MPN RESEARCH FOUNDATION
CHANGE YOUR PROGNOSIS
UPDATE

VOLUME XX, NO. 1 SPRING 2021 PERIODIC NEWSLETTER FOR THE MYELOPROLIFERATIVE NEOPLASMS COMMUNITY

IT'S ALL RELATIVE: STEPPING TOWARDS PROGRESS

Kapila Viges, Executive Director

As I have come to discover more about the MPN Research Foundation and the MPN community, I am struck by the tenacity I see. Patients and caregivers are determined to seek out medical and scientific knowledge and to be part of the solution. Clinicians are committed to not just treating the symptoms, but to improving the quality of life for their patients. Biopharmaceutical companies strive to develop patient-centric approaches to bringing new therapies to light, and the advocates remain steadfast in their role as change agents.

Even while navigating the complexity of a global pandemic, it's inspiring to witness the enthusiasm and capacity of MPN thought leaders to solve both large scale problems and tedious-yet-burdensome struggles for patients. I suspect it's the passion and influence that Bob Rosen and his entrepreneurial co-conspirators nurtured within the MPN Research Foundation, that was inspired by the commitment of all of you, and which is now knitted into the fabric of the MPN community.

In immersing myself further in the history of MPNs relative to where we are today it strikes me that, though we have come so far in the past 20 years, we still have so much farther to go in addressing MPNs and improving therapeutic options for patients. It reminds me of when I was a kid trying to wrap my head around the relativity of space and size. In elementary school we were introduced to the infinite scale of the universe when learning about the distance to the moon, to other planets, galaxies, and beyond. Then in middle school, we jumped to the opposite end of the spectrum in comprehending the infinitesimal scale of particles of matter from molecules to atoms, to subatomic and elementary particles unseen by the eye.

The analogies are a bit of a stretch, I know. But, we stand where we are today, only relative to the depths of knowledge of disease biology and breadth of potential agents yet to be discovered. The scale needed in pursuit of more knowledge is driven by the heterogeneity of the diseases and of the patients – leaving so many questions yet to be answered.

Although today we have two approved therapies, and a remarkable ten clinical trials in Phase 3 (as noted in Lindsey's article on page 4) patients are still left with ambiguity and worry:

- Will my disease get worse?
- If so, when and how will I or my doctor know?
- What are my current options?
- How do I make the best decisions today not knowing what the future might be?

It is the fear of progression that looms for patients, and keeps clinicians asking the questions:

- How do I explain the potential for progression to my patients when much is yet to be defined?
- How can I anticipate which of my patients might progress and what predictors will inform who may or may not advance through the disease?
- Could my patients' response to treatments or other symptoms be telling me more about their disease that is not captured in the current clinical data?
- How can I advance the standard of care for all patients based on what I'm seeing in my practice?

Continued on page 2

MISSION

THE MISSION OF THE MPN RESEARCH FOUNDATION IS TO STIMULATE ORIGINAL RESEARCH IN PURSUIT OF NEW TREATMENTS — AND EVENTUALLY A CURE — FOR MYELOPROLIFERATIVE NEOPLASMS (MPNS).

WWW.MPNRESEARCHFOUNDATION.ORG

MPN RESEARCH FOUNDATION
CHANGE YOUR PROGNOSIS

OFFICERS AND DIRECTORS OF THE MPN RESEARCH FOUNDATION

Robert Rosen*
Chairman Emeritus

Barbara Van Husen
Chairman

David Boule
Treasurer

JoAnn Mason
Secretary

Ed Bartholemy

Jen Bealer

Stephen Berger

Lisa G. Bretones

Stephanie Cindric

Brandon Goetzman

Sam Klepper

Pam Murphy

David Ricci

Rebecca Shapiro

Jeff Shier

MEDICAL ADVISOR

Raajit Rampal, MD, PhD
Memorial Sloan-Kettering Cancer Center

SCIENTIFIC ADVISORY BOARD CHAIRMAN

Andrew Schafer, MD
Weill Cornell Medical College

MPN RESEARCH FOUNDATION

180 N. Michigan Avenue | Suite 1870
Chicago, IL 60601
communications@mpnrf.org
mpnresearchfoundation.org

UPDATE EDITORIAL STAFF

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

*Deceased

© Copyright 2021, MPN Research Foundation

Many thanks to our sponsor:

abbvie

IT'S ALL RELATIVE – CONTINUED FROM PAGE 1

In convening our stakeholders, patients, researchers, clinicians, and advocates over the past several years, the call to better understand progression and find new treatments has become even louder and more clear. To address these questions and continue to strive for a better armamentarium of therapeutic options, as well as a better quality of life for MPN patients, the next step lies in aggregating clinical data, at scale, across patient populations and disease lifecycles. This can drive new knowledge and, thereby, new therapeutic agents and regimens.

To that end, the MPN Research Foundation has embarked on a journey to assemble a network of thought leaders, innovative researchers, and committed biopharmaceutical organizations, to advance our knowledge of MPN disease progression. This journey, which has evolved over the last few years, has now led us to establishing a Progression Research Network.

We convened this group of thought leaders in September 2020, amidst the pandemic chaos, to deliberate the concept and dedicate resources to addressing progression. By December, the Board of Directors, with the counsel of scientific advisors, funded six new projects specifically addressing questions of progression.

+ **IDENTIFYING AND VALIDATING ACTIONABLE BIOMARKERS IN MPN PROGRESSION**
Ann Mullally, MD, Brigham and Women's Hospital, Boston, MA and
Rebekka Schneider, MD, PhD, University Hospital RWTH Aachen, Germany

+ **INTERROGATING THE SPATIAL ARCHITECTURE OF MPN DISEASE PROGRESSION**
Stephen Oh, MD, PhD, Washington University in St. Louis, MO

+ **TARGETING THE HMGA1 EPIGENOME IN MPN PROGRESSION**
Linda Resar, MD, Alison Moliterno, MD and Leslie Cope, PhD,
The Johns Hopkins University School of Medicine, Baltimore, MD

+ **CHARACTERIZING THE ROLE OF INHERITED GENETIC VARIATION IN MPN DISEASE PROGRESSION** – Vijay Sankaran, MD, PhD, Boston Children's Hospital, Boston, MA

+ **EVALUATION OF TP53 PATHWAY REGULATORS IN PROGRESSION OF MYELOPROLIFERATIVE NEOPLASMS** – Bridget Marcellino, MD, PhD, and
Ron Hoffman, MD, Icahn School of Medicine at Mt. Sinai, New York, NY

+ **MPN STEM AND PROGENITOR CELL CLONAL FITNESS AS PREDICTORS OF PROGRESSION**
Joseph Scandura, MD, PhD, Weill Cornell Medicine, New York, NY and
Ron Hoffman, MD, Icahn School of Medicine at Mt. Sinai, New York, NY

We are eager to see how these six projects unfold and perhaps lead us down a path to a programmatic study of progression. In the meantime, we remain committed to capturing the impact of our ongoing research programs. On February 1, we kept the momentum going by launching the 2021 MPN Challenge, our signature funding program. You can read more about that on the next page, and review the Request for Application and application online at this link: www.mpnresearchfoundation.org/Announcement-of-2021-MPN-Challenge-Grant-RFA. Please send inquiries to grants@mpnrf.org. ■

2019 MPN CHALLENGE GRANTS: ONE YEAR COMPLETED

Rick Winneker, PhD,
Director, Strategies & Research Operations

In late 2019, the MPN Research Foundation announced seven new MPN Challenge awards. These are two-year $200,000 grants. Below are a few recent highlights of research progress even in the face of this challenging pandemic.

ORIGINS OF MPN: UNDERSTANDING THE TIMING OF ACQUISITION OF DRIVER MUTATIONS AND DYNAMICS OF CLONAL EXPANSION

Jyoti Nangalia, MBBChir, Phd, Wellcome Sanger Institute

The objective is to understand the origin of MPN through elucidating the timing of acquisition of driver mutations over the lifetime of MPN patients. Over 800 clonal hematopoietic colonies from 10 patients with JAK2V617F mutations were sequenced. The mean latency between JAK2V617F acquisition and clinical presentation was 31 years. The results to date reveal how driver mutation acquisition very early in life, along with life-long growth and evolution, drive adult blood cancer, providing opportunities for early detection and intervention.

DISSECTING GERMLINE GENETIC RISK FOR MYELOPROLIFERATIVE NEOPLASMS

Vijay Sankaran, MD, Boston Children's Hospital

This study is focusing on understanding the effect of germline genetic variants on hematopoietic stem cell (HSC) self-renewal leading to increased risk of somatic MPN driver mutations and subsequent disease acquisition. A large-scale genome-wide association study was completed that identified 17 MPN risk loci, 7 of which have not been previously reported. Results indicate an enrichment for MPN risk variants within the accessible chromatin of HSCs and that increased MPN risk is associated with longer telomere length in leukocytes and other clonal hematopoietic states. Gene mapping studies have identified a few genes having possible roles in altering the function of HSCs to confer disease risk.

DETECTION AND INHIBITION OF MALIGNANT RNA PROCESSING DEREGULATION IN MYELOFIBROSIS

Catriona Jamieson, MD, PhD. UC, San Diego

This project is focused on RNA processing dysregulation as a biomarker of disease progression from MF to AML. Whole genome stem cell sequencing studies were completed on 50 individuals with and without MPNs at various stages of progression and whole transcriptome sequencing on HSCs and progenitor samples from young and aged normal bone marrow, MPN patients and secondary and de novo AML. The results suggest a possible malignant feedback loop involving RNA editing enzymes and STAT3 activation during transformation of pre-leukemic stem cells (LSC) in MPNs to LSCs in AML. This malignant feedback loop may be inhibited by JAK2 inhibitors or the RNA splicing modulator, 17S-FD-895.

A JAK2 V617F–DIRECTED T CELL RECEPTOR TRANSGENIC T CELL IMMUNOTHERAPY FOR THE TREATMENT OF MYELOPROLIFERATIVE NEOPLASMS

Aude Chapuis, MD; Fred Hutch

The project is focused on developing novel candidate T-cell receptors (TCRs) recognizing tumor specific or overexpressed self-antigens in MPN cells. Recent results suggest that targeting HLA restricted JAK2V617F epitopes may not be feasible so the current focus is on several transcription factors and other potential targets expressed in JAK2 V617F-positive MPN/AML cell lines. Currently, TCRs against several of these epitopes are being further characterized for specificity, potency and safety. A mouse model for human JAK2V617F MPN that can be used to evaluate human TCR adoptive immunotherapy is being developed. This project is funded in part by the Fred Hutch.

DYSREGULATED IRON METABOLISM PLAYS A PIVOTAL ROLE IN POLYCYTHEMIA VERA

Yelena Ginzburg, MD,
Icahn School of Medicine at Mount Sinai

The project goal is to understand how iron deficiency develops in PV, how red blood cell formation remains high despite iron deficiency and whether iron metabolism is differently regulated in JAK2 mutated erythroblasts. Studies to date demonstrate that persistent erythropoiesis occurs in PV mice despite iron deficiency and that normal mechanisms to prevent erythropoiesis in iron deficiency are dysregulated.

Furthermore, *in vitro* studies using stem cells from PV patients and healthy controls show that iron restriction in PV does not limit erythroblast differentiation or proliferation. Studies are ongoing to understand how these adaptations occur. This area of inquiry is already being exploited in clinical studies to reverse iron deficiency and limit erythropoiesis to eliminate phlebotomy requirements in PV patients.

TARGETING THROMBOPOIETIN SIGNALING IN THE MPNS

Alison Moliterno, MD,
Johns Hopkins University School of Medicine

MPN driver mutations ultimately activate the thrombopoietin (THPO) signaling pathway, driving excess megakaryocyte proliferation, platelet production, thrombosis risk and bone marrow fibrosis.

Continued on page 7

CLINICAL TRIALS PAVE THE WAY TOWARDS BETTER QUALITY OF LIFE

Lindsey Whyte,
Longitudinal Research Project Manager

In her cover story, our new Executive Director Kapila Viges mentioned ten Phase 3 clinical trials currently ongoing. Clinical trials are an essential step in the process of making new treatments available for MPN patients. It takes a long time from initial studies in a lab for a therapy to gain FDA approval, to be prescribed by a doctor and available at the pharmacy. The number of trials currently open for MPN therapies is unprecedented and now more than ever, it is important for patients to consider if a trial might be right for them.

For many years the focus of MPN research was identifying the underlying cause of the disease and new therapeutic targets that can be used to develop new treatments. With the FDA approval in 2011 of ruxolitinib and 2019 approval of fedratinib, there are now two approved therapies that inhibit the mutant JAK2 protein, one of the main drivers of MPN pathogenesis. Even if a patient has a CALR or other MPN driver mutation, these drugs may alleviate symptoms and disease burden.

Drug discovery and development is now shifting from exclusively JAK2 targeted therapies and toward therapies targeting additional genetic targets and other disease characteristics. These new potential therapies would either augment the JAK2 therapy or help patients who cannot tolerate or do not respond to JAK2 inhibitors. Some examples of these are inhibitors of BET, MDM2, LSD1, IDH2, PI3 Kinase and proteins that affect the tumor cell death pathway. A hepcidin mimetic is also in a clinical trial for PV patients who are phlebotomy eligible.

With each new class of drug tested, we learn more about MPNs and how the disease affects different patients. One size does not fit all. **On the next page** you will find a list of many of the trials ongoing for MF, PV and ET patients. Each trial has unique characteristics which were designed to answer different questions. For example, some trials are only open for patients who have tried, and failed, a certain therapy like ruxolitinib. Some trials are testing new therapies **in concert with** ruxolitinib. Some trials test not only how the drug affects the blood counts and severity of disease (often referred to as allele burden) but also measure how the drug impacts (positively or negatively) the severity of symptoms like fatigue, pain and pruritis (itching). Whereas drugs for MF formerly were held to the standard of how they impacted spleen volume compared to best available therapy, now potential MPN therapies are measured on that **as well as** several other factors.

You may be wondering what you can do with this list? It's a lot of information and the details of each trial are complex. The first step is to ask yourself if your current therapy is meeting expectations of keeping your symptoms in check and maximizing your quality of life. If your answer to those questions is yes, then please consider sharing this list with other patients that may be struggling with their current line of treatment. If you are a support group leader, please send a link to our website where this list is kept and updated on a quarterly basis. The URL is www.mpnresearchfoundation.org/mpn-clinical-trial-list.

If your answer to the question about how your current treatment is working is "not well enough," then please consider bringing this list to your next meeting with your doctor. Ask him or her if any of these trials might be right for you. This list is intended for reference purposes only – it is NOT medical advice. But with so many trial options available, right now, we want to be sure that you AND your doctor have a tool that helps start the discussion.

Each of the trials on the list has a trial number and additional information can be found on www.clinicaltrials.gov by searching the trial number. Many trials also have websites where patients, caregivers and clinicians can read about the drug and trial and determine if it might be right for them.

Finally, if you are participating in a trial – THANK YOU! Without the participation of healthy volunteers and individuals with the target disease, drugs would not be able to get through the approval process. ■

STAY INFORMED!

WE'D LOVE FOR YOU TO RECEIVE THIS NEWSLETTER DIGITALLY! TO RECEIVE A COPY IN YOUR INBOX, LET US KNOW AT COMMUNICATIONS@MPNRF.ORG OR SIGN UP ON THE WEBSITE.

MPN RESEARCH FOUNDATION

CONNECT WITH US ONLINE

MPN Research Foundation @MPN_RF

MPN CLINICAL TRIAL PIPELINE

MYELOFIBROSIS (MF)

PHASE	DRUG (SPONSOR)	TRIAL NOTES
3	**Momelotinib** (Sierra Oncology) NCT04173494	Symptomatic and anemic patients previously treated with a JAK inhibitor
3	**Fedratinib** (BMS) NCT03755518	High or intermediate risk patients previously treated with Ruxolitinib. Sub-study is combo with Luspatercept for anemia *
3	**Pacritinib** (CTI Biopharma) NCT03165734	Patients with very low platelets (<50,000) who have had no or limited exposure to a JAK2 inhibitor
3	**Parsaclisib + Ruxolitinib** (Incyte) NCT04551066	New PI3 Kinase inhibitor therapy for patients who have not previously used Jak inhibitor or PI3 Kinase Inhibitor
3	**Parsaclisib + Ruxolitinib** (Incyte) NCT04551053	New PI3 Kinase inhibitor for patients with suboptimal response to Ruxolitinib alone
3	**Navitoclax** (AbbVie) NCT04472598	Therapy that focuses on cell death pathway to be used in combination with Ruxolitinib vs placebo
3	**Navitoclax** (AbbVie) NCT04468984	Therapy that focuses on cell death pathway Navitoclax in combination with Ruxolitinib vs best available therapy
3	**CPI-0610** (Constellation Pharmaceutic) NCT02158858	New therapy based on BET-inhibition – trial available for patients without prior Jak inhibitor experience ("Jak naïve")
3	**Imetelstat** (Geron) NCT04576156	Therapy focused on overall survival in high-risk patients who have failed previous therapy
2	**CPI-0610** (Constellation Pharmaceutic) NCT02158858	New therapy based on BET-inhibition – trial available for patients with or without prior Jak inhibitor experience
2	**Thalidomide + Ruxolitinib** (MSKCC) NCT03069326	Addition of Thalidomide to patients responding sub optimally or progressing on Ruxolitinib

MYELOFIBROSIS (MF)

PHASE	DRUG (SPONSOR)	TRIAL NOTES
2	**Bomedemstat/ IMG-7289** (Imago BioScience) NCT03136185	New therapy for intermediate or high-risk patients focused on inhibiting LSD1
2	**KRT-232** (Kartos) NCT03662126	New MDM2 inhibitor therapy for higher risk patients who have failed a JAK inhibitor
2	**KRT-232 + Ruxolitinib** (Kartos) NCT03669965	New MDM2 inhibitor therapy for patients with a sub-optimal response to Ruxolitinib
2	**Ruxolitinib** (Incyte) NCT02251821	For patients who are preparing for or who have just had a transplant
2	**Tagraxofusp** (Stemline Therapeutics) NCT02268253	Previously approved therapy for a rare blood cancer, BPDCN. This trial is for higher risk patients who failed previous therapy and for transfusion dependence
2	**Luspatercept** (BMS/Acceleron) NCT03194542	Drug approved for MDS; this trial is for MF patients with anemia with or without transfusion dependence
2	**Navitoclax** (AbbVie) NCT03222609	Therapy for int. or high-risk patients given alone or with Ruxolitinib (trial ending soon)
2	**Ruxolitinib Phosphate** (MD Anderson) NCT01787487	Combination with azacytidine for high-risk patients who have been previously treated or newly diagnosed
2	**Ruxolitinib + Enasidenib** (Mt. Sinai) NCT04281498z	For chronic MF or blast phase MPN patients with IDH2 mutation
2	**Selinexor** (Karyopharm Therapeutics) NCT04562870	Previously approved for lymphoma. This trial for higher risk patients who have failed ruxolitinib
2	**Parsaclisib** (Incyte) NCT04551053	PI3 Kinase inhibitor for patients on a stable dose of Ruxolitinib needing improvement of response

*Fedratinib was approved for use by the FDA in August 2019 in MF. Current trials of Fedratinib are for further exploration of its efficacy, dosing and long-term impact.

MPN RESEARCH FOUNDATION
CHANGE YOUR PROGNOSIS

LEARN MORE AT MPNRESEARCHFOUNDATION.ORG

This list is intended for reference purposes only – it is NOT medical advice. Patients should consult their doctors on whether any of these trials may be appropriate for them. List updated December 20, 2020.

MPN CLINICAL TRIAL PIPELINE

MYELOFIBROSIS (MF)

PHASE	DRUG (SPONSOR)	TRIAL NOTES
2	**9-ING-41** (Actuate) NCT04218071	Anti-cancer & anti-fibrotic therapy given alone or combined with Ruxolitinib in advanced & poor prognosis patients
2	**Ilginatinib** (NS Pharma) NCT01423851	JAK2 inhibitor alternative for patients who have failed Ruxolitinib
1 / 2	**KRT-232 + TL-895** (Kartos) NCT04640532	New MDM2 inhibitor in combination with a new tyrosine kinase inhibitor, TL-895 for JAK inhibitor intolerant patients
1 / 2	**CPX-351 + Ruxolitinib** (OHSU) NCT03878199	For advanced phase MPN patients using Ruxolitinib plus a previously approved secondary AML therapy
1	**ABBV-744** (AbbVie) NCT04454658	New BET inhibitor therapy – several study arms including ABBV-744 alone, or in combination with Ruxolitinib, or with Navitoclax
1 /2	**APG-1252** (Ascentage) NCT04354727	New therapy that focuses on cell death pathway for patients who have progressed after their initial therapy
1	**INCB057643** (Incyte) NCT04279847	New BET inhibitor therapy for MF patients who did not respond to treatment or relapsed
1	**PU-H71** (Samus) NCT03935555	New therapy that focuses on tumor cell death pathway. This trial is evaluating safety and preliminary efficacy in combination with Ruxolitinib
1	**TP3654** (SDP Oncology) NCT04176198	New therapy focused on fibrosis reduction when combined with Ruxolitinib in higher risk patients
1	**AVID200** (Mt. Sinai, Formation Biologics-BMS) NCT03895112	New anti-fibrotic therapy for higher risk patients who have failed or stopped a previous therapy and not eligible for Ruxolitinib. Shows increase in platelets in some trial participants
1	**Pevonedistat** (Wash U) NCT03386214	New targeted anti-inflammatory and pro-tumor cell death pathway therapy combined with Ruxolitinib

POLYCYTHEMIA VERA (PV)

PHASE	DRUG (SPONSOR)	TRIAL NOTES
2	**Bomedemstat/ IMG-7289** (University of Miami) NCT04262141	New therapy focused on inhibiting LSD1 for patients that have failed one standard therapy. Focus on improving blood counts
2	**PTG-300** (Protagonist Therapeutics) NCT04057040	New iron regulatory therapy focused on phlebotomy eligible patients

ESSENTIAL THROMBOCYTHEMIA (ET)

PHASE	DRUG (SPONSOR)	TRIAL NOTES
3	**Ropeginterferon** (PharmaEssentia) NCT04285086	New interferon therapy compared to Anagrelide
2	**Bomedemstat/ IMG-7289** (Imago BioScience) NCT04254978	New therapy focused on inhibiting LSD1 for patients that have failed one standard therapy. Focus on safety and lowering platelets
2	**Ruxolitinib** (Incyte) NCT03123588	Ruxolitinib vs Anagrelide in patients resistant to or Intolerant of Hydroxyurea

The MPN Research Foundation has compiled this list of trials which are currently (as of December 2020) recruiting patients. Clinical trials are an important step in the process of discovering new treatments for MPNs. The decision to participate in a clinical trial is one you should carefully consider. It is important to discuss clinical trial participation with your family and your physician.

By definition, a clinical trial is a comparison test of a medication or other medical treatment (such as a medical device), versus a placebo (inactive look-a-like), other medications or devices, or the standard medical treatment for a patient's condition. The number of patients participating in a trial can range from as few as 30 to hundreds or thousands.

MPN RESEARCH FOUNDATION
CHANGE YOUR PROGNOSIS

LEARN MORE AT MPNRESEARCHFOUNDATION.ORG

This list is intended for reference purposes only – it is NOT medical advice. Patients should consult their doctors on whether any of these trials may be appropriate for them. List updated December 20, 2020.

This project will determine if a novel THPO silencer can reduce MF in JAK2V617F-positive murine models. The first major study has been completed and thrombopoietin levels were reduced by more than 60% in both normal and JAK2V617F transgenic mice and megakaryocytic hyperplasia was mitigated in both contexts. Ongoing studies will determine whether THPO silencing mitigates myelofibrosis, stem cell behavior and cytokine release in normal, MPN, inflammatory and leukemia contexts.

FEASIBILITY OF A PATIENT PREFERENCES-CONTROLLED STUDY OF ALLOGENIC HEMATOPOIETIC CELL TRANSPLANTATION (HCT) VERSUS BEST AVAILABLE NON-TRANSPLANT THERAPIES (BAT) IN PATIENTS WITH MYELOFIBROSIS (ALLO-BAT STUDY).
Vikas Gupta, MD, Princess Margaret Cancer Center

This clinical trial is now underway and details can be found at clinical trial.gov website – trial NCT04217356. Patients are enrolling and an online prospective database for collection of clinical information has been developed. Six other sites in Canada and Australia are in various phases of trial site initiation or seeking support. The goal remains to compare the survival and longitudinal quality of life of patients undergoing HCT as compared to those who chose best available non-transplant treatment for MF in the coming year and whether this feasibility study is sufficient to move forward to full clinical trials.

Despite a challenging year grappling with the pandemic, our researchers continued to make progress and we are as focused as ever to advance our research mission. On February 1, we issued the 2021 MPN Challenge, which will no doubt provide us with another round of promising projects.

As always, we are grateful to the MPN community and our funders who make these programs possible to advance the collective pursuit of new therapies and better outcomes for patients. The generous bequest of the **Estate of Susan Ann Protter** has provided an anchor for our research, along with the long-standing commitments of the **Robert Rosen Fund** in honor of our founder, as well as the **Mason and Gould Family funds**. ■

VIRTUAL FUNDRAISING

Host your own DIY event to raise funds for MPNs!

Participants of HikeMF 2019, an annual fundraising event organized by Julie Libon and Lori Small. All funds raised for the past five years have been donated to MPN Research Foundation.

Pamela Soto,
Director of Individual and Major Giving

Did you know that virtual events can help drive donations to support MPN Research Foundation?

Now more than ever, online fundraising events are a great way to create awareness and encourage charitable giving for the MPN community, all while staying safe during this pandemic.

Let's join together against the fight for MPNs. #TeamMPN members participate in running, hiking, community activities, art shows, bake sales, long-distance marathons, bowling events, a cycling event – you name it! It's easy to plan and your event's donation makes a difference in funding research advancing treatment options in these blood cancers.

THREE EASY STEPS TO JOIN #TEAMMPN

STEP ONE: COME UP WITH AN IDEA that sounds fun and doable for you! Is there an athletic event that you've been eyeing? Or what about organizing a bowling game for charity? You could plan a virtual cooking event, including family and friends in different parts of the country. Not able to get together with family and friends for a birthday celebration? Create an online event and pledge your birthday to MPNRF and have friends honor you with a donation to us. There are so many possibilities to help fund our work!

STEP TWO: LET ME KNOW WHAT YOU'RE PLANNING! Email your ideas to psoto@mpnrf.org. Once you have picked a date and concept for your event, let's start planning.

STEP THREE: CREATE YOUR OWN ONLINE FUNDRAISING PAGE – WE WILL HELP! You can easily create a personalized fundraising web page to tell your story and collect donations for the Foundation. We partner with you to set up all the details, including messaging, photos, and a donation link. Ask everyone participating in your event to share **#TeamMPN** on Facebook, Instagram and LinkedIn. After your event, we will share a recap, including the impact of your donations.

If you are interested, email psoto@mpnrf.org. And if you aren't interested in planning an event but still want to help fund our research, it's just as easy to give online at our website: www.mpnresearchfoundation.org/Donate-to-MPN-Research. ■

PATIENT CORNER

Matt Meiselman, ET Patient, age 30
Warren, NJ

My "pandemic" began 9 months before the rest of the world's, starting with a seemingly innocent conversation with my doctor at a routine check-up. In August 2019, I had a small lump on my neck that a dermatologist had dismissed as inconsequential, and which my general practitioner didn't think was a big deal. I'd been feeling normal, so aside from unusual news that the readings on my liver and thyroid were slightly off, nothing was wrong.

In the days that followed, it became very clear that something was in fact very wrong. On my third day traveling in Barcelona, I became unable to walk for more than a minute or two without being overcome with exhaustion. The more I tried to push myself to move around, the worse I felt. A tourist-vacation is the last thing anyone wants to be doing when they can barely keep their head above their shoulders. I stayed in bed for most of the remainder of the trip, with no indication that anything was getting better.

Upon arriving home, I saw several doctors, ruling out conditions that I could have never previously dreamed of. One doctor suggested that I might have lymphoma and said that I should be *very worried*, only to call me five minutes after I had left his office to say that he'd read the test results incorrectly, and I shouldn't worry.

Eventually an MRI showed that I had a blood clot in my abdomen, and after a BMB I was finally diagnosed with ET.

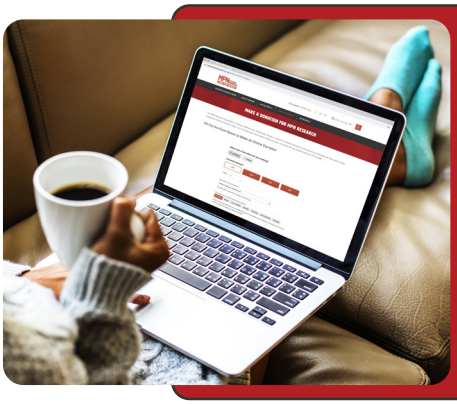
2020 has been difficult. Particularly in the Spring, everyone I know was struggling more than usual, and justifiably so. I could sympathize with it all, but I felt completely unable to empathize. Spring 2020 was when I finally started to feel physically and mentally well, and I felt profound gratitude during a time when everyone I knew was feeling the opposite.

By then, it only seemed rational to focus on how I could improve things, because it had become clear that improving myself was an absolute necessity. And over the past nine months I've been fortunate enough to be able work from home and spend time with my family, but the most significant change has been a total devotion to my own well-being.

One of the setbacks I've dealt with from ET was an inability to exercise. Every time I tried, I became more tired, and increasingly anxious and frustrated. This was leading to a substantial mental health crisis; frustration kept mounting and the best method I knew for combatting stress wasn't an option. However, I managed to turn this around early in 2020. I got my sleep schedule and diet tuned-in, started meditating and ultimately decided that I was going to push through the distress that accompanied moving my body. 2020 was clearly hard for me for reasons that don't align with the rest of the population.

My ability to deal with fatigue has dramatically improved, though it's still a struggle, and I've continued to go to further lengths to improve my short-term and long-term health. Learning how to implement these measures is bound to be a life-long process, and it's one that I feel I've fully embraced. I've made more personal growth this year than in the prior 28 years combined, and it's hard to imagine this could have happened without the bizarre combination of circumstances I was forced to deal with.

Trying to "make the best of a bad situation" is about as cliche as cliches get, but it also tends to be a way forward that many don't take seriously. I've chosen to use my personal challenges as an opportunity to get better. And I'm not nearly finished yet. ■



MAKE A DONATION TODAY

PLEASE HELP US ENGAGE THE MPN DIGITALLY. YOU CAN ALWAYS GIVE ONLINE WHEN YOU VISIT OUR WEBSITE.

MPNRESEARCHFOUNDATION.ORG/DONATE-TO-MPN-RESEARCH