MPN RESEARCH FOUNDATION
CHANGE YOUR PROGNOSIS
UPDATE

VOLUME XVI, NO. II FALL 2017 PERIODIC NEWSLETTER FOR THE MYELOPROLIFERATIVE NEOPLASMS COMMUNITY

ANNOUNCING OUR 2017 MPN CHALLENGE GRANTS

Through the MPN Challenge Grant, the Foundation makes annual grants for scientific work related to areas of unmet need in MPN research. Funding decisions are made after a committee of MPN scientists reviews over 40 applicants, after which the Foundation board of directors (comprised mainly of patients and patient family members) vote to approve the projects. The grants reflect our interest in understanding the effect of suppressing the JAK2 mutation specifically, and not the wild type JAK2 which is needed for normal blood production; immunotherapy; gene editing, specifically CRISPR cas9; inflammation's role in the disease; and overall interest in a better understanding of what is happening in order to identify other targets for development of better therapies for MPN.

THE PROJECTS FUNDED FOR 2017-2019 ARE:

Angela G. Fleischman, MD, PhD, University of California, Irvine

Project Title: Inflammation as a Driver of Clonal Expansion in Myeloproliferative Neoplasm.

The goal of this project is to determine how JAK2 mutated cells react to inflammation in comparison to normal blood producing cells. If inflammation plays a role to accelerate progression of MPN, this study would help define possible pathways to suppressing this inflammation.

James D. Griffin, MD, Martin Sattler (PhD), Sara J. Buhrlage (PhD), Ellen L. Weisberg (PhD), Dana Farber Cancer Institute

Project Title: Inhibition of deubiquitinating enzymes as a novel targeted therapy for JAK2-dependent myeloid malignancies.

The goal of this project is to find a strategy to specifically target the JAK2-V617F mutation while leaving the wild type JAK2 mutation alone. The existing JAK2 inhibitors don't differentiate between the wild type JAK2 and the mutation which is correlated with diagnosis of MPN.

Vivian G. Oehler, MD, Marie Bleakley, MD, PhD, Fred Hutchinson Cancer Research Center

Project Title: Characterizing myeloproliferative neoplasm neoantigens and T cell responses for therapeutic applications. The goal of this project will be to further our understanding of the potential of immunotherapy as an option for MPN.

Stephen Oh, MD, PhD, Washington University in St. Louis

Project Title: Leveraging NFKB Pathway Dysregulation for Therapeutic Benefit in Myeloproliferative Neoplasms. The goal of this project is to test the therapeutic potential of pevonedistat, which has been shown in a preliminary study in mice to reduce white blood cell counts and target the NFkB pathway which can become hyperactivated in MF and AML.

Rebekka K. Schneider, MD & Rafael Kramann, MD, Department of Hematology, Erasmus University Medical Center, Cancer Institute, Rotterdam, The Netherlands & Department of Nephrology, RWTH Aachen University, Aachen, Germany

Project Title: Functional and molecular dissection of the fibrotic transformation and clonal selection in myeloproliferative neoplasms. Using CRISPRCas9 gene editing techniques, the goal of this project is to determine whether the S100A8/S100A9 molecule contributes to the growth of bone marrow

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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.

MPN RESEARCH FOUNDATION

CHANGE YOUR PROGNOSIS

REFLECTION FROM A ROLLING STONE

By Robert Rosen, Founder

How would you judge our work as a patient, a caregiver, an MPN researcher, or a clinician?

In a strategy session several years ago, the Foundation established a "wishful thinking" goal of doubling our fundraising by 2017. At the time we were raising about $1.5 million a year. I had no idea how we were going to get to the higher plateau. Happily, we are now close. This year we are realistically expecting to raise a minimum of $2.5 million.

We'll need every penny to execute some of our long term plans. If you've been following all of the action, you know that we have expanded our research aspirations to outside of our annual grant program.

- We are building an ambitious progression marker project, a complicated multifactorial collaborative project to help us learn about markers of progression in order to direct future research.
- We have added myMPN, a registry with lofty ambitions.
- We are close to putting the finishing touches on our collaborative interferon project, another ambitious multi-year project that we hope will yield important insights on the mechanisms of action of interferon.
- We will be funding five more individual research projects, all aimed at understanding mechanisms such as:
  - Immunotherapy for MPN patients
  - A new targeted therapy for JAK2-dependent malignancies
  - A project focused on T Cell and neoantigen therapies
  - Other projects with potential translational benefit

You can see that there's no moss growing under this rolling stone. I believe that the Foundation has vitality, purpose and the resources to continue its good work.

But for you, a patient, can we say that we are closer to better treatments or a cure?

In our early days, we roughly patterned the MPN Research Foundation on the structure and work of the Multiple Myeloma Research Foundation (MMRF). MMRF is larger and has more resources, so it's not a totally fair comparison. But I'm a competitive person who can't resist comparisons.

The MMRF website states:
"The MMRF and MMRC, which is both the foundation and the research consortium...have helped bring in ten drugs to market in the time it normally takes for one. They currently have dozens of treatments in the pipeline including those that target genomic markers, immunotherapies, and antibodies and novel agents and mechanisms. Multiple Myeloma patients can now expect a survival of three times longer than before."

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CALLING ALL PATIENTS: MYMPN NEEDS YOUR DATA

By Lindsey Whyte, Project Manager and Michelle Woehrle, Executive Director

In September 2017, people with PV, ET and MF began sharing information about their journey with their disease in myMPN, our new registry that will gather vital patient-reported data for researchers. The "How do you feel today?" survey can be updated by participants on a daily basis. The survey records symptom data in real time, creating a longitudinal repository that will help us to identify potential triggers of advancement of the diseases, among other valuable information. Our health event form offers the ability for patients to record (as the name suggests) "events" such as hospital stays, thrombotic or bleeding events, transfusions, medication or diagnosis change, etc. As patients proceed through the surveys, there are opportunities to see how their experience compares to others in myMPN. Over 100 people are already participating regularly in the registry!

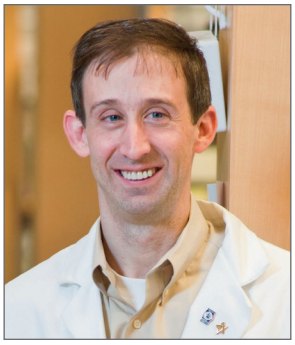
MPNRF's goal is to amass data that can be used to help patients. Until now, we have only anecdotes about how they feel. Without a safe, reliable, responsibly accessible means of recording and sharing data like myMPN, these experiences are siloed in patients' minds, their medical records and social media posts. Eventually, we'll also have the option for patients to securely share electronic health data from their medical providers if they choose to which will only strengthen the quality of the data researchers have to work with.

Dr. Ruben Mesa, formerly of the Mayo Clinic and who has recently been named director of the UT Health Cancer Center, is the chair of the myMPN Steering Committee. This body has guided the creation of the protocol and surveys and will help us determine strict data access policies to allow researchers to better understand unmet need for people living with PV, ET and MF without compromising patient identities. Our ongoing data collection will add to the body of knowledge generated by past surveys such as Incyte's Landmark Study. We hope to expand participation outside of the United States soon and translate the surveys to languages other than English.

Anyone with a diagnosis of PV, ET or MF who is over 18 years old is invited to participate today. Get started now at **www.mympn.org**! ■

MYMPN IS A VALUABLE TOOL THAT PATIENTS CAN USE TO MOVE THE PROCESS OF DRUG DISCOVERY AND DEVELOPMENT FORWARD. UPDATE YOUR PROFILE AT THE REGISTRY AS OFTEN AS POSSIBLE WITH ANY RECENT HEALTH EVENTS. THE DATA COLLECTED WILL PROVIDE RESEARCHERS INSIGHTS INTO THE PROGRESSION AND SYMPTOMS OF MPNS, RESULTING IN MORE EFFECTIVE THERAPIES REACHING THE CLINIC FASTER.

THE OLD VERSUS THE NEW: COMPARING THE ACTIVITY OF RUXOLITINIB VERSUS ANAGRELIDE IN ET



By John Crispino, Scientific Advisor

Anagrelide has potent activity against megakaryocytes and therefore has been a mainstay of therapy to reduce the platelet count in ET. Although the mechanism of action isn't clear, studies in the past two years suggest that the drug reduces megakaryocyte maturation and impairs proplatelet formation by dysregulating transcription factors and/or signaling pathways. Recently, a study suggested non-inferiority of anagrelide compared to Hydroxyurea. Despite this finding, in clinical practice, anagrelide is often a second or third option for ET patients who require cytoreduction.

The JAK inhibitor ruxolitinib targets cells with activated JAK/STAT signaling and may provide additional benefits beyond reducing peripheral blood counts. Based on the ability of ruxolitinib to reduce platelet count and the extensive clinical experience in myelofibrosis and PV, a number of clinical studies are underway to evaluate ruxolitinib in ET. In the setting of hydroxyurea resistance or intolerance, the evidence-base is not yet established regarding a second line therapy.

In the US, Incyte is sponsoring a Phase 2 study of ruxolitinib versus anagrelide in ET patients with who are resistant or intolerant to hydroxyurea (RESET-272; NCT03123588). With an estimated enrollment of 120, the study aims to compare the ability of ruxolitinib versus anagrelide to lead to platelet and white blood cell count control over one year. The study is open to individuals with ET with elevated platelets and WBC who are resistant or intolerant of hydroxyurea and who have not previously been treated with either ruxolitinib or anagrelide. A similar study, sponsored by the French Innovative Leukemia Organization and Novartis is underway in France (NCT02962388). These rigorous studies will provide important insights into whether targeting JAK/STAT signaling provides greater clinical benefit than selectively impairing megakaryocyte maturation. ■

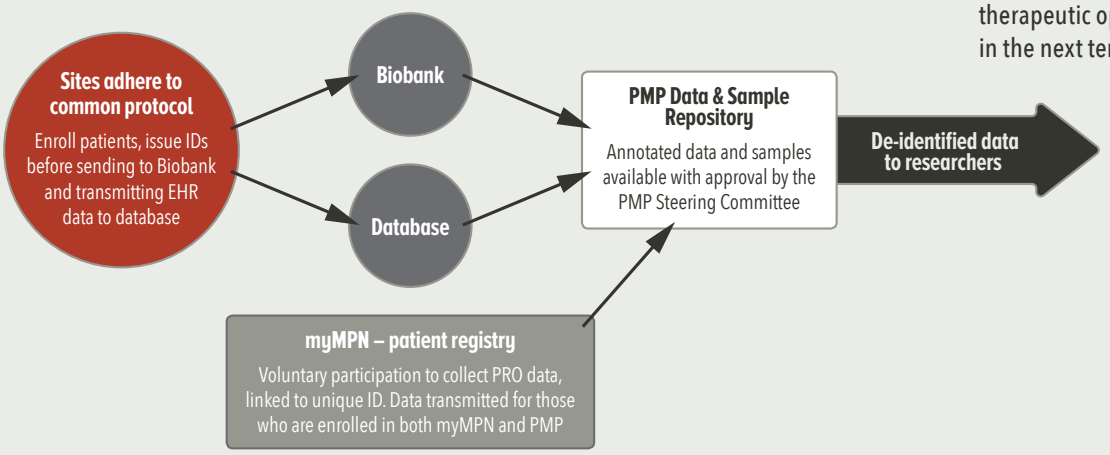
WHAT WE DON'T KNOW ABOUT PROGRESSION MIGHT KILL YOU — HERE'S WHAT THE FOUNDATION PROPOSES TO DO ABOUT IT

By Michelle Woehrle, Executive Director

In 2015, the MPN Research Foundation assessed the state of MPN research and the Foundation's relationship to funding science that is having a positive effect on the lives of patients. With only one FDA-approved medication developed since the discovery of JAK2 mutations, we were anxious to understand available prospects for breakthrough therapies for people with PV, ET and MF. And if there were none, what could we do about it? Although we know many genetic markers for MPN, including correlation with prognosis, we do not have a complete understanding of how the disease progresses to more acute and deadly versions. We need to know more about what is happening with people before they convert in order to identify a way to stop it.

> WE NEED TO KNOW MORE ABOUT WHAT IS HAPPENING WITH PEOPLE BEFORE THEY CONVERT IN ORDER TO IDENTIFY A WAY TO STOP IT.

MPN Progression Marker Project:



We took our idea to Srdan Verstovsek at MD Anderson. Srdan helped us identify how we might attack this, which is by a multi-year project that would collect samples and data from patients, using both their electronic medical records and their own self-reported experience with symptoms through our patient registry. Our scientific advisors John Crispino (Northwestern) and Raajit Rampal (Memorial Sloan-Kettering) rounded out the trio of advisors.

With this core team, we developed a five-year study during which time we'd enroll several hundred patients at multiple sites, collecting saliva and blood from them every 6 months. Samples would be tested for cytokines and screened for genetic changes, and all samples and data would be housed safely for subsequent analysis by qualified researchers who would be granted access to de-identified data by the Foundation. The goal: to identify markers, including genetic markers, that lead up to progression from ET/PV to MF in order to identify additional targets for development of therapies as well as better explain the mechanism by which this disease transforms, in the hope of stopping it.

We have buy-in from some of the most illustrious MPN researchers around the country who believe this will be essential to getting to the next big discovery for MPN. Far too often the patients we serve are left with incremental improvements in quality of life, and nothing to prevent transformation to a more acute or deadly version of the disease. We want to ensure that there will be transformational therapeutic options for people with MPN in the next ten years. If all of us working on behalf of patients pull together in the same direction, there's no reason we can't have the kinds of breakthroughs we are seeing in other diseases.

We will update you again as this project develops further. ■

MPNRF GRANTEE SNAPSHOT

In 2016 we began working with Richard Winnekar as a part-time research project manager to check in with our researchers. Richard determined whether researchers had delays starting their project (related to contracting, IRB approval, access to medication or samples, etc.) and how their progress against goals was evolving. Each grantee has specific aims they describe in their application, so that we have clear goals for each project.

We wanted to highlight progress on two of the five grants we provided continuation funding for in 2016:

One small step for MPN, One large step for cancer biology
Leonard Zon, MD, Boston Children's Hospital

Leonard was given $100,000 per year for three years, in order to create a zebrafish model for MPN to study the effect of the environment on genetic mutations that lead to MPN. Now that he created this model, the next step is to use it to confirm how genetic changes lead to manifestation of an MPN, or progression to MF from ET or PV. The beauty of the zebrafish model is that it can be used to demonstrate this in a relatively short amount of time. In addition to succeeding in creating a zebrafish MPN model, the data from this project supported an NIH program-project grant to David Scadden and Stuart Orkin, who are renowned stem cell biologists.

NUTRIENT Trial
Robyn M. Scherber, MD

In addition to the MPN Challenge Grant projects, we are also funding the **NUTRIENT (NUTRitional Intervention among myEloproliferative Neoplasms) Trial**, which will develop a diet rich in anti-inflammatory properties and enroll 30 MPN patients who will be checked for cytokines and JAK2 burden as well as symptoms. This study will be jointly conducted by Robyn Scherber (Oregon Health Sciences University), Angela Fleischman (University of California, Irvine) and Ruben Mesa (University of Texas, San Antonio). ■

FINDING HELP ACROSS THE HORIZON: WHAT GLOBAL COLLABORATION CAN ACCOMPLISH

By Bill Crowley, Director of Development

When the 2011 earthquake and tsunami hit Japan, causing a nuclear meltdown and more than 15,000 deaths, people all around the world donated their money and clothes in support. Every country in the world pitched in for Japan, and this help could not be underestimated.

I believe this is a really good example of global cooperation.

When crises occur, communities jump into action. People will accept any help. In the case of a cancer diagnosis, it's no different.

In 2013 the MPN Advocates Network was founded by representatives from three MPN groups in the Netherlands, Spain and the UK. Even though only three countries were represented, they had a cosmic objective: to create a global network of MPN patient groups. ***The goal of the network is to increase collaboration between MPN patient groups and provide a platform for international joint activity*** outlining the most promising treatment options for patients to discuss with their medical teams. An objective source of reliable information can be a tremendous benefit for MPN patients.

The network flourished in 2016 when the MPN Research Foundation joined the Advocates Network, along with organizations from Israel, Canada, Germany, Italy, Belgium and Switzerland.

In November of that year, the MPN Advocates Network convened the first global conference for MPN Advocates. "MPN Horizons 2016" was held in Belgrade, Serbia. Patient advocates came from Australia, Azerbaijan, Belgium, Brazil, Canada, Chile, Denmark, Finland, Germany, Hungary, Israel, Italy, Japan, the Netherlands, Norway, Poland, Serbia, Spain, Slovakia, Sweden, Switzerland, the UK and the USA.

The conference offered a unique opportunity for MPN patient representatives and advocates to discuss the issues facing MPN patients globally and share best practices. Discussions topics covered everything from MPN research and current and emerging therapies, to symptom management, advocacy and support.

Now we look ahead to the second MPN Horizons conference, to be held in Frankfurt, Germany October 27-29.

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CHANGE YOUR LIFESTYLE, CHANGE YOUR SYMPTOMS

By Kelley Goewey

Four years ago, I was diagnosed with ET. After three years of inconclusive testing, my first feeling was one of relief. I was happy to have a concrete answer, a name for what was wrong with my body. The rest of it hit me later. Incurable. Chronic. Chemotherapy. Cancer. For the first few months following my diagnosis, I would catch myself writing those words on any piece of paper that happened to be nearby.

I've had migraine headaches my whole life, but as my platelet count rose they increased in frequency until I was having constant, often debilitating headaches. My fatigue was unmanageable. I had bone pain and insomnia and I struggled with depression. Every doctor I saw for those first years postdiagnosis told me there was nothing I could do to impact my own health.

And they were wrong.

While lifestyle changes may not cure my ET, they go a long way towards helping me manage my daily symptoms. And most changes are not difficult.

- Staying adequately hydrated has been fundamental for me.
- Acquiring double daith piercings in my ears significantly reduced the intensity of the chronic pain I have lived with for the past seven years.
- My platelet count went down after I stopped eating red meat.
- Yoga has recently mitigated some of my bone pain and improved my overall health.
- Acknowledging and seeking treatment for my depression was particularly critical for me.

I'm finding doctors who are willing to partner with me in my healthcare, who see me as more than words on a chart. I'm figuring out my migraine triggers and my insomnia cycles. I can't control how the ET will develop, but I can control my exercise, hydration and attitude. Embracing my own agency in my health has negated that helpless fear that paralyzed me after my diagnosis. I want to be as healthy as I can be. ■

This is Kelley's personal experience. Any change in lifestyle or treatment regimen should be made in consultation with a licensed professional physician. Since receiving her Essential Thrombocytosis diagnosis in 2013, Kelley Goewey has learned to cope with her chronic illness through research, lifestyle changes, and intermittent blogging.

ANNOUNCING OUR 2017 MPN CHALLENGE GRANTS

(FROM PAGE 1)

fibrosis and loss of normal blood production. If confirmed, this presents a possible therapeutic target for drug development.

You can view a complete list of the research we have funded in our 15 years at www.mpnrf.org. Our ability to fund these projects relates directly to the interest of people living with PV, ET and MF and their friends and families interest in supporting the Foundation. If you like the work we do, please consider making a donation to support our research today. ■

REFLECTIONS FROM A ROLLING STONE

(FROM PAGE 2)

These are powerful words which highlight what's happening in the sister disease, but not in ours. Two years after the groundbreaking discovery of the JAK 2 mutation, we only have one new FDA approved drug, Jakafi. We really expected to have more by now. Maybe we were naive as to the complex process of drug development.

What we can say is this: Three to four years ago there were perhaps 6 or 8 major pharmaceutical companies and a small number of bio-techs working in our space. Today at last count there are over 35 large and small companies in our space developing novel treatments for MPN's. These companies have around 30 compounds in early stage clinical trials. We are working with them all.

Hope and good work are abundant. ■

FINDING HELP ACROSS THE HORIZON: WHAT GLOBAL COLLABORATION CAN ACCOMPLISH

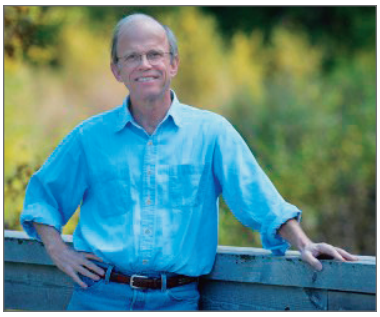
(FROM PAGE 5)

This year, the goal of the conference is to build capacity in MPN patient advocates organizations, to grow their skills and knowledge of how to work locally with their groups, improve their ability to meet the needs of their patient communities and strengthen their advocacy activities.

By encouraging cooperation at a global level between advocates, researchers, clinicians and healthcare organizations, MPN patients everywhere will have a stronger voice to change their prognosis. ■

THALIDOMIDE AND ME

By Landon Jones



"Thalidomide?"

The four syllables did a macabre soft-shoe dance deep into my memory. My hematologist had just asked if I would be interested in a clinical trial combining my current drug, ruxolitinib, with thalidomide.

To anyone who remembers the early 1960s, thalidomide was at the center of a pharmaceutical scandal – and a worldwide tragedy. Marketed by the German company Chemie Grünenthal as a sleeping pill and promoted as an antidote for morning sickness in pregnant women, it instead produced a devastating array of birth defects, most prominently malformed arms and legs. The photos were heartbreaking. Of 10,000 cases reported worldwide, an estimated 5,000 of the children survived, most born in 1960-61, almost all of them now in their late 50s.

I swallowed hard. I also knew enough about thalidomide to know that it is something of a zombie drug. It has returned to the market as a treatment for multiple myeloma, leprosy, Crohn's disease, and multiple sclerosis.

Now two hospitals, Memorial Sloan-Kettering in New York and MD Anderson in Houston, were organizing a clinical trial for 25 patients with progressive myelofibrosis. This was a lottery I had never expected to enter.

My doctor outlined my situation by drawing a sketch on a sheet of notepaper. I had been diagnosed with primary myelofibrosis in 2011. I started taking ruxolitinib – or "rux," as they call it – soon after it was first approved by the FDA a little later. But rux loses efficacy for many patients after a couple of years, and my blood counts seemed to suggest that was happening. Moreover, I had two genetic mutations associated with rux losing its effectiveness.

As the doctor explained, I could consider getting into one of the ongoing drug trials at various hospitals around the country – if they would take me – or enter the one he and his colleagues had recently started with thalidomide.

"What's the best-case result?" I asked.

He paused. "It's not a cure," he said. "But it can buy you some time."

> "IT'S NOT A CURE," HE SAID. "BUT IT CAN BUY YOU SOME TIME."

That night, as my commuter train passed through Newark, N.J., I gazed at the shells of long-abandoned buildings standing near the railroad tracks. I had seen these brick ruins thousands of times on my daily trips to New York but now for the first time they reminded me of the photos I had seen of Dresden after it was bombed in World War II. It was as if I had found a grim outer symbol for the way I felt on the inside – hollowed out and afraid.

But my doctor's words stayed with me. Could I buy some time? Otherwise, the next step for me could be a stem-cell transplant, a much scarier prospect.

Two weeks after the conversation with my doctor, and after having read a list of theoretically possible side-effects that was longer than Martin Luther's 95 theses, I signed the consent form and took my first thalidomide pill at bedtime.

There had been some surprises for me. One is that I pay for the drug myself (or my insurance company will). The drug company which makes ruxolitinib, Incyte, pays for the costs of the clinical trial. Another is that the study could last up to 36 months, though I can leave anytime I choose, if I wish. And the list of risks included the disquieting information that the drugs could affect how certain parts of my body work – namely, my "liver, kidneys, heart, and blood."

After taking the pill, I slept like a baby. When I woke up the next morning, I felt a palpable sense of relief. I was rested and refreshed (thalidomide is a sleeping pill, after all) and full of optimism. Maybe it was the power of suggestion, or maybe I had finally exhaled. Or maybe it was because I had decided to let my body be my friend.

Patient Update

The four months since the trial began have been heartening. My doctor is enormously pleased that my blood counts have all either improved or stabilized. A package of thalidomide arrives by overnight delivery every four weeks, but only after I answer a stern questionnaire attesting to my responsible sexual habits. Otherwise, I have returned to my corrupt habits of tennis and fly fishing. May that always be the case. ■

Landon Jones is the co-translator of Pia de Jong's new memoir about the year she spent following her newborn daughter's diagnosis with what was thought to be a terminal leukemia. It is called Saving Charlotte: A Mother and the Power of Intuition, and was published by W.W. Norton.

BEHIND THE MPN GRANT REVIEW PROCESS

By Emily Doering

I don't know about you, but I truly did not have a firm grasp on what all went into the process of grant money being awarded to a researcher. In my head I just thought "People with a lot more money than me arbitrarily give money to someone and hope for the best". Rationally, I knew that couldn't be all there was to it, but until recently I didn't have evidence to the contrary. That being said...

In June, I was given the opportunity to attend MPN Research Foundation's annual grant review session. I was one of several other patients in the Peanut Gallery, along with Foundation board members and other influential people in the MPN Community. The review board consists of eight members with a variety of expertise, opinion and backgrounds. Some are researchers, some are clinicians, some are involved in the MPN field, and some come from outside of it. The core goal for all was to make sure that the support offered by MPN Research Foundation grants was going to most worthy applicants.

That is no easy task – this year alone, 43 applicants applied after the Foundation sent out their Request for Applicants (RFA). That's 43 incredibly detailed, complicated grants, with multiple goals to be reviewed, and analyzed. Out of the 43 applications, 23 were reviewed by the review board. The three review board members are assigned the roles of primary, secondary, or tertiary reviewer. Once they complete review of each of their assigned grants, they rate the grants on a scale of 10.

At the round table, each primary reviewer presents the application and discusses the grant's merits or shortcomings. The secondary and tertiary reviewers then do the same, and the round table is open for discussion, questions or critiques before the reviewers grade the grants. Occasionally there is a large difference in the grades. When that happens, all of the reviewers have the opportunity to discuss the grant further, and determine if anyone wants to change their ratings.

Once all the grants have been discussed, and grades given, the grades are all totaled and a final ranking is assigned to all. The top contenders will be notified when grants are official.

I'd like to thank the MPN Research Foundation for allowing me to join them for this incredibly educational event. I look forward to hearing about the grant winners and their research over the coming months and years.

As always, you are your own best advocate. If you do not take care of yourself, who will?

Until next time,
Lina ■

The above article was re-purposed from Lina's blog, "The Life of a Vaguely Neurotic MPN Patient," which can be found at www.linampn.com. Find Emily on Twitter at @linampn.

THE GIVING SEASON WILL BE HERE SOON – ARE YOUR TAXES READY? HOW CHARITABLE GIVING CAN IMPACT YOUR TAXES

By Bill Crowley, Director of Development

Charitable giving during the holiday season is a recognized tradition all over the world. From donating to your favorite charity to volunteering at a soup kitchen, charitable giving is every bit as important to the holiday season as spending time with friends and family.

From a financial standpoint, charitable giving should be on your mind at the close of the year.

No matter what types of charitable giving you prefer, it's important to know the tax implications of your choices. Some types of charitable giving have different tax breaks than others and some may receive different types of deductions. Because charitable giving becomes a tax deduction before your income is actually taxed, you can lower your overall taxable income and possibly enter a lower tax bracket. Deductions generally rely on three factors:

- The recipient (qualified charities are the only ones that can receive a donation that is tax deductible, so gifting to your family will not give you a tax break);
- How you structure your donations; and
- The form in which you donate

Tax Implications of Various Forms of Charitable Giving

Cash donations: Usually, this type of giving is fully deductible for the exact amount you gifted. If you donate more than $250, you'll need a receipt. The receipt should display the amount of the donation, describe any property given, and indicate whether the organization provided any goods or services in exchange for the gift. If you gift the charity in cash rather than a check or credit card, you'll need to request some kind of bank statement or receipt from the recipient, no matter the amount.

Appreciated long-term assets: In most cases, you can deduct the full fair market value of long-term securities that you have held for more than one year. However, the deduction is limited to 30% of your adjusted gross income (AGI), compared to the 50% limit for donating cash to charities. Donating your stocks directly to a charity can offer more tax benefits and can lower your income tax bracket.

IRS Tips for Deducting Charitable Contributions

The Internal Revenue Service (IRS) cites many guidelines when it comes to charitable contributions that are tax deductible. If tax deductions are a part of your financial strategy for giving, here are a few tips:

Qualified charities: The IRS has guidelines on qualified charities. For example, if you want to deduct your charitable contribution, you must donate to a qualified charity. Additionally, you cannot deduct gifts to political organization or candidates.

Records to keep: Accurate record keeping is important. As you make contributions throughout the year, you must keep records to prove the types of donations are you making. Regardless of the amount you donate, you will need a record if you choose to make any deductions. ■

***Disclosure:** This information is provided to you as a resource for informational purposes only. This information is not intended to, and should not, form a primary basis for any investment decision that you may make. Always consult your own legal, tax or investment advisor before making any investment/tax/estate/financial planning considerations or decisions.*

HARVEY GOULD:
A SOURCE OF LIGHT ON THE LONG AND WINDING ROAD

By Lisa Gould Bretones

There must have been music playing when my dad, Harvey Lawrence Gould, came into the world. One of my earliest memories is his gravelly voice singing *Jet Plane* by the fireplace on a Saturday night. He lived his whole life like a folk song – a beautiful melody, purposeful lyrics, passion, rhythm and harmony.

When my dad was first diagnosed with myelofibrosis (MF), he was in his prime. He lived a full life: he traveled extensively with his wife Karen, he wrote and produced music, he rode and raced horses, he enjoyed a marvelous circle of friends, adored his three daughters and their expanding families, and he was at the pinnacle of his career as a litigator. Dad was a tall, handsome man with a magnetic presence, a witty charm, a booming voice, and a wicked sense of humor. He loved his work and was notably at his best when arguing a case in front of a jury, using the combination of his expansive intelligence, his skills as an orator, and his considerable wit. Only 55 years old when diagnosed, it was a huge shock and blow to be forced to give up his partnership at the height of his career, and to face the impossible idea that he may not grow old with his true love.

> WITH HIS SIGNATURE COMBINATION OF WIT, HUMOR, RAW HONESTY THROUGH BEAUTIFUL WRITING, HE GAVE HOPE TO COUNTLESS MPN PATIENTS AROUND THE GLOBE.

At first Dad was decidedly private about his diagnosis. He did not want it discussed outside of the family – he felt it was personal and private. However, as he began to explore his prognosis and treatment options, he saw how little the medical community knew about his disease. He interviewed various specialists, explored clinical trials, and conducted considerable research. He found that different doctors had different opinions; that certain medical centers and clinics were promoting different approaches, and that even the specialists couldn't keep up with the ever-changing science and treatment options. He also discovered that although there was information available, it was not centralized and it required adept searching. Dad quickly realized that those who did not possess his ability to dig through complex information, his inquisitive nature, and his access to medical teams in an urban center such as San Francisco, may feel even more lost than he did. This thought began to haunt him... and at the same time started to provide purpose.

So he began using his voice. He wrote a blog he called "The Long and Winding Road" on the MPN Forum website, a blog which became beloved to many in the MPN Community. Other patients followed the twists and turns of his journey, both medical and personal, to become informed about their own cases. His blog brought hope, comfort and strength to others coping with similar diseases. With his signature combination of wit, humor, raw honesty through beautiful writing, he gave hope to countless MPN patients around the globe. As one reader wrote, "You are giving hope to the discouraged and strength to the fainthearted." He took phone calls and wrote emails to other patients – people he had never met – often staying up until all hours of the night to ease the fear, confusion and overwhelm of his fellow MPN patients.

As I watched my dad battle his disease, I was often inspired. One favorite story illustrates his spirit: A few years after his diagnosis, Dad decided that he wanted to again experience the thrill of a fox hunt in Ireland. In a routine visit to his oncologist, Dad explained his intentions. Dr. Damon responded that this was a bad idea, because his enlarged spleen might rupture. But Dad persisted as he always did, and eventually Dr. Damon said, "OK, Harvey, but if you fall, just don't fall on your right side – your spleen will rupture and you'll bleed out."

Dad's response: "Ok, I'll be sure to fall to my left." And off they went to Ireland.

Although he surely had his dark moments, my dad simply refused to give in to the darkness of fear. Simply put: he fiercely chose life. He fought so hard to stay here because he loved and cherished this beautiful life. In my father's memory, I challenge myself every day to live in the moment, to find joy and music and laughter, to be there for others and to give them my love and attention.

It was fitting that, 14 years after his diagnosis with MF, we said goodbye to Harvey with music. My sisters and I sang to him one last time at his funeral:

> *The Leader of the Band is tired and his eyes are growing old*
>
> *But his blood runs through my instrument and his song is in my soul*
>
> *My life has been a poor attempt to imitate the man*
>
> *I'm just a living legacy to the Leader of the Band*
>
> – Dan Fogelberg

May his memory be for a blessing. ■

It is in my Dad's loving memory that my sisters (Jennifer Golbus and Ashley Gould) and I dedicate the Harvey Gould Fund, *which will support research efforts through the MPN Research Foundation, specifically targeted at identifying factors that lead to the rise and progression of myeloproliferative neoplasms.*

HARVEY GOULD FUND
MPN RESEARCH FOUNDATION

Lisa and Harvey at Lisa's wedding in 1999

Give me a kiss, show me a smile

Well, I'll be seeing you in a little while

And if you need a taste of home, close your eyes

Close your eyes and you will see a little piece of me

Always with you, like you're always with me

May the road rise up to meet you

May you dance and sing in the rain

May you hold me in the palm of your hand

Until we meet again

Lyrics from *Always With Me* by Lisa Bretones, in memoriam

To hear the song, please visit https://tinyurl.com/ybogpwqp

MOVING ON:
MPNforum Magazine TO RELEASE ITS FINAL ISSUE

By Ericka Cannaday, Operations and Outreach Associate

Since 2011, *MPNforum Magazine* (www.mpnforum.com) has been providing an informative and often controversial platform for diverse voices in the MPN community. Led by Zhenya Senyak, *MPNforum* has been an open source, MPN patient-supported, all volunteer publication that tackled tough subject matter such as how to manage symptoms, clinical trial reviews, caregiver coping mechanisms, patient-recommended hematologists and gene editing technology. The Forum has led initiatives for fatigue research, symptom reduction and inclusion of a Patient Advocate in clinical trials. More than a dozen papers in scientific journals include contributions from *MPNforum* editors and writers.

Senyak has announced that the December ASH issue will be the last for the magazine.

MPNforum is managed, staffed and funded entirely by patients and caregivers with volunteer participation from scientists, hematologists and healthcare providers. This online magazine has been one of the most followed independent international MPN patient and caregiver resources registering well over 600,000 page visits.

The MPN Research Foundation would like to thank all of the staff and contributing writers at *MPNforum Magazine* for their huge contribution to the MPN community over the past six years. It will certainly be missed!

Archives of articles and columns from past issues will continue to be available in the graphic catalog at https://mpnforum.com/building-tables/. ■

ZHENYA SENYAK, PUBLISHER/EDITOR OF MPNFORUM MAGAZINE

MORE THAN A DOZEN PAPERS IN SCIENTIFIC JOURNALS INCLUDE CONTRIBUTIONS FROM *MPNFORUM* EDITORS AND WRITERS.

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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.

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