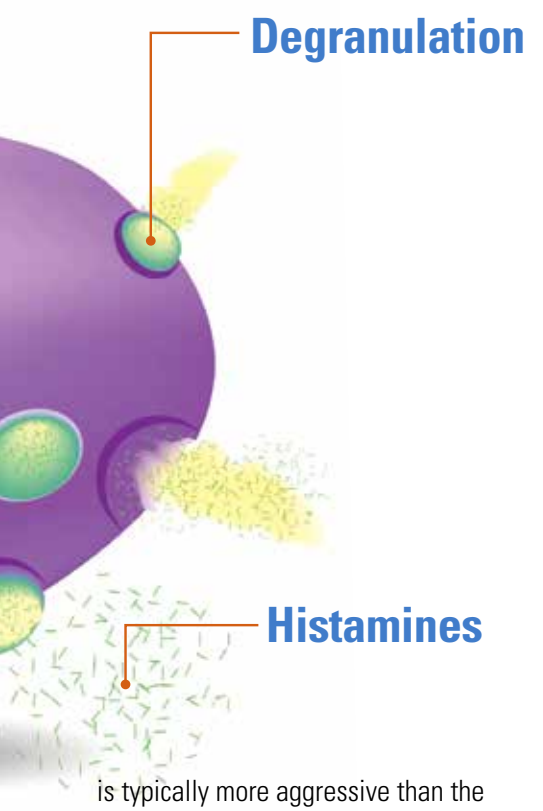
- **severe diarrhea**
- **malabsorption of nutrients with body wasting**
- **bone fractures**
- **an enlarged spleen**
- **liver failure**
- **bone marrow failure with transfusion requirement**

The main goal of treatment for ASM is to reduce the number of mast cells in the body.

Common treatments include

- **interferon-alpha**
- **hydroxyurea, an oral chemotherapy agent**
- **IV chemotherapeutic agents (typically cladribine)**

Mastocytosis can also occur in patients with an associated clonal hematological non-mast cell lineage disease (SM-AHNMD), meaning along with an additional bone marrow disease such as chronic myelomonocytic leukemia, myelodysplastic syndrome, myeloproliferative neoplasm, acute myeloid leukemia, or B-cell lymphoma. In this case, the associated disease



is typically more aggressive than the mastocytosis and is the target of therapy.

Mast cell leukemia (MCL) is a very rare entity, which is suspected when there are abnormal mast cells in the blood. MCL is treated with a combination of IV chemotherapy agents.

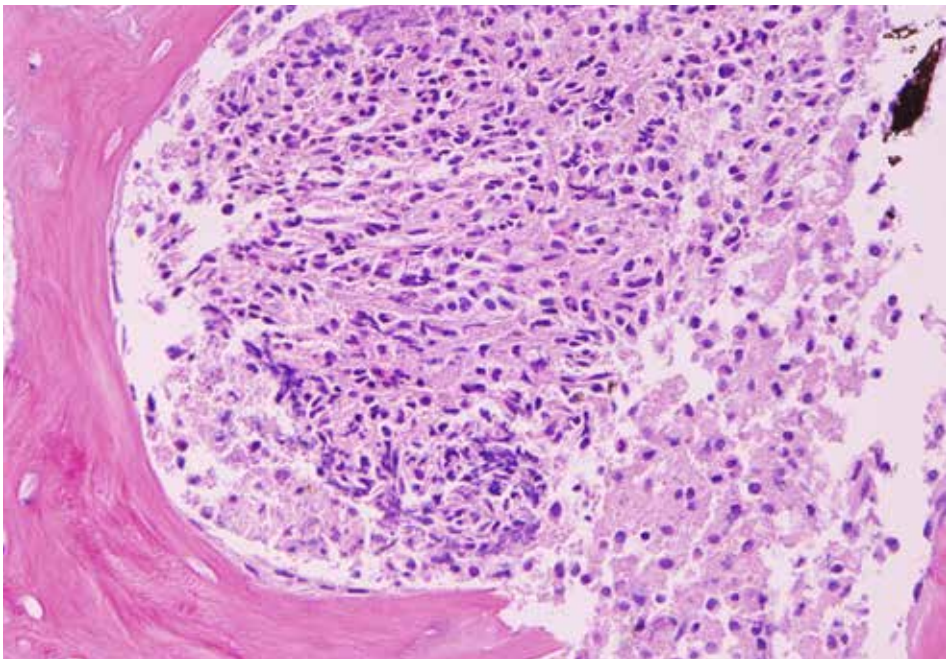
Unfortunately, while therapies for ASM and MCL may be effective in reducing the number of mast cells in the blood and alleviating symptoms, none have been shown to eliminate the disease or prolong life. The only potentially curative therapy for advanced forms of mastocytosis is stem cell transplantation (SCT). However, SCT does not always eradicate disease or prevent relapse, and it is associated with significant complications. However, with the discovery that up to 90% of patients with mastocytosis have a mutation in the KIT gene (D816V) encoding a tyrosine kinase (an enzyme in mast cells that drives their growth) new targeted therapies are being tested. Imatinib (Gleevec), a tyrosine kinase inhibitor, is the only drug approved by US Food and Drug Administration for the treatment of ASM. However, because cells with the KIT D816V mutation are resistant to imatinib, it is not a treatment option for most patients, only for those without KIT D816V mutation (or unknown mutation status). Newer drugs targeting the KIT D816V mutation are currently being tested in clinical trials.

Clinical trials are an option for patients with advanced forms of mastocytosis for whom standard therapies have failed. Therapies being tested in clinical trials are listed below.

Clinical Trials in ASM

- **BLU-285 (NCT02561988)** – a tyrosine kinase inhibitor that specifically targets cells with the KITD816V mutation. Open at MD Anderson Cancer Center.
- **Ibrutinib (NCT02415608)** – a tyrosine kinase inhibitor that has been used to treat other hematologic malignancies
- **SL-401 (NCT02268253)** – a biological agent that binds to and kills cells expressing CD123 (a receptor on the surface of mast cells). Open at MD Anderson Cancer Center.
- **Brentuximab vedotin (NCT01807598)** – a biological agent that binds to and kiss cells expressing the CD30 receptor. Open at MD Anderson Cancer Center.
- **Cladribine + Interferon alfa-2a (NCT01602939)** – two therapies currently used to treat ASM being tested in combination

To find out more information on these trials use the NCT number to search on www.clinicaltrials.gov. For more information on mastocytosis and resources for patients, you can visit The Mastocytosis Society website at www.tmsforacure.org.



Bone marrow biopsy from a patient with systemic mastocytosis showing the infiltration of mast cells in the bone marrow.

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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: Kate J. Newberry, Ph.D.
For questions, comments or to subscribe, please contact Kate Newberry at **kjnewber@mdanderson.org**

Resources for Patients

2016 Patient Education Symposia hosted by MPN Advocacy & Education International

- **May 18, 2016** in Sioux Falls, South Dakota
- **May 19, 2016** in Fargo, North Dakota
- **June 23, 2016** in Boston, Massachusetts
- **September 30, 2016** in New York City

For more information visit www.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** (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.

Other Online Resources:

MPNforum Monthly…the MPN community's hometown paper

MPNforum Monthly 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.

MPDSUPPORT.ORG

Founded in 1994 by patient advocate, Robert Tollen, the **MPD-SUPPORT** 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: https://www.facebook.com/groups/375525335856981/

MPN Education Foundation

Formed in 2004, the **MPN Education Foundation** aims to bring information, reassurance and support to MPN patients and their loved ones all over the world via a website (www.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 www.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 www.apfed.org.

The Mastocytosis Society

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. www.tmsforacure.org.

PV Reporter and MPN Cancer Connection

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: www.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: www.mpncancerconnection.org.