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Executives:
Jennifer Gillette - LMSW
Arpita Gandhi - M.D., M.S. of Oregon Health & Science University (OHSU) Knight Cancer Institute
Mark H - myelofibrosis survivor

Operator: Thank you for standing by. My name is Tina, and I will be your conference operator today. At this time, I would like to welcome everyone to the Myelofibrosis: Let's Learn More from an Expert about this Rare Disease.

All lines have been placed on mute to prevent any background noise. After the speaker's remarks, there will be a question-and-answer session. To ask a question, press star one on your telephone keypad. To withdraw your question, press star one again.

It is now my pleasure to turn the call over to Jennifer Gillette. Please go ahead.

Jennifer Gillette: Thank you, Tina. Good afternoon, everyone. Thank you for joining us. I am the Staff Social Worker at the National Bone Marrow Transplant LINK, and I'd like to warmly welcome you to our call today. Today's program will focus on Myelofibrosis: Let's Learn More from an Expert about this Rare Disease.

We'd like to extend a special thanks to our generous sponsors, Blood Cancer United, Incyte, and Sanofi. We also thank our esteemed LINK partners for their continued support.

Today's program outline goes as follows. We'll have a brief introduction to the National Bone Marrow Transplant LINK, and then we will have our featured presentation from Dr. Arpita Gandhi, who is from Oregon Health and Science University, Knight Cancer Institute. And then we will also hear from a survivor, Mark of Portland, Oregon, a myelofibrosis survivor. We'll open up the call at about the midpoint to questions and answers, and then we'll conclude the call.

So for those who may not be familiar with the LINK, our mission is dedicated to helping individuals and families navigate the transplant and cellular therapy journey from diagnosis through survivorship. We do this by providing education, emotional support, and trusted resources.

Some of those resources we provide is a content-rich Facebook community featuring daily inspiration, educational updates, and survivor tips. We have wonderful educational books, referrals, and emotional support from a licensed social worker. We have our last Wednesdays of the month program where we connect fellow survivors with writing workshops, meditation, crafting, and an exercise program. We have our arts program. We have our Lunch & Learn programs like you're on today, featuring healthcare professionals alongside patient and caregiver voices discussing transplant, CAR T-cell therapy, survivorship, and related topics. We have our Marrow Master's program; currently, we're at about 45,000 downloads. Those are very popular and are on all types of topics related to BMT. We also have educational webinars in the fall. Our Coffee Klatch support group. Our peer support program, where you can be connected with trained peer support volunteers. And our Celebrating Second Birthdays program, recognizing your transplant anniversary with personalized birthday cards and honoring survivorship milestones. Our Survivors Thrive Book Club, and more. So, if you feel like you need some more support, please reach out.

A couple of housekeeping items today. Before we begin our program, I ask that when it comes to our question portion, if you could try to be concise and ask one question at a time and re-enter the queue, just so we can try to get to as many people as possible. We also will do our best to address as many questions as possible, but due to limited time, that may prevent us from answering all of them. Also, please remember that this program does not provide individualized medical advice. You can take this program to stimulate conversation with your healthcare team, but we do not provide any individual medical advice on this program.

So that being said, it is now my pleasure to introduce our featured speaker, Dr. Arpita Gandhi. Thank you so much for being here.

Dr. Arpita Gandhi: Absolutely. Jennifer, thank you for having me and Mark. This is a really special program and I'm delighted to be here.

I am Dr. Arpita Gandhi. I'm a bone marrow stem cell transplant physician in the adult program at Oregon Health and Sciences University at Knight Cancer Institute in Portland, Oregon. I have been here for some time, and I will start by saying that I absolutely adore Oregon. And Oregon has a way of helping you grow. And I will tell you a bit about my journey, which will be an introduction to today's program.

And let's get started. So when I went to my medical school and medical training, I wanted to be a stem cell transplant physician. And through that training, I focused on myeloid malignancies, particularly acute myeloid leukemia (AML) and myelodysplastic syndromes (MDS). However, as I started practicing, in the early part of my career, it occurred to me that there is a special group of disease, which is rare, somewhat hit or miss in terms of how frequently a transplant physician gets to see these patients for consultation. And that's what it was fascinating. It occurred to me that there's a chance this particular group of patients can benefit from special attention from allogeneic stem cell transplant physicians with more of a multidisciplinary care.

And I started my journey several years ago to focus on myeloproliferative neoplasms (MPNs), specifically myelofibrosis. So at OHSU, at Knight Cancer Institute, we started, and I led the program to incorporate myelofibrosis with a special niche in allogeneic stem cell transplantation.

To get us started on today's conversation, we will start by discussing disease biology. We will talk about what patients feel, how they're doing, what sort of resources are required in diagnosis, as well as in the treatment of myelofibrosis. We will cover briefly what agents are available commercially, so FDA-approved agents. And we will then dive into when and how allogeneic stem cell transplantation can be incorporated in patients' treatment paradigm. And today we have one of my very special patients who will share his journey to stem cell transplantation and in the post-transplant setting.

So myelofibrosis, many of you on the call, if you are personally diagnosed with this disease or know someone who has this diagnosis, you are aware that these patients initially have…can start out with minimal symptoms that may or may not get recognized right away. These symptoms are generally inflammatory. Patients can have fevers, night sweats, body aches, etc. And one wonders why patients develop these symptoms. And the reason for that is that myelofibrosis is a highly inflammatory disease. So you end up feeling like you have a flu syndrome. And this occurs because patients with myelofibrosis have a disease pathway caused by certain mutations in majority of the patients. Not every patient with myelofibrosis has mutations, well-known mutations, such as JAK2, MPL, and CALR. But these mutations cause activation in the JAK-STAT pathway that results in an inflammatory state. This causes a proliferative biology where patients can have increased cell formation. And then there is natural course of the disease, which we will discuss.

So to actually explain myelofibrosis during my patient consultations, what I end up doing is I use the analogy of a vegetable garden. So for example, tomato plants-so it's summer or it's spring, and you would like to have a tomato garden, and what would you do? You need a pot, you need soil, you need seeds. So the seeds in this analogy are stem cells. The soil is the actual bone marrow, and bone marrow is where you get the nutrition. That's your microenvironment in your marrow, the soil. And the pot is the bone. So we have the pot, we have soil, and we have seeds, and seeds are the stem cells. So, in our seeds, which are the stem cells, these mutations can cause the hyperproliferative state. And the hyperproliferative state then causes the… along with the inflammatory state, can result in fibrosis of the marrow. And the way I like to explain that is it's a scarring of the marrow that is classically defined on the bone marrow biopsy. The question comes about: “Does every patient with myelofibrosis need a bone marrow biopsy?” It's mostly yes. In order to make a pathologic diagnosis of myelofibrosis, you would have to do a bone marrow biopsy, which requires a review. By the way, the bone marrow biopsy is actually done at the bedside. So it's not a big procedure. It doesn't have to be an OR admission. It's done in the clinic. It's a relatively safe procedure.

And this bone marrow biopsy is given to the pathologist, who reviews it under the microscope and describes the features of what they're seeing in terms of what levels of cellularity the marrow has. And the most important aspect of this is: “Does the patient have fibrosis?” And that is determined by reticulin staining. That comes in the grades, three different grades. Zero would be no fibrosis; Grades 1, 2, and 3. One is the lowest; three is the highest. When you have the highest level of fibrosis, it's very likely that this has been going on for quite some time, or it is, and it's somewhat of an advanced-stage disease. And I use the word somewhat carefully because myelofibrosis is highly variable, and it's important that you don't take away big conclusions from the word advanced-stage disease here. And it's best to discuss if you have a bone marrow biopsy that says Grade 3, it's best to discuss that with your oncologist to really understand the level or how advanced is your disease to be discussed with your oncologist. But generally speaking, when you have Grade 3 fibrosis, it's very likely that you have- your seeds are then supposed to… the seeds in our analogy, they need good soil; they need good nutrients. And they need good chemical signaling in your marrow to make cells. And in our case, in human body, stem cells go on to make red cells. So that's what gives you…that's required for oxygenation in our blood circulation, which gives you energy. So if you don't have red cells, you have a lot of fatigue, which is what many myelofibrosis patients can experience.

Platelets. Platelets are required for clot formation. And so if you have a nick or cut due to an accident, you need platelets to form a nice blood clot so you don't bleed extensively. And then you have a white count. So white count, or the WBC on your blood check, tells us what level of immunity you have. So white cells are immune cells. They help us fight infections. So when there is fibrosis, especially when there's advanced-stage fibrosis, there's likely not enough great nutrients or not great signaling present in the marrow for the stem cells to go on to make cells to then produce three different types of cells in our blood. This can result in low cell count or what we call cytopenias. These cytopenias then make patients feel extremely symptomatic. Like we discussed earlier, patients can have fatigue, and because it's an inflammatory disease, it can give sweats, bone aches. Furthermore, the cytopenias and the high grade of fibrosis: if you don't have any space to create cells, what will happen? That's an important question to ask.

The next step in our human body is that it causes, it results, this process results in what we call extramedullary hematopoiesis (EMH). Many patients then go on to develop hematopoiesis, the process of making blood cells into the spleen. So the spleen starts to get bigger. The spleen is an organ that sits below the rib cage, on the left side of your abdominal cavity. And when the spleen gets bigger, patients end up having more symptoms, abdominal pain, it pushes on their stomach, they get full really easily. So the amount of food they are eating, perhaps if you were to eat, for example, one bowl of pasta for lunch on a routine basis, maybe you can only eat half a bowl of pasta. This is what we call early satiety, and that's a common symptom that patients experience with myelofibrosis. And the spleen plays a big important role and is a big conversation for me in my transplant clinic, because everything that happens in the pre-transplant setting impacts outcomes in the post-transplant setting.

So, patients, there is a fair amount of data that would suggest that having massive splenomegaly will then have a potentially negative impact on stem cell transplant outcomes after the transplant has been done. Then question becomes, “Who needs transplant?” “How do you really go about stem cell transplantation in patients with myelofibrosis with and without splenomegaly?” So we are going to focus our conversation more on patients who meet the indications for transplant and are suitable for transplant. So, for example, a patient is presents with a low cell count, they undergo a bone marrow biopsy, we covered that. Now the bone marrow biopsy shows the high-grade reticulum fibrosis. The patient has splenomegaly. The bone marrow biopsy showed diagnostic features for myelofibrosis. What happens next? Well, the patient is either already being seen by an oncologist or now gets referred to the oncologist. The oncologist will likely make sure that the bone marrow biopsy had certain tests completed, such as cytogenetics or looking at the chromosomes, and also mutation panel. Mutation panels can be extensive or limited, particularly covering the classic mutations, the JAK2, CALR, MPL, and other high-risk mutations that are known to cause advanced-stage disease or progression to the next level of the disease. This information together will help us provide a prognosis in patients.

So there are different tools. We have what we call the Dynamic International Prognostic Scoring System (DIPSS). In brief, it is known as the DIPSS Plus for myelofibrosis. And we also have a novel risk-stratifying score, which is MIPSS. And MIPSS70, M-I-P-S-S-70, uses molecular information, which then helps a certain patient population who may get upstage. So if you use MIPSS, there's a chance that if you have high-risk mutations, you may have an actual high-risk disease versus in the DIPSS, which does not use the novel approach of using mutations, you may end up being an intermediate-risk patient. Now, as from a patient standpoint, it's important to know outcomes that could be particularly different for intermediate risk versus high risk. Especially if you are a low-risk patient and happen to have a high-risk mutation, it's a really good conversation or an important conversation to have if you're an oncologist. So, I think the point I would like to emphasize is that you need... In 2026, it is important to know molecular information about myelofibrosis. Molecular information helps us identify and accurately risk-stratify patients for how they are going to do in the short-term and long-term, particularly the risk of progression to acute myeloid leukemia. Having said that, anyone who has intermediate-2 or high-risk disease meets the indication for an allogeneic stem cell transplant consultation. Prior to having an allogeneic stem cell transplant consultation, patients are usually started on JAK inhibition to control symptoms.

So what is JAK inhibition? We spoke about different mutations. We talked about JAK2, CALR, and MPL mutations. So JAK inhibition is done using JAK inhibitors such as ruxolitinib, momelotinib, pacritinib, and fedratinib. Ruxolitinib is a well-known, well-established agent that we have been using in myelofibrosis since 2012-2014. It was FDA-approved for myelofibrosis patients who have lots of symptoms and also spleen. So it's really good at controlling symptoms for patients that are due to the inflammatory state. And there is also really good at controlling the spleen size or shrinking the spleen. A normal spleen size is anywhere in the range of 10-12 centimeters in one dimension.

And many of our patients, especially for me in the stem cell transplant clinic, I have patients who have spleen size that is greater than 20 centimeters. And as you can imagine, a spleen or a big balloon sitting in your abdomen can be quite symptomatic and uncomfortable. So having these agents, these medicines that can help shrink the spleen is actually really, really important for patients' quality of life. And then to determine how to successfully conduct stem cell transplantation. So we're really happy as stem cell transplant docs that we have different agents to help our patients feel better and shrink the spleen in the pre-transplant setting.

So to quickly jump to stem cell transplantation, and then I'll hand it over to Mark. Stem cell transplantation consultation covers lots of different topics, but the most important one is time to transplant and complications of transplant. Historically, large registry datasets would suggest that myelofibrosis patients after stem cell transplantation have an early risk of complications and mortality in the first one year. That is historical. And the outcomes in the contemporary era, or now in 2026, they appear to be significantly better. And I say significantly more on a subjective level, but that level of data is being analyzed. And in my practice, I would say patients are doing better, significantly better than they would have approximately 10 years ago. And that is due to improved strategies to stem cell transplantation and prevention of complications such as Graft-versus-host disease (GvHD). We use better chemotherapy regimens for stem cell transplantation and better strategies to prevent stem cell transplant complications. In order to proceed to transplant, your transplant team would talk to you about identifying donors. Currently, patients' outcomes are best noted with fully matched donor transplants when compared to mismatched donor transplants. So that's an important piece of information to take away. Time to transplant is an ongoing conversation with patients and the transplant doctor. And having an excellent caregiver plan after a stem cell transplant is also critical in patients with myelofibrosis or all patients who undergo stem cell transplantation.

So I think I will pause here. I would like to hand this over to Mark, who has undergone stem cell transplantation and will now share his journey. Mark, I would defer to you on where you would like to start in terms of your journey.

Mark H: Sounds good. Thanks, Dr. Gandhi. I think I'll pick up where my diagnosis started and then walk through the process of making a decision, getting the diagnosis, and then ultimately where I am today in terms of recovery.

I was originally diagnosed with Dr. Gandhi in the fall of 2024, but there were a bunch of things that led up to that. My diagnosis stemmed from being monitored for a bunch of years, actually since about 2005, for a disease called essential thrombocythemia (ET), which was thought to be a precursor to be getting myelofibrosis. So they call my form of myelofibrosis secondary myelofibrosis because it came after ET. And as a result of having that first blood disorder, that essential thrombocythemia, I was being monitored about every three months for blood work. But for close to about 20 years, I had ET; other than the initial symptoms, after I was treated on medication, I had very, very few symptoms.

So I was very successfully treated. Starting in the spring of 2024, my oncologist started knowing some changes in my blood work, some anomalies, and he referred me to Dr. Gandhi. And Dr. Gandhi quickly ran me through a bunch of tests in the summer of 2024, which ultimately led to that diagnosis of myelofibrosis. And at the time, If I remember correctly, Dr. Gandhi, you may be able to correct me, but I think at that time I was either medium or high risk on the myelofibrosis stratification tools.

Dr. Arpita Gandhi: You were intermediate, correct, yes.

Mark H: Okay. Back when that happened, back at the time of my diagnosis, I actually didn't notice much in the way of symptoms. It was my oncologist who referred me because of changes in my blood work. But as the months went on and I had time to think more about it, in retrospect, what I thought was sluggishness from having fallen off of my workout routine and maybe a little bit out of shape was probably fatigue from being anemic. And some unintentional weight loss was probably a byproduct of an enlarged spleen, which caused me to get full faster than I had been getting full. And I think Dr. Gandhi mentioned that in her comments.

At the point of the diagnosis, Dr. Gandhi said that I didn't need a transplant right away, but she thought I probably would need one at 18 to 24 months. And of course, as this research was going on, I was getting diagnosed or going through tests; I was doing a ton of research on my own about the disease and disease treatment options. And frankly, I was a little scared of getting a transplant. But right away we started being on one of the drugs that Dr. Gandhi mentioned, because by the name of Jakafi or ruxolitinib, is one of those JAK2 inhibitors, hoping to at least... by myself some time before needing a transplant. I really hoped that would be years, but that unfortunately didn't work. And in fact, I had some pretty significant side effects. I got more anemic and really fatigued on that drug. So we switched off of momelotinib and onto another JAK2 inhibitor, another one that she mentioned called momelotinib. And the Jakafi side effects that I was experiencing went away there, so that was good. But unfortunately, over the ensuing weeks and months, I continued to deteriorate. And so we're starting to look more and more like I would need a transplant probably sooner rather than later. But around that time, we identified an experimental Phase 1 drug that was being tested that I think ultimately is very promising. But unfortunately for me, the closest trial center for that particular drug, rather than being at OHSU where Dr. Gandhi practices, it was at Stanford. And I live in Portland, Oregon, very close to OHSU. But regardless, I was accepted into that trial, and because I wanted to go with a transplant and I was really hopeful about this trial, I started that in the summer of 2025. So I was going back and forth to Stanford every two weeks from Portland. So this is my third course of treatment. And yet again, unfortunately, that trial drug, even though it was working for a number of people, it had little to no impact on my disease. My blood work continued to deteriorate, my fatigue was getting worse, and that enlarged spleen state that Dr. Gandhi mentioned kept getting worse and worse. And so at that point, it felt like I was running out of options, and we started planning for a transplant for kind of late 2025.

So fast forward a few months, I went into the hospital in late December, and I had my transplant on New Year's Eve and stayed in the hospital for about five weeks straight. I was lucky that, because I live in Portland, I'm close to OHSU, where Dr. Gandhi practices, and OHSU is one of the country's best cancer and bone marrow centers. And I had absolutely outstanding care from Dr. Gandhi and the other doctors and nurses that I've worked with.

The recovery process, for me at least, and I think for a lot of patients, is a long one. I ultimately went home in early February. For several months after I got home, I had to stay within about 30 minutes of the hospital after transplant, and I had to have a caregiver with me 24 hours a day, seven days a week without exception. After I got home, I was fairly weak. I was able to get up and around, but I was the weakest I'd been ever at that point. And I was going back to the hospital for checkups about three times a week and getting blood transfusions at least weekly while we were waiting for my bone marrow to begin to recover and my system to start producing its own blood cells. At this point now, I'm down to about one visit a week. And my hope is that over the next month or two, we'll get that down to maybe twice a month or even once a month. After I had my transplant, I did have some mild graft-versus-host disease, which I understand is fairly common for people receiving transplants. For me, that was…that came in the form of skin rashes, but I think it was ultimately a pretty mild form of graft-versus-host disease or GvHD. And in terms of caregiving, I was really lucky. My wife was able to be my caregiver, and I can't emphasize enough what a big role that is and how much is required of that person. Not surprisingly, my wife or my life revolved around the transplant process and treatment and follow-up at the hospital, but for her, it did too, in terms of the way we manage our lives and our household and getting back and forth to being checked out. But I am happy to say that I'm now to the point where I'm feeling much better and much stronger, certainly much stronger than I was last year. This time, for sure, I'm still in the recovery process, but I really am starting to feel more like my old self. And I feel like my life is starting to get back to normal, even if I still am in recovery. And the next big goal for me, not a medical one necessarily, but a life one, is getting back to work. And that'll be a really important part of reclaiming my old life. And for me, that was a big, big part of my identity. So I'm hoping I'm able to do that sooner rather than later.

And I guess, kind of wrapping up, if there's just one point that I can make for other patients who might be going through this, or maybe they're in the early stages of diagnosis, just how important it is to find a good NPN specialist. Over the course of being treated for ET and then ultimately myelofibrosis, I worked with four doctors, all of whom I respected a ton and got good advice from. And they evaluated my diagnosis; they evaluated different treatment options, sort of getting opinions and second opinions over and over. But myelofibrosis is such a rare disease that even a really talented oncologist would rarely, if ever, see the disease. So seeing a specialist, at least based on my experience, is really, really important. But talking to multiple doctors helped me build confidence in my treatment plan. I guess the thing for me, though, ultimately it was Dr. Gandhi's knowledge and judgment about the likely course of my disease that consistently proved to be the most accurate of anyone I spoke with.

And that knowledge and judgment and the rapport that I built with her, that trust that I built with her, ultimately got me comfortable with the decision to move forward with the transplant, even though early on I resisted it in a pretty big way. So, if I would leave people with nothing else, it would be two things. One, there absolutely is hope here, but really, really importantly, find an NPN specialist if you're dealing with myelofibrosis. That was it for me.

Arpita Gandhi: Thank you, Mark. I think that's a…thanks for making that really important point to end with your story. I do think, as a physician who focuses in myeloproliferative neoplasms, I do think there is a lot of research happening right now. There are really, really promising clinical trials in the non-transplant setting that patients can benefit from. And so I think one of the biggest things is how can we make patients feel better, right? Do you remember when you were on Jakafi, and your anemia got worse? You felt awful. And one of the things that we focused on was how can we get you to feel better. And so we switched to momelotinib. So it's the decision to switch to a different agent, such as momelotinib or others, is two-part. One, we know the disease, the mechanism of action of these agents and how they work. And particularly for momelotinib, we were fortunate to have that agent for you because it helped boost your hemoglobin, not by a lot, but I think it did by a point or two for hemoglobin. And I think you did feel some energy. And it controlled your symptoms. That was the other important thing. It controlled your symptoms. And when you went on the clinical trial, which was really important to you to give it a shot, cutting off of the JAK inhibition made you feel worse. And so just to kind of cover that sort of journey of clinical trials, it is really important for our patients to know that different centers have different clinical trials, and they should definitely talk to their oncologist. As a matter of fact, we worked together with Mark, myself, and the physician at Stanford worked together to get Mark back and forth to hopefully take advantage of this novel agent. It didn't work out for Mark, but it was definitely worth the effort.

There is something to be said about the trust and the relationship between the patient and the physician, whether it's with your oncologist or with your stem cell transplant physician. It is critical. Many of my patients always say, “Is it bad that I'm going for a second opinion?” Absolutely not. You should seek second opinion, and you may choose to just come back to the person you're working with. But it's really important to receive, be your own patient advocate and to receive the best available care, whether it's at the center where you are getting treated, or it could be somewhere else. So that is very important to me and to my colleagues, and so I would definitely want our listeners to take that away.

Mark, you said earlier that you were scared of transplant initially when you heard about it. Can you…We have a few minutes. Would you be open to commenting on that in brief or at whatever extent you like?

Mark H: Yes, you bet. I'd be happy to. I think there were two or three parts to being worried about, or as you said, scared about going for a transplant. One was just by my nature, I got trapped in a little bit of a doom loop using- I think you coined the term Dr. Google, Dr. Gandhi, if I remember right.

Arpita Gandhi: Yes, I did.

Mark H: For sure, the transplant process is a big, big commitment. It's a time commitment, and you and your family will feel it. That part word being scared me off a bit. And then being blunt about it, also there is some mortality data around transplants that can be a little bit scary when you're first staring to down the barrel of that sort of thing. So that really had me in a mindset of wanting to do everything I possibly could to treat the disease and hopefully get stronger and feel better, deal with my symptoms, but avoid the transplant. And so we, as you described, tried a couple of different JAK inhibitors, and then you worked with the physician, the specialist at Stanford, to get me into that trial down there. But eventually we ran out of options, and it just became clear to me- and certainly it was, I think it was to you maybe a little bit earlier, that transplant was really going to need to be the place where I ended up and sooner rather than later.

Arpita Gandhi: And did you seek resources when you were scared? Social worker team, other places, online, or anywhere else?

Mark H: Yes, I did a bunch of research on my own. Some of that made me feel worse, but I do think there's this truth in the notion that knowledge is power, and that helped me advocate for myself, which I think is something that you mentioned. And then this maybe sounds obvious, but it was really important for me around that time. You were a great resource for me and pointing you to other resources as well. But staying really close to family and friends was especially important to me. And so I was fortunate in that regard that I had those personal resources close to me and people who were sickened by me and keeping an eye on me, getting me out and around and getting my mind off of the disease and more on life.

Arpita Gandhi: Absolutely. And every transplant center, including ours, will have social worker support. We can always refer you to internal and external resources for patients because this is really, it does take a village to go through transplant. It cannot be done by yourself or just by you and one caregiver. It's a massive effort. So always ask for help. Always share your concerns, worries. I think Mark was really good about that. And we knew exactly what he was concerned about or worried about. I think the majority of the time, Mark, you were really concerned about family and your work. And it seems like you might be going back to work or not in the very near future. And I think it's really nice to see this full circle where you are starting to feel good. Do you mind sharing how far out you are? It's okay if you don't want to.

Mark H: Yes, I think I just went through a bone marrow biopsy. In fact, yesterday I had my roughly six-month bone marrow biopsy. And so I think we're waiting to see what those results look like.

And if I'm on the uptrend, then I would go back to work just as soon as I possibly can. I miss that part of my life, the people that I worked with and the work that I did. I'm sorry, Doctor, I lost part of your question. What was the other piece of it?

Arpita Gandhi: No, I think that was it, that, you know, how far out are you? And it's really good to see you coming back on this side of transplant, right, that you were just about…you're only about six months out of transplant, and you are feeling good enough. And actually, you've been asking to go back to work since month three or month four, though I think you are probably ready now.

For our listeners, it is important to know that your immune system is pretty compromised, at least until six months, if not more. So it is important to talk to your stem cell transplant team regarding time when you can go back to work. And it really just depends on the type of work you do and how high-risk it can be for infections.

Mark is doing…the other thing about Mark, and I'll take two more minutes to highlight a few things that are really important to me from transplant standpoint. Mark was sort of; it was hard from deciding when we were going to transplant or not. So the time to transplant, determining the time to transplant was a challenge for us. And I see that pattern nearly for almost all patients. So it's not a unique thing to Mark. I just think it's a unique thing regarding myelofibrosis, and that is completely okay as long as the patient and the physician work together and do frequent reassessments so that you don't miss the opportunity to go to transplant before you become very sick or too sick to go to transplant. So I think that's totally fine. The other thing, Mark, you did really well was you were just naturally really good at lifestyle choices. So I didn't really have to do a lot of work.

And to highlight that for our listeners, it is important, you know, we don't really have a very specific diet that we prescribe as transplant physicians for anyone, myelofibrosis or not myelofibrosis. And so you just have to have a good, well-balanced diet. So that's one thing.

Number two, smoking and alcohol is not a great thing, not a great thing for non-cancer lifestyle choices when done in excessive amounts. And of course, because we use lots and lots of chemotherapy and you're immunocompromised, smoking and alcohol can increase risk for having transplant complications. And so it's important to discuss those things with the transplant team.

Number three, which is really important, exercise. That's a unique one for myelofibrosis because patients really feel awful due to the inflammatory state, and so they're not able to do a lot of exercise. And it just depends, you know, there's a lot of heterogeneity in the disease and who's going to be very symptomatic and who's not going to be symptomatic. But in some patients who are symptomatic, what's fabulous about these JAK inhibitors is that they make you feel good. So when you feel good because the inflammation is down, and hopefully in patients who have anemia and they have fatigue, you can hopefully feel better with more anemia-directed JAK inhibitors.

And if you feel better, you can perhaps have more exercise tolerance. And we always like that in the pre-transplant setting. So I think the JAK inhibition is really helping us in multiple ways.

One, like we said earlier, it helps people feel better due to the reduced inflammatory state. Number two, it helps us shrink the spleen, and it really just does help us when the spleen is smaller; patients can eat better, perhaps. And because of the reduced inflammatory state, we hope that patients will have an improved exercise tolerance. All things that are really good in the pre-transplant setting. And then one thing we did not cover is your spleen-directed therapy. How was your experience in terms of treating your spleen in the pre-transplant setting? I'd love to hear your patient perspective.

Mark H: I think I mentioned that before diagnosis, I had lost a little bit of weight. And I didn't really think too much about it. I wasn't trying to lose weight. But in retrospect, as we measured my spleen via ultrasound, I did have that massively enlarged spleen. I think Dr. Gandhi mentioned that she has some patients with spleens that measure in excess of 20 centimeters. And I was one of those patients, and it got bigger and bigger. So initially, it affected my appetite; I was able to counteract that by just making sure I ate more. Took in more calories. But as the disease progressed, my spleen actually got larger and larger. And eventually, I did start to feel it. I would get pain right up under my left rib cage. And I had to be really, really conscientious about eating more. Because if I just ran by appetite or to the point at which I felt full, it almost certainly would have caused me to lose weight. And the different treatments that we tried, all of, I think most of them- Dr. checked me on that, but I think most of them- one of the hopes was for each of them was that my spleen would shrink, but that didn't have a lot of effect on me. If it had some, it was not as great as we hoped it was. So before I had my transplant, in an effort to shrink my spleen, since an enlarged spleen is linked to poorer outcomes post-transplant. We did do radiation on my spleen to attempt to shrink my spleen before I went in for the transplant process.

Arpita Gandhi: Yep, and was that a scary process as spleen radiation?

Mark H: It's weird from the point of standing or lying inside of this machine and being sort of secured in place as these big instruments move around you, but it was completely seamless and I didn't have any side effects. I didn't get sick at all from the radiation treatment.

Arpita Gandhi: Good. And last question, do you have any spleen symptoms right now?

Mark H: My spleen feels fine. I just recently had an ultrasound that suggested it was still larger than normal and probably larger than we'd like, but it isn't affecting my appetite, and I'm not having any spleen pain post-transplant.

Arpita Gandhi: Yep. Well, I think we will take a pause. Thanks for answering all of those questions. And we are happy to take… Do you have any other comments before we take questions, Mark?

Mark H: No, that's it for me. Thank you.

Jennifer Gillette: I want to thank you both so much for all of that information. And Tina, could you please tell our callers how they can ask a question?

Operator: Absolutely. To ask a question, simply press star one on your telephone keypad. And we do ask that you limit your questions to one and then re-enter the queue for further questions. Again, that's star one to ask a question.

Our first question is from the line of Marietta. Please go ahead.

Marietta: Yes, hi. So I have myelofibrosis and have talked with my oncologist about doing a stem cell transplant. My biggest hesitation is with regard to the 24/7 care aftercare because I'm a single person and I don't have somebody that can provide the 24/7 care, and I don't know kind of who to talk to about that or how to go about?

Arpita Gandhi: Well, first of all, I'm glad that you are getting plugged in with a transplant team. You know, 24-hour caregiver, one of my…outside of myelofibrosis is a passion in terms of the academic interest. My other passion that I strongly, strongly think that we don't talk enough about, is caregiver needs. And I appreciate you bringing that up because you are not alone. Many patients have challenges in terms of securing a 24-hour caregiver. We come across, on average, a couple of times a month, I would say. And so our social worker team usually ends up spending a lot of time with our patients. So be sure to reach out to your social worker team. Be sure to reach out to NMDP and other resources where you can get ideas and suggestions on how to approach this. You don't always have to have one caregiver. So in Mark's case, his wife was a caregiver. However, you can try to arrange for multiple caregivers who can take turns at a time, so a week or two weeks at a time. And it is important to find a caregiver because Mark would tell us right now that he needed a lot of help from his wife initially, and then he started slowly becoming more independent. And the reason for that is fatigue, and medication compliance is so critical that if you miss certain meds, you can end up with some transplant-relevant complications, and that's important for us to prevent that. So don't have a great solution, but please talk to the social worker team and try to come up with more creative ideas, like putting together a caregiver plan, so it's multiple caregivers. And if you are, are you in Oregon by any chance?

Marietta: No, I'm in Minneapolis, Saint Paul.

Arpita Gandhi: Okay. So you definitely also reach out to NMDP for more resources and ideas on this.

Marietta: And how can I get hold of them?

Arpita Gandhi: You can e-mail us, and I can connect you. Not a problem. And they have a website.

Marietta: It's MMDP?

Arpita Gandhi: NMDP, National Marrow Donor Program.

Marietta: Okay.

Arpita Gandhi: Yes, feel free to e-mail as well, okay?

Marietta: Okay, thank you.

Operator: And your next question is from Robert. Please go ahead.

Robert: Hello, how are you? I am actually a stem cell transplant survivor since February 2025 and doing quite well. I'm a 67-year-old retired dentist, and I retired and was diagnosed three months later. I have two things. One, I wanted to ask Dr. Gandhi; I don't know that she's there.

Arpita Gandhi: I'm here. Yes, congratulations. I'm happy to hear that you're doing good.

Robert: Yes, things are going very well. The only complication was gout. So a severe case of gout. I had it previously where it's under control, but then right after the transplant itself, knee swell up, everything, it's a steroid issue. So that we hadn't actually talked about prior. But I think that's something that…I don't know if you ran into it ever with any of your cases. But I think if the patient knows beforehand, it's a little bit better to have an idea because it's an inflammatory process and it was in an area where I had a knee surgery when I was younger at ACL. The other thing I just wanted to... Yeah, have you run into that with gout afterwards?

Arpita Gandhi: You know, not specifically gout, but we have seen joint inflammation, and I'm not claiming that you have graft-versus-host disease, but sometimes could be an inflammatory state due to graft-versus-host disease. So we have seen that. I'm assuming that you are having ongoing conversations with your transplant team about this.

Robert: Oh yes, well, we resolved it.

Arpita Gandhi: Okay, good, very good.

Robert: Five and a half weeks versus three. I mean, everything else was going tremendously well. The other thing I would say, you know, Mark was excellent. I mean, being a dentist and over the years, having patients and telling them, you know, what I thought should be done from my standpoint and expertise. I always did not like the fact that someone who came in who was Doctor Google to the nth degree.

So when I was diagnosed, I let my wife and my 40-year-old daughter become my health advocates. I did literally 5% reading online of what my disease actually was because my feeling is not to pollute your head with too many negative thoughts because during this process, it is a very important thing to have a mental attitude and an inner strength to get through this disease because there were times where after I got the transplant and I'm in the hospital I felt like there was a 500 pound person on me and I had to fight to get them off because my immune system was like you say beaten up. So I would tell people that are going through the process now, try to have someone else do most of the research, because I did it over in Hackensack in New Jersey. Dr. Nanato was great. And you really have to have confidence in your doctor and your, like you say, the care team with you because they're going through everything with you. And family and friends is 100% you need on board. So if there's…and just for the donors, I am someone who, and doing things for Blood Cancer United, and I would be happy to speak with anyone with myelofibrosis who's either going to go through it or afterwards.

Arpita Gandhi: Thank you so much for being available, and thank you for sharing that important point, which is that you do need the right mindset. It is critical that you are ready for this journey. It's a marathon, and so it can be a long one in some cases.

Robert: Yes, yes.

Arpita Gandhi: And congrats for doing good.

Robert: Yes, it's great. I'm doing everything.

Jennifer Gillette: Thank you. We appreciate you being here. We can take one more question if there's a question in the queue.

Operator: Our next question is from Andrea. Please go ahead.

Andrea: Hi, this is a question for Dr. Gandhi, and I'm not an MF patient. I'm a caregiver. And my question is, do you use reduced-intensity transplant for MF, and what class of patients would you use it for if you do use that? Thank you.

Arpita Gandhi: Yes, absolutely. And thank you for asking this important question. We do use reduced-intensity conditioning. I think the field in myelofibrosis and transplant potentially may be switching gears and headed in the direction of using more and more reduced-intensity conditioning, which is what Mark received as well. We use a reduced-intensity regimen. I think you said what population. I think that was your question. Am I right?

Andrea: Yes.

Arpita Gandhi: Okay. So reduced-intensity conditioning is generally used for or was generally designed for patients who are of older age, which can be center-based, but in the range of 60 to 65 and above, and also for patients who are younger but have multiple medical comorbidities. And in myelofibrosis, there is a well-observed hypothesis that patients do end up having more chemotherapy-related toxicities due to the ongoing inflammatory state. And so reduced-intensity conditioning can be used in patients who are not in that older patient category but are younger and may have multiple medical problems. So we use it in both. And I think we're seeing good results.

Andrea: Great. Thank you.

Arpita Gandhi: Thank you again.

Jennifer Gillette: Yes, and I would like to thank again our speakers, our sponsors and partners, and all of you for joining us today. I cannot believe it's already an hour, but wonderful presentations. Thank you to Dr. Gandhi and Mark for sharing. And we hope today's discussion provided helpful education, encouragement, and insight for you as well.

We will have this recording on our website within a few days, and also, we'll be sending you a survey. So, if you could fill out that and help us to just keep planning great programs for you, we'd certainly appreciate it. And if there's any other support needed, please feel free to reach out to us. We thank you for being a part of the community, and we invite you to join us next month for our Lunch & Learn on the impact of chronic graft-versus-host disease on patients and caregivers. So everyone have a wonderful afternoon and thank you again for attending and to our wonderful speakers.

Arpita Gandhi: Thank you, Mark. Thank you, Jennifer. And thank you to our listeners.

Mark H: Good talking with you all.

Operator: Thank you again for joining us today. You may now disconnect.