



# MPN Quality of Life Study Group

## A Quarterly Report for MPN Patients

### A Great Beginning

The MPN QoL Study Group is excited to put forth our third issue of this quarterly report for MPN patients. It has been very rewarding to receive such positive feedback regarding our first few issues. MPN patients have found this report a useful resource for keeping up-to-date with emerging research and developing stories within the MPN community. Feel free to share this with anyone that you think could benefit from reading it, whether it is another patient, a friend, a caregiver, or a family member. We hope you enjoy this issue!

### What's New in this Issue?

In this issue, we cover a wide range of stories, including some recent updates regarding myMPN and some preliminary data that has been gathered from this registry. Participation in myMPN has seen a steady increase since its launch in September 2017, and there is already some exciting data that has come from it. We provide an overview of myMPN, its progress, and how you can get involved as a patient.

Next, we take a look at the first-ever meditation study to be conducted in MPN patients. Meditation has emerged in recent decades as a popular non-pharmacologic approach in other cancer patients, but much of the research has focused on meditation for breast cancer patients. Dr. Huberty, in collaboration with Dr. Mesa (UT Health San Antonio) and colleagues at the Mayo Clinic have partnered with Calm (a smartphone-based meditation application) to deliver a meditation intervention to MPN patients. In this issue, we discuss some of the preliminary participation and satisfaction data that we have gathered thus far.

We also discuss emerging research from Dr. Holly Geyer (Mayo Clinic) and colleagues exploring the relationship between pain and emotional health. We provide a link to a recent Patient Power talk that Dr. Mesa participated in, sharing his opinions on yoga for MPN patients. Finally, we share some of our favorite responses from patients that participated in our team's meditation study.

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#### Special points of interest

- Discover how myMPN is being received in the community
- Learn what the experts think of yoga for MPN patients
- Hear it from us first: What are some of the findings of the first-ever meditation study in MPN patients?

# myMPN: Updates on Patient Participation



myMPN was created in 2015 by the MPN Research Foundation with the goal of gathering data directly from MPN patients, or MPN patients’ stories, that can help inform clinicians and researchers of MPN disease progression and disease characteristics. This data will inform future research, treatment approaches, and our understanding of how MPN progresses. The conceptualization and refinement of

this idea was a collaborative 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. myMPN opened to patient enrollment in September 2017 and, since then, has seen some very promising participation amongst the MPN patient community.

*In 6 months, over 450 MPN patients have initiated their myMPN profile!*

## How to participate?

The MPN Research Foundation encourages patients to create a myMPN profile and enter in basic demographic and disease-related information. Once your profile is set up, you are encouraged to complete the “How do you feel today” survey on an ongoing and regular basis. Finally, you choose who can access your de-identified (not traceable back to you) information and data. To set up your profile, visit the link below:

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

As of February 2018, myMPN had a total of 454 US MPN patients that had initiated their online profile setup. Of those, 355 patients completed introductory demographic and disease-specific information. The table below highlights some of the data that has been gathered thus far from those patients that have entered their completed demographic and disease-specific information into their online profile. It is important to note that all of the data gathered from patient profiles is de-identified and is not traceable to any of the MPN patients that have a myMPN profile.

Variable	Percentage/Average
<b>Gender</b>	
Male	36.3%
Female	63.7%
<b>Diagnosis</b>	
Essential Thrombocythemia	45.0%
Polycythemia Vera	39.0%
Myelofibrosis	12.0%
<b>MPN-SAF 10-Item Score (0-10 possible range)</b>	
Essential Thrombocythemia	1.9
Polycythemia Vera	2.3
Myelofibrosis	1.9
<b>Most Frequent Therapies</b>	
Aspirin	75.5%
Hydroxyurea	42.1%
JAK Inhibitor	17.6%
No therapies	9.9%

## Yoga for MPN Patients: What do the Experts Think?



Our research group (MPN QoL Study Group) was the first to study the effects of yoga on MPN patients, with both a feasibility study of online yoga conducted in 2015/2016 and a pilot study of online yoga conducted in 2016/2017. Through our research, we have demonstrated that 1) online yoga is feasible to administer to MPN patients and 2) online yoga has preliminary evidence to suggest it can improve MPN patient fatigue, anxiety, depression, sleep disturbance, total symptom burden score, and inflammation.

Dr. Mesa has been instrumental in the collaborative development of this research, being Co-Principal Investigator on both studies. Dr. Jennifer Huberty (Arizona State University) has partnered with Dr. Mesa (UT Health San Antonio) and colleagues from the Mayo Clinic. Drs. Huberty and Mesa both have an interest in advancing this research as yoga is a potentially effective and easily disseminable non-pharmacologic strategy that MPN patients could use to reduce their overall symptom burden and improve their quality of life. So far, the research seems to be indicating exactly what Drs. Huberty and Mesa had hoped for. Drs. Huberty and Mesa are continuing to advance the research investigating the use of yoga for MPN patients with a grant currently in review with the NIH to conduct a nationwide randomized controlled trial of online yoga in MPN patients. Dr. Mesa has actively voiced his opinion of yoga for MPN patients and discussed the benefits of yoga in a recent video featured in Patient Power hosted by Andrew Schorr. To view this short (~5 min) video, click on the link below:

[MPN Patient Power: Yoga for MPN Patients](#)



### [Udaya.com](#)

Dr. Jennifer Huberty has conducted online yoga interventions in MPN patients with a long-standing partnership from Udaya.com, an online-streaming yoga platform. If you are interested in participating in online yoga through Udaya.com, here is how you can get started:

1. Meet with your physician to discuss your interest in participating in yoga. Your physician will be able to give you guidance on certain things to look out for or to avoid when participating in yoga.
2. Go to [Udaya.com](#) and set up an account. You can try Udaya.com free for 30 days before upgrading to a paid membership of \$9/month using the discount code: ASUxUDAYA (membership is normally \$12/month).
3. You can access the very same 12-week yoga prescription that we used in our prior studies by going to Classes > ASU Research > MPN Study.

# The Relationship Between Pain and Emotional Health



Dr. Holly Geyer of the Mayo Clinic in Phoenix, AZ

Pain is a frequently reported issue among MPN patients. More specifically, pain is often experienced by MPN patients as bone pain and abdominal pain (from enlarged spleen or enlarged liver). Researchers from our team (MPN QoL Study Group) have identified that bone pain and abdominal pain are two of the more common symptoms and two of the most severe symptoms that MPN patients experience. Additionally, “abdominal discomfort” is a common symptom that MPN patients would like to resolve. This is not surprising as the burden of symptoms experienced by MPN patients has an impact on overall sense of well-being, work productivity, activities of daily living, and overall quality of life. Furthermore, many of the symptoms experienced by MPN patients interact with each other. In the case of pain, it is possible that pain is affecting MPN patients’ emotional health and causing increases in stress, anxiety, depressive symptoms, etc. Researchers from our team have begun to delve into this relationship with some of their recent work.

*MPN patients that report severe bone pain or abdominal pain are more likely to report reduced or compromised emotional well-being and quality of life.*

## Info on Pain in MPNs

To learn more about different types of pain in MPNs, click on the links below to view short videos provided by Patient Power:

[Why does bone pain occur?](#)

[What type of pain is associated with PV?](#)

[Is spleen pain normal without an enlarged spleen?](#)

[Can MPN exacerbate arthritis?](#)

## Inside Story Headline

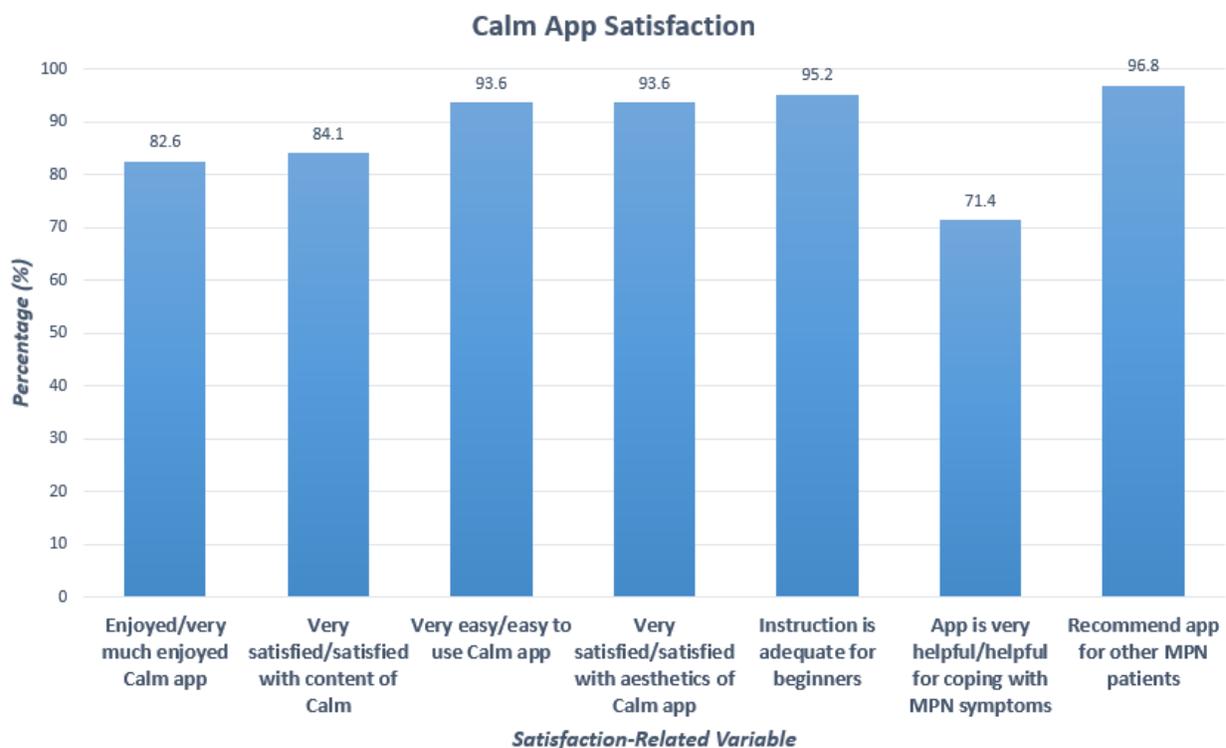
Due to the frequency and severity with which pain is reported among MPN patients, Dr. Holly Geyer (pictured on the left) and colleagues aimed to investigate the relationship between pain (abdominal pain or bone pain) and a variety of health indices, including emotional health and quality of life. In an abstract that is set to be presented at this year’s European Hematology Association Conference in mid-June in Stockholm, Sweden, Dr. Geyer demonstrates that MPN patients that report severe pain are more likely to report:

- ↓ physical functioning
- ↓ role functioning
- ↓ cognitive functioning
- ↓ emotional functioning
- ↓ social functioning
- ↑ irritability
- ↑ depressive symptoms
- Difficulty concentrating
- Difficulty sleeping
- ↓ Overall quality of life

These findings point to the need for more research that examines methods of screening for and managing pain among MPN patients as it may be related to other symptoms that patients are experiencing. Anxiety and depression rates are high among MPN patients, further supporting the need for methods of targeting pain as this may also indirectly improve anxiety and depression in MPN patients.

## Smartphone-Based Meditation for MPN Patients

MPN patients often cite increased levels of anxiety, depressive symptoms, sleep disturbances, and fatigue. Meditation is a complementary treatment strategy that has been shown to improve some of the negative long-term side effects of cancer and its treatment, including anxiety, depressive symptoms, sleep disturbances, and fatigue. However, none of this research has focused on MPN patients. Dr. Jennifer Huberty (Arizona State university), in partnership with Dr. Ruben Mesa (UT Health San Antonio) and colleagues at the Mayo Clinic, recently conducted the first-ever meditation study in MPN patients. This study is unique in that it was delivered entirely through a smartphone app called “Calm”. Participants in the study were asked to participate in 4 weeks of an educational control group followed by 4 weeks of meditation, which consisted of 10 minutes of daily meditation via the Calm app. This study is set to conclude this month (April 2018) as all study participants will have completed the intervention. We don’t have any of the pre-post changes in MPN symptoms at this time, but we do have some very exciting participation and satisfaction-related data to share, including what MPN patients thought about the meditation intervention and what impacts were reported. Overall, weekly meditation participation with Calm averaged ~68 min/week, which is very promising considering that we prescribed 70 min/week. The graph below shows the % of MPN patients responded positively to the Calm app intervention.



If you are interested in learning more about how to meditate using the Calm app, visit their website at [www.calm.com](http://www.calm.com). Here, you can sign up for a free account and have access to daily meditations (called the “Daily Calm”) and a basic introductory course called the “7 Days of Calm”. You can also sign up for a paid account and gain full access to the meditation app. Calm can be downloaded from the App Store (iPhones) or the Google Play Store (Androids).

## 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.



## Patient Reactions to Meditation App Study

I (Ryan Eckert) was fortunate enough to have been the one looking through the feedback that was received from MPN patients that participated in Dr. Jennifer Huberty's (Arizona State) meditation app study. I was amazed at some of the feedback that we received regarding the use of the Calm meditation app, with a few of the comments we received literally bringing me to tears. As someone who was involved in the research on a broader level (developing study materials, cleaning data, working on manuscripts, etc.), it was incredibly moving to hear some of the personal stories as to how the use of the Calm meditation app impacted the lives of some of our participants. The anonymous quotes below are a few of my favorites that I thought I would share the rest of the MPN community:

*"I truly loved having the opportunity to use this app; it is something that I hope to continue in the future. I used this opportunity to take time with my 7 year old daughter, and we did the meditation together. As a cancer patient, mom...it is important to spend quality time with my child(ren). This app helped me focus on what is important, and to take time to breathe, which is hard sometimes when quality of life is compromised. Thank you."*

*"During day 4 or 5's meditation, I was pleasantly surprised by the calming effect that was palpable physically through the meditation. :)"*

*"Thank you for helping me develop a good habit."*

*"I think that I started sleeping better, and I got back in the gym for the first time since being diagnosed."*



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