

MPN RESEARCH FOUNDATION

CHANGE YOUR PROGNOSIS UPDATE



VOLUME XVII, NO. 2 FALL 2018

PERIODIC NEWSLETTER FOR THE MYELOPROLIFERATIVE NEOPLASMS COMMUNITY

A TOOL FOR TIMING

Michelle Woehrle, Executive Director

The decision of whether or not to undergo a stem cell transplant (and also when) is on the minds of many people living with Myelofibrosis, and possibly some with PV and ET as well, who anticipate needing one at some point in their journey with MPN. This year we worked with Zhenya Senyak of MPN Forum to create a new web-based tool which seeks to improve outcomes for MF patients undergoing transplant by encouraging them to have a robust and early dialogue with their care providers.

The Stem Cell SCT Spectrum Transplant Timing Tool (SSTT) is based on a clinically validated scale. It provides a color signal in response to information entered by a patient, indicating a risk level. The tool is designed to generate meaningful dialogue between a patient and their physician about their treatment options. Along with the color signal, the SSTT indicates median survival times without a stem cell transplant, based on what is entered, and includes notes and resources to support patient and hematologist transplant discussions.

The tool is the collaborative work of a myeloproliferative neoplasm taskforce from around the world. The Taskforce is composed of 18 world-renowned distinguished MPN and transplant specialists, patient advocates and SCT patient survivors.

HEMATOLOGISTS: *Dr. Claire Harrison*, Professor and Clinical Director, Guy's and St. Thomas' Hospital London | *Dr. Ruben Mesa*, Director, Mays Cancer Center of UT Health San Antonio MD Anderson Cancer Center | *Dr. Richard T. Silver*, Professor of Medicine, Weill-Cornell | *Richard T. Silver MD* Myeloproliferative Neoplasms Center | *Dr. Srdan Verstovsek*, Department of Leukemia, UT MD Anderson Cancer Center, Houston

TRANSPLANT SPECIALISTS: *Dr. Koen Van Besien*, Director, SCT program, Weill-Cornell | *Dr. Nicolaus Kroeger*, Medical Director, SCT, University Hospital, Hamburg | *Dr. Jeanne Palmer*, Medical Director, BMT, Mayo Clinic, Phoenix | *Dr. Uday Popat*, Professor Dept of SCT, MD Anderson

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PROJECT DIRECTOR: *Zhenya Senyak*, Editor & Publisher, MPN Quarterly Journal/MPNforum

Nothing can take place of the discussions between YOU and your doctor, which can take into account a larger picture than what this tool provides. We hope this will be a helpful launch point for necessary conversations that we know are being delayed or not had at all. For some people, the difference in waiting or not is the difference between a successful outcome and a poor outcome.

"There is an optimal time to start SCT," says Senyak, "simply because the odds of success soar in our favor when we start early rather than late in the game. The SCT Spectrum Timing tool can help inform the timing of that decision."

The SCT Spectrum Transplant Timing Tool is available free on mobile phone, tablet and PC, and can be found at www.mpntransplant.com. ■

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MISSION

The primary mission of the MPN Research Foundation is to stimulate original research in pursuit of new treatments — and eventually a cure — for myeloproliferative neoplasms (MPNs). In addition, the MPN Research Foundation promotes collaboration in the scientific community to accelerate research and serves as a powerful patient advocacy group for patients and their families.

WWW.MPNRESEARCHFOUNDATION.ORG

MPNRF HOSTS IMMUNOTHERAPY SYMPOSIUM

Brandon Goetzman, MPNRF Board Member

Recently in Chicago, the MPNRF hosted a group of MPN Researchers with a symposium focused on adoptive T cell therapies. Stem cell transplant (SCT) remains the only potentially curative therapy for MPNs. Many believe this is because the donor's stem cells generate a T cell immune response against the patient's cancerous MPN cells, preventing the cancerous cells from replicating and leading to disease. Adoptive T cell therapies are a subcategory of immunotherapy that have shown success in other forms of blood cancer. The premise of T cell immunotherapy is that it could be possible to create a therapy using T cells such as T Cell Receptor Therapy (TCR) or Chimeric Antigen Receptor T Cell (CAR-T) Therapy to selectively kill an MPN patient's blood cancer cells with less risk than traditional stem cell transplant.



Front Row, left to right: Ann Mullally, MD | Najla Arshad, PhD | Camelia Iancu-Rubin, PhD | Nina Bhardwaj, MD, PhD | Vivian Oehler, MD | Angela Fleischman, MD, PhD | John Crispino, PhD. Second Row, left to right: Brandon Goetzman | Robyn Scherber, MD | Richard Winneker, PhD | Barbara Van Husen | Michelle Woehrlé | Brady Stein, MD | Craig Adams, PhD | Erik Nelson, PhD | Michael Deininger, MD, PhD | Saar Gill, MD, PhD

Over the last year, the MPNRF observed a number of MPN researchers focusing their efforts on immunotherapy and decided it was time to bring them together to discuss the opportunity for these therapy approaches to be developed for

the fight against MPNs. During the symposium, four MPN researchers, Dr. Vivian Oehler (University of Washington), Dr. Najla Arshad (Yale University), Dr. Nina Bhardwaj and Dr. Camelia Iancu-Rubin (both with the Icahn School of Medicine), and Dr. Michael Deininger (University of Utah), presented their work highlighting research progress. The presentations were followed by a workshop discussion led by Dr. Saar Gill (University of Pennsylvania) and Dr. John Crispino (Northwestern University) on opportunities, risks, and potential next steps. The attendees participated in a robust debate on the potential for T cell immunotherapies to be used in MPNs in the future, and while there are current research hurdles that must first be surmounted, progress is occurring.

The MPNRF is eagerly searching for novel breakthrough therapies and remains hopeful that to-be-developed immunotherapies could play a role in slowing disease progression, or even cure the disease. The Foundation has funded four researchers thus far focused on immunotherapy, with the most recent investment related to discovering neo-antigens to selectively target MPN cancer cells. This research is being led by a team at Fred Hutchinson Cancer Research Center and the University of Washington (for more, read MPNRF's Spring 2018 article titled "New Study: T Cell Immunotherapy Targets.")

So far immunotherapy clinical trials in MPNs have been limited to checkpoint inhibitors that are FDA-approved for other cancers, and which work by "releasing the breaks" of the immune system against cancer cells by targeting PD-1/PD-L1. Results from these drug trials in MPNs have yet to be published. A first-in-human therapy vaccine targeting mutant CALR has been designed by a team of researchers in Denmark, and this team is expected to begin enrolling patients in a trial in Denmark soon.

"The MPNRF team and board members hope that immunotherapy can be the future of MPN therapy," says Michelle Woehrlé, MPNRF's Executive Director. "We're actively investing in this research in hopes that one day it will have an impact on the lives of patients around the world." ■

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MPN RESEARCH FOUNDATION UPDATE

A periodic newsletter published by the MPN Research Foundation to provide members of the MPN community with information on current research and the Foundation's activities.

MPN RESEARCH FOUNDATION

180 N. Michigan Avenue, Suite 1870
Chicago, IL 60601
Tel (312) 683-7249 | Fax: (312) 332-0840
mpnresearchfoundation.org

UPDATE EDITORIAL STAFF

Ericka Cannaday, MPNRF Update Coordinator
Joe Shansky, Editor
Michael Garzel, Layout Editor

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MYMPN EVENT REPORTING: THE GOOD, THE BAD AND THE UGLY

Lindsey J. Whyte, Longitudinal Research Project Manager

Our registry launched in September 2017 and participation has grown steadily, with more than 625 U.S. participants having completed initial surveys. A lower number of participants regularly complete the quality-of-life survey (“How do you feel, today?” or HDYFT) and are reporting health events such as blood draws, thromboses, medicine changes, and others as they occur. More than 950 event surveys have been completed by almost 500 users reporting well over 1,000 events (more than one event can be reported on one survey)! Have you filled one out lately?

Some participants may not be familiar with the event survey and the important purpose it serves in our longitudinal data collection project. Here are some guidelines.

HOW DO I KNOW IF I HAVE AN EVENT WORTH REPORTING?

Researchers are striving to piece together what causes the health of some people with MPNs to remain stable with minimal intervention, while others have debilitating symptoms, and still others progress to Myelofibrosis or other forms of blood cancers. When large numbers of patients contribute their personal experiences with a disease, we can query the data for commonalities. Suddenly, something as unsurprising to an ET patient as a skin ulcer is recognized as a reaction to a particular medication. As we amass data from more patients representing different stages of life, disease indications, symptoms and therapies, hypotheses can be formed and researched to try to arrive more quickly at better treatments.

This is why it’s important that **all participants in myMPN continue to update their profile periodically** (ideally every 1-2 weeks) with symptom and quality of life data via the HDYFT survey, as well as with events that occur in their health. With the advent of Blood Cancer Awareness Month we are rolling out a new graphic (shown above). “The Good, the Bad and the Ugly” is meant to convey that surveys can be filled out any time, regardless of how you’re feeling. If you’re feeling great, tell us via the HDYFT survey. If you don’t feel well, fill out a HDYFT survey. If something happened recently, ALSO fill out an event form. Here is a list of some of the events that are currently being recorded by participants in myMPN:

- Phlebotomy
- Transfusion
- Blood draw
- Diagnosis change
- Medicine change (medication and/or dose)
- Planned or unplanned hospital stay
- Splenectomy
- Pregnancy
- Thrombotic or bleeding event
- Blood testing for genetic markers
- Out-patient procedure
- Bone marrow biopsy

The good, the bad, the ugly



We want to hear it all.
Fill out a survey on myMPN, today!

myMPN participants will certainly experience events that are not listed above. An example of a survey that we expect to add soon is a skin lesion, as we know that they occur often, possibly as a side effect to certain medications. This is a great example of why, even if you think your health event is unrelated to your MPN, it’s still important to report it. Just in case! Contact us if there is an event that you think we should consider adding a survey for.

WHAT ELSE IS IMPORTANT TO REPORT, IN ADDITION TO YOUR EVENT?

Don’t forget that data from HDYFT surveys becomes more valuable each time a user fills out a new survey! Since we are interested in looking at trends in MPN patients over time, we want to see how the user’s experience changes from day-to-day and week-to-week. Unless myMPN users participate regularly, we won’t have that data. Similarly, HDYFT surveys that are completed at the time of a health event can tell us something important about how the participant is affected leading up to and/or directly following the event. If a high degree of discomfort, fatigue or another symptom is reported just prior to a thrombotic event, a participant may learn to look for this leading indicator in the future and can potentially take proactive or preventative measures.

As more events and their corresponding symptoms are entered into myMPN, we will be able to share correlations and possible connections with users and the medical and research community. When considering a new medication for a patient, a clinician soon will be able to refer to published data from myMPN that testifies to the effects, positive and negative, of a certain medication from the perspective of THE PATIENT!

We already have 117 reports of medicine change via event forms. This is in addition to data entered by users in the primary survey, which asks, “What medications are currently being taken and have previously been taken, but have been discontinued, and why?”. Until now, there has not been a resource for clinicians to “hear” the collective patient perspective on medications they’ve tried, failed and succeeded on. This valuable resource for practitioners will only grow as patients share more of their day-to-day experiences via the event and HDYFT surveys.

Finally, a great reason for myMPN participants to record their events, and how they feel leading up to and following them, is because they will have the data to refer to when it is time for a visit to their hematologist or other doctor. In a future issue of our newsletter and online, we will provide a step-by-step explanation of how to download a summary of all survey responses entered within a certain period of time. This information can then be shared during a doctor’s appointment, allowing the patient to refer to the data rather than having to recount the details from memory. If you would like to know how to do this, don’t hesitate to contact us at (312) 204-6647 or by email at myMPN@mpnrf.org.

Keep up the great work of regularly visiting www.mympn.org! ■

DOING OUR PART

JoAnn Mason, Member of the MPNRF Board of Trustees



JoAnn Mason

The mission of the MPN Research Foundation is incredibly important to me. A member of my family was diagnosed with Polycythemia Vera 17 years ago, and since that time I've done what I can to raise money for MPN research. For me, that means reaching out to my personal network, sharing our family's story, and educating our friends and colleagues

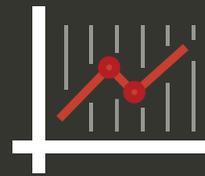
about these rare cancers with names that are so difficult to pronounce! I am always humbled by the generosity of my community, and amazed that all it takes is an ask. Every year, with the help of the staff at the Foundation, I put together a letter asking people in my network to contribute, and every year people respond.

From time to time, the Foundation hosts events to connect with our donors, and I hope to do one in Washington, DC in the coming year. But even if you don't have the time or resources to plan an event or write to everyone in your address book, you can still raise a significant amount of money for the MPN Research Foundation. Sometimes all it takes is an email or a post on social media. More and more the Foundation is receiving support from individuals who feel inspired to raise money from their personal networks. My family is incredibly proud of the funds we've raised and are grateful that the MPN Research Foundation directs these funds to research that matters to us.

If the advancement of MPN research is important to you, why not use your own connections to raise money for the Foundation? Having financial resources available to fund the next scientific breakthrough is crucial. One day there will be a cure for patients diagnosed with MPNs, and the only way to get there is by funding research in the MPN field. My family is proud to do our part.

If you are interested in raising funds for the MPN Research Foundation, contact Ellen Bouleanu, Associate Director of Major Gifts, at ebouleanu@mpnrf.org. ■

MPN INTERFERON INITIATIVE IS DELIVERING RESULTS



Rick Winneker, Director of Strategies and Research Operations

The MPN Interferon (IFN) Initiative is a multi-year program that was launched in December 2017. The goal is to understand the mechanism of action of IFN in achieving remissions in MPN patients. This new information should lead to better patient selection for IFN therapy and possibly new drug targets that may lead to improved therapies. The Principal Investigators (PIs) and a group of MPNRF staff and advisors have been working together to track progress and promote collaboration during quarterly conference calls. Below is an update on the four projects:

1. *Overcoming resistance to interferon in MPN stem cells*

Ann Mullally, PhD (Boston MA) Steven Lane, MD, PhD (Brisbane, Australia) and Michael Milsom, PhD (Heidelberg, Germany). This team is studying the effects of IFN on MPN stem cells to determine why some patients respond to IFN. Sequencing of more than 100 genes from IFN-treated patients with MPN is underway to identify markers of response and resistance. The MPN Alliance Australia and MPNRF are partnering together to provide support for this project.

2. *Mechanism of action of interferon alpha in MPN therapy*

Jean-Luc Villeval, PhD and Isabelle Plo, PhD (Villejuif Cedex, France). Results from 50 patients have shown that IFN targets JAK2V617F mutated early progenitor cells more efficiently and rapidly than mature ones. These cells are also more responsive to IFN than calreticulin mutated progenitors. Using an MPN mouse model, they have also shown that a combination of IFN with arsenic amplifies the curative effect of IFN.

3. *Novel Agents for the Treatment of Malignancies*

Leon Platanius, MD (Chicago IL). The goal is to identify proteins that determine the IFN response in MPN patients, so-called "molecular switch proteins"; and ultimately target these proteins to improve the IFN anti-tumorigenic effect. Proteins found in complexes induced by IFN are now being identified and their role is being explored using JAK2V617F expressing cells and MPN-patient derived samples.

4. *Using a vascular niche platform to develop interferon-based strategies to eradicate MPN stem cells and phenotypes*

Joseph Scandura, MD, PhD (New York, NY). A cell-based blood formation factory has been established to study the development of mature blood cells from stem cell precursors and where MPN driver mutations alter blood cell production. This system is now being used to identify the steps where IFN changes how MPN mutations affect blood cell formation and how to best use IFN-based therapies to eliminate these cells.

The entire team of researchers, advisors, and MPN staff are now planning their next face-to-face meeting at the ASH Annual Meeting and Exposition convening in late November 2018. ■

CLIMBING TOGETHER

Jolanda Visser, Australian Alliance



Jolanda Visser

My journey with Essential Thrombocythemia started in 2003, when I was 33. As a result of an unexplained skin problem, I was referred for a complete blood count test. After discovering an elevated platelet count and a following up with a blood test a month later, I secured an appointment with a hematologist who advised me that I needed a bone marrow biopsy. An official diagnosis of ET was the outcome. This result stunned my hematologist, as he had never met a patient with ET who was younger than 65. I was advised to take aspirin and amazingly, as soon as I started the aspirin,

my skin issue disappeared. As I was not suffering any symptoms, it was easy for me to ignore the fact that I had ET.

However, within six months, my counts were over 750,000 and my specialist advised me that I was to start Hydroxyurea. I was unsure about starting the medication without any symptoms. A friend of mine strongly recommended that I should see another hematologist for a second opinion, which I did. This specialist advised me that she would certainly not start me on medication as this decision should be based on symptoms and risk of thrombosis rather than platelet counts alone. We agreed that we would monitor the platelets and continue the aspirin.

For the following three years, I would only be confronted with ET when I had to go for a blood test and was advised that my platelet count continued to rise. However, life was good, and I was busy with work and family.

In March of 2006, I ended up in the emergency department with a TIA-like event and symptoms. Life changed after this episode, as I started to develop severe headaches, dizzy spells, and fatigue. It started to impact my quality of life and I had to start working around my symptoms. In 2008, it was no longer possible for me to function normally, due to the extreme headaches and dizzy spells I was suffering. My hematologist and I decided to start treatment, Hydroxyurea, after I returned from my holiday.

However, she unfortunately passed away while I was on leave. Upon my return, I was transferred to a different hematologist who said that he was not convinced that my symptoms were related to my ET, and did not believe that treatment would make any difference. During one of my visits after this, I asked for a copy of the blood test results and noticed that there was a mention of the JAK2 V617f mutation test in 2005. When I came home, I researched this mutation and realized that ET was classed as a blood cancer. At my next appointment, I asked my specialist about the mutation and whether ET was indeed a cancer. His answer did not clarify much, as all he

said was that ET is a neoplasm so therefore it is a cancer and the JAK2 test was done in 2005, after the mutation discovery had taken place in 2005. Strangely, in four years nobody ever advised me that I tested positive to this mutation nor did they explain how this could affect me.

After nine months, I advised my specialist that I could no longer manage the way I was living my life. I was in constant pain, tired and afraid that I may pass out or fall while I was on my own, due to dizzy spells. So, we agreed that I would start Hydroxyurea. And although the medication never completely removed my headache, it certainly stopped the dizzy spells and also positively increased my energy levels.

I gained back some quality in my life and became used to my new 'normal'. That is, until I ended up back in the emergency department and on stroke watch in the hospital in 2013. This episode changed my whole life. My headaches became uncontrollable; I suffered continuous blurred vision and was so tired that I just could not function as I did before. We increased my Hydroxyurea and pain medication and I swallowed aspirin as if there was no tomorrow, but nothing made a difference. Over a few months, I increased my existing pain medication and tried new medication to try and fight the headache. I became quite desperate and lonely. Whenever people looked at me, they were surprised at how well I looked and they found it difficult to understand how I could feel so rotten on the inside. I reduced my working days from five to four; however, I genuinely struggled and have to admit that it was the darkest time in my life. The increased Hydroxyurea caused a serious skin problem and I changed over to Roferon A. I hoped that this would start an improved chapter in my life. And although the interferon managed my counts, I was suffering bad side effects, which was why I stopped this interferon after 18 months.

During this dark period in my life, I started reading everything I could find on the internet and I reached out for support. Unfortunately, the internet did not always have information that was relevant and applicable in Australia. Initially I only found support in the U.S., which, was a bit of a struggle, as a lot of discussion was about access to treatment that we did not have in Australia, Pegasus interferon. Much of the information and support was just not relevant to Australian patients.

Eventually, after a virtual trip around the world, I found a group of patients in Australia. One by one, we shared our experiences and realized that most of us have been on a similar journey. All of us experienced a lack of access to better treatment options, no relevant Australian MPN information, and often a lack of understanding by the medical profession. To improve access to relevant information and understanding, the MPN Alliance Australia was formed in 2015. The MPN AA is a group of very dedicated patients who aim to ease the lives of newly diagnosed and existing patients. We created a MPN-dedicated website, lobbied for better treatment options, and co-hosted the first

(CONTINUED ON PAGE 7)

STRENGTHENING OUR COMMITMENT TO PATIENT SUPPORT

Lexi Moore,
Community Engagement and Outreach Coordinator



Lexi Moore

As an organization that was created by patients for patients, MPN Research Foundation is proud to play a vital role in the MPN world. Everything we do is for the benefit of those who are affected by Essential Thrombocythemia, Polycythemia Vera and Myelofibrosis, and part of that mission is to provide an informational hub of educational resources and

helpful tools for people living with Myeloproliferative Neoplasms.

Through my daily interactions with patients, I see how those who are facing these rare diseases can feel isolated. My primary focus as the newest member of the foundation and the Community Engagement and Outreach Coordinator is to educate patients, their caregivers, families, and friends across our community to ensure that no one faces their cancer journey alone.

My goal is to ensure that all MPN patients have the opportunity to connect with others who understand the challenges they face, whether that be by joining an in-person or online support group and/or attending educational events. I encourage you all to participate in the conversations happening on social media and to read our blog posts, news updates, and monthly emails. These platforms offer up-to-date information about MPN treatments and ongoing research. Staying informed and connected is empowering and can inspire hope for the future.

I know I have a lot to learn, but in my role, I will strive to provide the essential tools and resources to everyone in the global MPN community. I believe there is great strength in numbers, and we should all remember to lean on each other as we work towards a cure. ■

MAKING PLANS

Ellen Bouleanu,
Associate Director of Major Gifts

Are you planning for the future? So are we. A path to a cure will be found, and when that day comes the MPN Research Foundation (MPNRF) will need financial resources to fund the next big scientific breakthrough. Including the MPNRF in your will represents a deep commitment to MPN patients around the world and means our organization can keep advancing our mission until we find a cure. We all have to create a plan for what happens to our resources after we are gone, and using your will to plan a gift to the MPN Research Foundation is a meaningful way to create a lasting legacy.

Planned gifts allow a donor to support the work of the Foundation while balancing personal financial goals. There are a few options when it comes to leaving a bequest, and if you are interested in pursuing this method of support for the Foundation, I encourage you to review these options with a financial advisor.

- **UNRESTRICTED BEQUESTS:** gives MPNRF the flexibility to direct your gift where it is needed most. Example phrasing for will or trust: "I give, devise and bequeath \$XX (or XX% of the residue of my estate) to the MPN Research Foundation (Tax ID #36-4330967), located in Chicago, IL for general use and purpose."
- **RESTRICTED BEQUESTS:** the donor designates a specific initiative or area of interest to support with their gift
- **SPECIFIC BEQUEST:** specific assets, such as cash or securities, are designated to the MPNRF
- **RESIDUARY BEQUEST:** the donor specifies a percentage of what remains in the estate after all other specific bequests have been executed and all debts and expenses have been paid
- **CONTINGENT BEQUEST:** this option gives either a portion or all of your estate to MPNRF when a named individual beneficiary dies before you. For example: "I give \$25,000 to my brother Charles, but if he does not survive me, the bequest should be given to the MPN Research Foundation."

If you include the MPN Research Foundation in your estate plans, we encourage you to let us know! Send me an email (ebouleanu@mpnrf.org) or call directly at 312.683.7249, so we can acknowledge your commitment in our annual report.

Thank you for your support! ■

MPN RESEARCH FOUNDATION

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PARTNERS MATTER IN THE MPN COMMUNITY



Ellen Bouleanu, Associate Director of Major Gifts

PARTNERSHIPS ARE IMPORTANT.

They bring people together in pursuit of a common cause and put many minds to work on a problem, increasing the likelihood that a solution is found. That's why we're getting into the business of creating partnerships. The MPN Research Foundation believes that researchers in the field should be collaborating across institutions to solve some of our hardest questions. We are eager to bridge the divide and offer a framework for these kinds of relationships to develop and thrive.

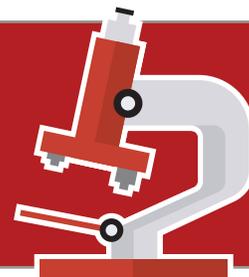
We are also focused on creating partnerships among the many MPN advocacy groups. When MPNRF was founded, there were very few of these organizations around. Today, there are over a dozen around the world that are actively working to educate, advocate, and fund research in the MPN field.

In March of 2018, MPN Research Foundation and fellow MPN advocacy organization, MPN Alliance Australia (MPN AA), proudly announced a research-focused partnership for the MPN Interferon Initiative. Interferon remains the only treatment that provides disease-altering effects for MPN patients, but we don't understand *why it works* and we don't know *why it works for some patients and not others*. Understanding its mechanism of action for MPNs can lead to better interferon compounds and potentially new drugs that can change the prognosis for MPN patients.

We are excited and grateful for the opportunity to begin an international collaboration with MPN AA, and advance our cause for MPN patients around the world! ■



CLINICAL TRIAL HIGHLIGHTS



Research on Myeloproliferative Neoplasms has picked up heavily over the last few years. There are now several MPN Clinical Trials underway. A complete list can be found on our website at www.mpnresearchfoundation.org/Clinical-Trials.

The trials listed below may be of interest as they are currently enrolling patients:

Cyclophosphamide

Sponsor: MD Anderson Cancer Center
Contact: Stefan Ciurea, MD
713-792-8750, sciurea@mdanderson.org
Diagnosis Type: Myelofibrosis Patients

PU-H17

Sponsor: Samus Therapeutics
Contact: Kris Awerkamp, BSN, RN
kawerkamp@td2inc.com
Diagnosis Type: Myelofibrosis

Givinostat

Sponsor: Italfarmaco
Contact: Paolo Bettica, MD, PhD
p.bettica@italfarmaco.com
Contact: Silvia Di Tollo, PhD
s.ditollo@italfarmaco.com
Diagnosis Type: Essential Thrombocythemia Patients

IMG-7289

Sponsor: Imago Biosciences
Contact: 415-529-5055
info@imagobio.com
Diagnosis Type: Myelofibrosis

Luspatercept

Sponsor: Celgene and Acceleron
Contact: 888-260-1599,
clinicaltrialsdisclosure@celgene.com
Diagnosis Type: Myelofibrosis

Ruxolitinib + Navitoclax

Sponsor: AbbVie
Contact: AbbVie, 847-283-8955
abbvieclinicaltrials@abbvie.com
Diagnosis Type: Myelofibrosis Patients

SL-401

Sponsor: Constellation
Contact: Srdan Verstovsek, MD, PhD
713-745-3429
Diagnosis Type: Myelofibrosis

Oral Rigosertib

Sponsor: City of Hope Medical Center
Contact: Jorge Cortes, MD 713-794-5783
Diagnosis Type: Myelofibrosis Patients

Pacritinib

Sponsor: CTI BioPharma
Contact: Debra Jones, 206-282-7100
djones@citibiopharma.com
Diagnosis Type: Myelofibrosis

CPI-0610 +/- Ruxolitinib

Sponsor: Constellation Pharmaceuticals
Contact: Debbie Johnson, 617-714-0531
Diagnosis Type: Myelofibrosis

Ropeginterferon

Sponsor: PharmaEssentia
Contact: Allison Rosenthal
Rosenthal.Allison@mayo.edu
Diagnosis Type: Polycythemia Vera

Idasanutlin

Sponsor: Hoffmann-La Roche
Contact: 888-662-6728
global-roche-genentech-trials@gene.com
Diagnosis Type: Polycythemia Vera

CLIMBING TOGETHER

(FROM PAGE 5)

ever MPN patient program with MPN Advocacy & Education International in Melbourne, Australia.

The MPN AA recently joined forces with the MPN Research Foundation to partner in the MPN Interferon Initiative. This is an exciting opportunity – to be able to establish a partnership that stretches across the world for the benefit of MPN patients around the globe.

Years ago, somebody described to me a picture of our life's journey as

climbing up to the top of a mountain. As we are on our way up, there are people in front of us that lead the way and pass on experiences as they have gone before us. And then there are the people who follow behind us, and we are the ones who pass on our experiences and provide our support so that they too can reach the mountaintop.

That's how I sum up my journey and experience as a patient advocate. We learn, share, and join forces to support others along the way, with the aim of easing all of our burdens. ■

CATCHING YOUR PEACE: YOGA FOR WELLNESS



Jennifer Acker, Content Writer for MPN Research Foundation



Linda Reekie

For Linda Reekie, there was no hesitation about participating in a study examining the benefits of yoga for MPN patients. A polycythemia vera patient of seven years, Linda learned about a yoga study offered through the Mayo Clinic, in partnership with Arizona State, and viewed it as the perfect opportunity to potentially improve her symptoms without the use of more pharmacological intervention.

One of the most common symptom burdens of MPN patients is persistent fatigue, and for Linda this has

unfortunately been the case. Since her diagnosis, Linda has battled migraines, fatigue, and of course, the anxiety that ensues with a cancer diagnosis.

"I think most MPN patients get into both a physical and mental slump due to the symptoms of their disease and the side effects of the medications they are on. My slump has been both gradual and progressive. When the opportunity to be a part of this study came up, I jumped on it as though it were a lifeline," says Linda.

Although it had been forty years since Linda had last practiced yoga, she wasn't afraid to give it a try again. The incentive was different now. The idea of having more energy and feeling better without the use of another prescription drug was appealing enough to Linda. And so, in early 2018, she became a participant in an eight-week study on the benefits of yoga for MPN patients, conducted by Dr. Jennifer Huberty of Arizona State University in partnership with the Mayo Clinic. Linda participated in yoga and meditation classes online and made modifications to poses to fit her abilities. Over the course of the study, she noticed that both her energy level and quality of sleep were improving, stating: "I had read that meditation and exercise were beneficial for quality sleep, but I didn't realize how true that was until I participated in this regimented program."

Ryan Eckert, the research coordinator of this study, and his team measured participants' inflammation levels with blood draws.

"Participants' blood levels of certain markers of inflammation were measured at the beginning and end of the study, and we found a significant reduction in tumor necrosis factor-alpha, which is a biomarker associated with inflammation," Eckert says. "In MPN patients, there is research demonstrating that increases in biomarkers of inflammation, including TNF-a, are associated with a worsened overall symptom burden. This is the first study in MPN patients that

has demonstrated the utility of yoga for improving biomarkers of inflammation."

Since participating in the study, Linda is hooked on the benefits of yoga and meditation. And it works for her.

"In addition to keeping me limber, yoga allows my blood to flow better, which is so critical to PV patients," she says. "When I do not practice yoga or walk for a couple of days, I feel sluggish and tight. My head feels heavy and I don't feel clarity of thought. I know this is true because I have personally experienced the difference."

Linda isn't alone in reaping the benefits of this study. "The most common type of feedback we received during post-study interviews had to do with the benefits of the meditative component of yoga on sleep quality. MPN patients found themselves sleeping better and could turn to their newly acquired meditation skills to help themselves fall asleep when they were experiencing difficulties." Eckert says.

For Linda, participating in this study has been life-changing. She now meditates daily, and has even convinced her husband to follow her lead. Although practicing regularly isn't always easy for her, she's now committed to setting aside time to experience the healing benefits of yoga and meditation.

"As far as the mindfulness meditation is concerned, it reminds me to be more present in the moment and not stress about the possibilities that could be in my future. This is a huge benefit to patients with MPNs because the tendency is to worry about progression of our disease."

Living with PV presents its share of challenges for Linda, but some things have changed for the better. Slowing down with a gentle yoga flow and meditation was perhaps just what Linda, a naturally fast-paced native New Yorker, was in need of.

"I appreciate waking up each morning and welcoming a new day. I used to think that these sentiments were corny and trite. Now I get it. I enjoy everything that I used to take for granted before. I had to slow down somewhat. My senses are more heightened than they used to be, and I'm more aware of the taste of food, and the beauty and sound and smell of the beach. I love that!"

In living with an MPN, a new normal slowly evolves – a new balance that must exist in order to find peace. For Linda, learning how to catch that elusive peace and hold onto it, one breath at a time, has brought her world into balance. In turning to yoga, Linda has discovered a world rich in beautiful simplicity. A world bathed in both light and shadow. A world where cancer and breath coexist, just as naturally as the ocean and its waves. ■