



## MPN Quality of Life Study Group

*A Quarterly Report for MPN Patients*

### MPN Research Collaboration is Established:

#### A Big Step Forward for MPN Research

Dr. Mesa recently announced his transition from Deputy Director of the Mayo Clinic Cancer Center to Director of the UT Health San Antonio Cancer Center. Although Dr. Mesa had to say goodbye to a place that he has called home for the last eight years of his professional career, he has welcomed the exciting possibilities that exist for MPN research by continuing to collaborate with both Arizona State University and the Mayo Clinic. The collaboration between these three institutions (UT, ASU, and Mayo) will be essential in advancing MPN research. The collaboration includes research related to the use of complementary and alternative medicine to improve MPN patient symptom burden and quality of life as well as the advancement of pharmacotherapy to treat the MPN disease process. Dr. Mesa and all of the researchers that make up the MPN Quality of Life (QoL) Study Group are excited to continue to advance MPN research in search of better, more effective treatment.

### Share Your Story

Seeing as this is the inaugural issue of the MPN QoL Study Group Report, we would like to take a moment to announce our interest in engaging MPN patients in the development of this quarterly report. We hope to engage the MPN Community as it is often a place that many patients turn to when looking for strength and courage during difficult times. If you are a patient that would like to share your successes, hardships, triumphs, or lessons learned, we would love to share your story in the next issue of this report. Please contact Ryan Eckert at [rmeckert@asu.edu](mailto:rmeckert@asu.edu) with your story (200-300 words, written from your point of view, include a title).

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#### Special points of interest

- Collaboration between Arizona State, University of Texas, and Mayo Clinic promises exciting advancements in MPN research
- See pages 2-5 for exciting ongoing research in the MPN community and ways to get involved with some of this research

# The SIMM Study: Use of Integrative Medicine

## Study Background

Despite the improvements in the treatment of MPNs with standard medical therapy, both patients and providers are often left dissatisfied with unmet symptom burden needs. Integrative medicine, which is the use of complementary treatment methods in conjunction with standard medical therapy, is often turned to



in other cancer patient populations as a means to manage unmet symptom burden or treatment-related side effects. The Survey of Integrative Medicine in Myeloproliferative Neoplasms (SIMM) was developed by the Mayo Clinic in collaboration with Arizona State University and aimed to identify utilization patterns of integrative medicine and symptom burden associations among MPN patients. This survey was sent out to be completed by MPN patients in 2016.

*Integrative medicine interventions are associated with fewer MPN-related symptoms, reduced depression and fatigue, and higher quality of life.*

## Future Research

The findings of this survey provide support for more research that looks into the effects that integrative medicine has on MPN patients. There are ongoing efforts studying the effects of meditation and diet on MPN patient symptom burden and quality of life. Future issues of this newsletter will shed light into the findings of these studies once they have concluded.

## Results of the SIMM Survey

858 MPN patients completed the survey. The following summarizes the types of integrative medicine strategies that these patients utilize most often:

Activity	% That Reported Utilizing
Aerobic activity (i.e., walking, jogging, etc.)	51.5%
Massage	28.4%
Yoga	25.6%
Nutrition	25.2%
Strength training	23.8%
Meditation	18.9%
Breathing exercise	18.4%
Chiropractic	16.2%
Support groups	14.5%

It was also demonstrated that many of the integrative medicine strategies MPN patients utilized were associated with a lower symptom burden. The following table summarizes these associations:

Activity	Association
Aerobic activity	↓ total symptom burden, ↑ quality of life, ↓ depression, ↓ fatigue
Massage	↓ total symptom burden, ↑ quality of life, ↓ fatigue
Yoga	↓ total symptom burden, ↑ quality of life, ↓ depression
Strength training	↓ total symptom burden, ↑ quality of life, ↓ depression, ↓ fatigue
Meditation	↓ depression
Breathing exercise	↓ total symptom burden, ↑ quality of life, ↓ fatigue
Support groups	↓ total symptom burden, ↑ quality of life, ↓ fatigue

# Online Yoga for MPN Patients



*Principal Investigator on the MPN Yoga Study, Dr. Jennifer Huberty, participating in the filming of an online yoga video with Udaya Inc.*

## Results of the MPN Yoga Pilot Study

A total of 48 MPN patients completed the pilot study. Of those that completed, 27 participated in the yoga group and 21 participated in the wait-list control group. The average weekly yoga participation was ~41 min/week, a little less than the 60 min/week that was prescribed. Despite the yoga participation being a little less than anticipated, there were still many significant findings, including the following:

- (1) improvements in tumor necrosis factor-alpha (TNF- $\alpha$ ) from baseline to week 12 (TNF- $\alpha$  is associated with MPN symptom burden)
- (2) Improvements in depression over the course of the study
- (3) Improvements in quality of life from baseline to week 12

## Future Research

The work we describe here will support a grant application to the National Institutes of Health. This grant will secure funding for a large-scale, randomized controlled trial further investigating the effects of online yoga for MPN patient symptom burden and quality of life.

Additionally, based on interview feedback we have received from study participants in both the feasibility study and pilot study, we are currently implementing a meditation study in MPN patients. Many MPN patients told researchers that the meditation component of the yoga classes was helpful, particularly in helping to fall asleep at night. Therefore, we thought that it would be beneficial to study the effects that meditation has on MPN patients, especially considering that meditation has proven to be beneficial in other cancer patient populations.

## Study Background

In 2016, we completed our first online yoga study demonstrating that online yoga was feasible to implement and could improve fatigue, pain, anxiety, depressive symptoms, and sleep disturbance in MPN patients. Following this feasibility study, we sought to further examine the effects of online yoga on MPN patients with a pilot study, which recently concluded early in 2017. This pilot study was possible through a partnership between 5Arizona State University, the Mayo Clinic and Udaya Entertainment Inc. ([www.udaya.com](http://www.udaya.com))

Participants in the pilot study were randomized to a yoga group or a wait-list control group. Those in the yoga group were asked to participate in 60 min/week of online yoga for 12 weeks, whereas those in the control group were asked to wait 16 weeks prior to participating in yoga. Those in the yoga group were asked to complete blood draw and salivary cortisol measures at baseline (week 0) and post-intervention (week 12). All study participants were asked to complete symptom burden surveys at baseline, mid-point (week 7), post-intervention, and follow-up (week 16).

# Participate in Ongoing MPN Research

## Bone Marrow Transplant Survey

### Background

MPN researchers are currently working in parallel with the National Marrow Donor Program and the Center for International Blood and Marrow transplant registry to secure study funding from the Patient Centered Outcomes Research Institute (PCORI). The overarching goal of this study is to comprehensively understand the quality of life in advanced myelofibrosis patients to inform patients and caregivers of the therapeutic options they have. Very little is known about how available therapeutic options for advanced myelofibrosis (e.g., clinical trials, standard supportive care, and bone marrow transplantation) affect overall quality of life. Therefore, the purpose of this collaborative effort is to gain an insight into perceptions of current therapeutic options, particularly bone marrow transplant, as well as the effects that transplant has on quality of life.



*Dr. Jeanne Palmer works in the Bone Marrow Transplant Department at the Mayo Clinic in Scottsdale, AZ.*

### Participate in this Research Effort

MPN patients that have NOT yet received a bone marrow transplant are encouraged to participate in this survey. Additionally, all MPN patients and not just myelofibrosis patients are encouraged to participate as the purpose of this survey is to investigate MPN patient perceptions and feelings surrounding bone marrow transplant. If you are interested in participating in the first phase of this study, please follow the link to this active survey here:

<https://redcap2.mayo.edu/redcap/surveys/?s=mjAdrlxJtX>

The results of this survey will help researchers understand what factors are important to patients when considering a transplant and will help inform the design of a clinical trial that evaluates the trajectory of quality of life in myelofibrosis patients.

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## myMPN Registry

### Background

The myMPN Registry was created in 2015 by the MPN Research Foundation with the goal of helping people living with MPN change their prognosis. The conceptualization and refinement of this idea was a collaborator effort amongst MPN researchers around the world with many researchers on our team participating, including Drs. Ruben Mesa, Amylou Dueck, Holly Geyer, and Robyn Scherber. After years of hard work, the registry is now finally open for enrollment as of September 2017!

### How you can Participate

The myMPN Registry is a tool that MPN patients can use to record their demographic information, symptoms, and experience with different treatments and therapies. The data gathered from this registry will be used to understand more about MPN patients and the types of treatments that are working for specific patients and at specific times during the course of their disease course. If you are interested in enrolling into the myMPN Registry, please click on the link below to find out more information:

<http://www.mpnresearchfoundation.org/myMPN>



# The NUTRIENT Study: Effects of Diet on MPN Patients



## Background

It has been shown that inflammation plays a key role in the development of MPN patient symptom burden and the progression of the disease itself. Increased markers of inflammation have been linked with a greater symptom burden as well as a poorer disease prognosis. As the interest in complementary and alternative medicine increases, researchers in our collaboration are beginning to study the effects that these types of therapies can have on MPN patient symptom burden and disease progression.

## NUTRIENT Study

The NUTRitional Intervention among MyEloproliferative Neoplasms Trial (NUTRIENT) is an exciting ongoing effort led by researchers Dr. Robyn Scherber and Dr. Angela Fleischman that aims to explore the effects diet has on MPN patients, particularly on inflammation and symptom burden. This study kicked off with a survey of over 1100 MPN patients that aimed to determine nutritional needs and preferences. The following summarizes the major findings of this survey:

- Increased consumption of alcohol, baked goods, dairy, and pasta were all associated with a lower symptom burden
- Increased consumption of fast food, pre-made snacks, soda, refined sugar, and tacos were all associated with higher symptom burden
- 34% of patients endorsed using diet to help control symptoms and/or disease
- 96% of patients would be willing to restrict diet if it helped control symptom burden
- 98% of patients would be willing to restrict diet if it could help to stabilize their MPN disease course or reduce their risk of their MPN worsening

## Why Does this Study Matter?

This study is important because the survey data provides some insight into the dietary preferences that MPN patients have as well as some of the associations that certain dietary intakes have with symptom burden. Interview data we have recently collected confirms some of the findings in this survey, including the enthusiastic interest amongst MPN patients in learning more about how diet affects MPN and how to make better food and supplement choices. The findings from the survey and interviews are going to inform the development of a tailored dietary intervention for MPN patients, allowing our research team to better understand the effects that diet has on MPN patients. Once we understand the effect that diet has on MPN patients, certain dietary practices could be prescribed to patients in order to alleviate symptoms or to reduce inflammation. It is important to note that MPN patients should simply strive to eat a normal and healthy overall diet. Don't make any specific modifications to your diet until more is known and especially before discussing those changes with your physician.

## Contact Us

Please feel free to contact us with questions or comments you may have. We are always looking to improve the content and topics that are covered in this report, so please let us know if there is anything you would like to see in future issues.

Please contact Ryan Eckert at [rmeckert@asu.edu](mailto:rmeckert@asu.edu) with your questions/comments.



## What's Next?

One of the goals of this report is to share ongoing efforts to improve patient care and treatment. Those of us that make up the collaboration between University of Texas Health San Antonio Cancer Center, Arizona State University and the Mayo Clinic are excited to have so many great research projects ongoing and in the works. In future issues, look for us to continue providing you with updates on our ongoing efforts as well as important research in other fields that is important for the MPN patient community.

Furthermore, we are hoping to engage the MPN patient community through the sharing of patient stories. We think this will provide an excellent opportunity to inspire patients in the community to be actively involved in their treatment and to look forward to exciting therapeutic developments in the years to come.

I, personally, have been working on research projects within the MPN patient community now for over two years. I have had the pleasure of speaking to many different patients that have participated in our studies and am always inspired by the passion that patients have not only for improving their own life, but for helping to improve the lives of other patients in the community. For many, this is accomplished through participation in research, knowing that they are contributing to the development and advancement of treatment approaches and therapies. For others, participating in support groups or patient advocacy groups provides a positive outlet through which they experience personal growth and inspire others to grow as well. I am excited to be a part of such a strong community and to have the opportunity to help through the advancement of MPN research.

- Ryan Eckert, MPN Research Program Coordinator



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