

## **After Frontline Treatment Failure: Learning from One Patient's Myelofibrosis Journey**

### **John O. Mascarenhas, MD**

Professor of Medicine  
Tisch Cancer Institute,  
Division of Hematology/Oncology  
Icahn School of Medicine at Mount Sinai  
New York, New York

### **Susan**

Patient

**Dr. John Mascarenhas:** Hi, I'm John Mascarenhas, a professor of medicine at the Icahn School of Medicine at Mount Sinai in New York City, and I'm a specialist in hematology with a focus in myeloproliferative neoplasms and leukemia. I'm very happy today to be joined by my patient, Susan, who I'll also introduce in a second, to highlight the critical role of the patient as an active member of the treatment team, particularly as it relates to blood cancers like myelofibrosis.

Susan, can you introduce yourself as well?

**Susan:** Yes. I'm a 75-year-old patient. I was diagnosed about 15, 14 years ago. It's had a tremendously negative effect on my life. When I first went to the doctor and complained of tiredness, he thought I had iron deficiency anemia and treated me for that for over a year. Then when I told him nothing was working, he finally decided to send me to a hematologist. I was then diagnosed.

**Dr. Mascarenhas:** Just to give the listeners a sense, what was the time period between when you first started to feel unwell and had this supposed diagnosis of iron deficiency to actually being seen by a hematologist and being worked up for other reasons?

**Susan:** I think it was almost two years.

**Dr. Mascarenhas:** Okay. That's a story that I've heard many a time before. It's not unique to you, but it can happen.

I think it's important for the audience to realize that sometimes these diagnoses are not made right at onset. Sometimes they're misunderstood or misdiagnosed or confused or confounded by alternative diagnoses. It can sometimes take time to get to the right person, to develop a plan to formally evaluate someone with a bone marrow biopsy and the rest of the workup that then actually confirms the diagnosis of myelofibrosis.

It took time for you to get to that hematologist to then have that workup. Can you paint a picture of what did that look like in terms of-- I'm assuming the workup involved the bone marrow biopsy and then the discussion about the diagnosis. Can you paint us a picture of what that looked like at that point?

**Susan:** Well, the first indication I got that something was wrong was when my doctor had difficulty doing the biopsy. She said there is a condition that may account for that, and it's called myelofibrosis. That was my first introduction to it. I really didn't hear more about it until my next several visits with her. I did look it up on my computer, and I found all kinds of sites with what I think is misinformation. I was anxious to find out what it was and how it would affect me and what I should look for.

**Dr. Mascarenhas:** You just brought up two really interesting and important points. In fact, as physicians, we do bone marrow biopsies with an aspiration in myelofibrosis because fibrosis or scarring in the bone marrow, sometimes the bone marrow is inaspirable. It's actually very interesting that the physician had the foresight and the concern level to even convey that initially to you.

Of course, naturally, you looked for more information to learn about it. You pointed out something that I think is really important is that one needs to be careful. We have a lot of information at our fingertips through the internet, and not all of it is accurate or pertinent to the patient. Having that discussion with the physician and following from that point becomes very, very important. Once you sat down with your hematologist to discuss and review the diagnosis, can you give us a sense of what that looked like?

**Susan:** I mostly wanted to know what the future would hold, and she tried to tell me, based on her experiences with other patients, what to expect in the form of symptoms, in the form of treatments.

**Dr. Mascarenhas:** It was a discussion, a back and forth with the physician about what the disease could look like based on her experience of seeing other patients and what was affecting you at that time with the diagnosis. Just remind us what were you feeling. What were the untoward effects of having that diagnosis at onset at the time of diagnosis?

**Susan:** Well, the first thing was I was always incredibly tired. That was fatigue, tiredness, shortness of breath. I would get lightheaded occasionally. I would get cramps in my legs. My plans for my retirement were totally upended because I couldn't really travel and do much walking. I had to rearrange my life.

**Dr. Mascarenhas:** Did you have systemic symptoms like fevers, night sweats? Did you have bone pain?

**Susan:** No, I didn't have those. I didn't have those, and my spleen was in the normal range. It was at the upper end of the normal range and size. I didn't have a lot of the other symptoms that I've heard about.

**Dr. Mascarenhas:** How did the discussion evolve in terms of the initial treatment plan, and what were the goals of that initial treatment plan in terms of addressing your symptoms?

**Susan:** Well, I was lucky to get a spot in the MPN Education Foundation conference in Arizona. I heard all the doctors present different treatment ideas and the newest research developments. This happened shortly after my diagnosis, and I went to my next doctor's appointment, and I asked, "Would it be possible for me to be treated with interferon?" that I had heard about it at this conference.

It just so happened that she knows Dr. Richard Silva, who's been working with interferon. She sent me to see him for evaluation, and he determined I was an okay candidate for interferon treatment, but he wasn't saying a word about its effectiveness, but he was willing to have me try it. I did for six and a half years.

**Dr. Mascarenhas:** When you say "try it," were you on a clinical trial with the drug? Were you being treated by him? Were you being treated locally by your physician?

**Susan:** No. I was treated at Sibley Hospital. The hospital applied for permission to give me the shots, and the insurance company approved it.

**Dr. Mascarenhas:** Okay. Maybe what we'll do now is maybe let's highlight the fact about something you mentioned earlier, which was there was a period of time in which you were diagnosed with iron deficiency, which is not an uncommon situation before you came to the attention of your hematologist who then did a workup that provided an accurate diagnosis and then a treatment plan with interferon. During that period where you were labeled as an iron deficiency anemia patient, were they giving you oral iron, IV iron? What did it look like at that point?

**Susan:** Yes, it was oral supplements.

**Dr. Mascarenhas:** Presumably, your hemoglobin was not, in fact, improving on the oral iron supplements.

**Susan:** Right, it was not. No.

**Dr. Mascarenhas:** I think that that's an important point is that sometimes this can go on for quite some time, and the obvious negative impact and a delay in treatment would be going down a treatment avenue in which it won't have a benefit to you like iron replacement for myelofibrosis in which the issue is not iron deficiency. Then there's

another aspect, I think, that's important when talking about a delay in treatment, and that is that some of the treatments, for example, interferon are often best used earlier on in the disease state.

Once patients have a more progressive disease and myelofibrosis is a chronic and progressive disease and people can get advancing fibrosis in the bone marrow and lowering blood counts and more complex disease at the molecular level, it does become less likely, I would say, for some of the therapies, including interferon, to be as effective.

That may or may not have been some of the thought process when Dr. Silva was evaluating you for interferon and considering that as an option. That is definitely an option and with increasing evidence, an option that can be considered with the goal, in many patients, to not simply correct cytopenias, which are low blood counts but potentially even modify the course of the disease, which is a whole discussion in itself. For some patients, that's the primary treatment goal. For other patients, it may be addressing symptoms, spleen burden, low blood counts.

I guess one question I would pose to you, Susan, is as a patient, from a patient's perspective, going through what you've gone through, what advice would you give, or what thoughts would you have in terms of how, one, a patient could advocate for themselves and prevent or hasten a delay that can naturally happen when a diagnosis is not correctly made?

**Susan:** Well, I think I should have been a little more forceful with my primary doctor who thought I was anemic because of iron deficiency. He said it may take time for it to have an effect, so I gave it time, but I think I should have contacted him and said, "This is not doing anything. Is there something else that could be, and can we try and find out what it is?"

I didn't advocate enough for myself, I think, in that instance, but I think when I heard about the different treatments at the conference in Arizona, I was a little more forceful, and I made a decision that I would like to try the interferon with the concurrence of my doctor, though. I didn't want to do it with her not approving it or going along with it.

**Dr. Mascarenhas:** It sounds like a pivotal point in your story, actually, is taking the initiative to attend the conference, to learn from what those experts were discussing at the conference, and then bringing that back. I think a lot of credit goes to your hematologist, too, to be open to referring you to another physician for other expert advice and working with you as part of the care team.

I think that's one of the major points of this discussion today, is that the patient is an integral part of the care team and advocating and being involved. Having that right balance with the physician and the care team I think is essential. I think you've highlighted that really well. Maybe we could just go back now and delve a little bit more

into the course you had on interferon. What did it look like? Were there good aspects to it? Were there negatives to it? Then the transition from interferon to your next line of therapy?

**Susan:** The interferon actually did quite a lot for me. My blood counts went up. My hemoglobin hovered around 10. My platelets were in the normal range where they had not been before. I felt a little better, except occasionally, I would have bouts of nausea, but I figured that was tolerable. This lasted about six years and then my spleen started to grow.

My hemoglobin started to slowly descend, and we figured it was time for me to check with Dr. Silva and see if he thought we should switch to something else. That's what I did. I went to see him, and he suggested ruxolitinib.

**Dr. Mascarenhas:** In your case, the "failure" of interferon was, ultimately, because it sounds like you had real success with it for a period of time and then you had this progressive spleen, so a decision to move to ruxolitinib was recommended. Presumably, you went back to your local physician and started ruxolitinib. Can you give us a sense of what that looked like and how effective that was?

**Susan:** At first, I didn't think it was doing anything, but after a few months, my blood counts did go up. My platelets went up. I had a little more energy than I had had. I did not have the same nausea that I had with the interferon, and my spleen was stable. It was no longer enlarging. I felt better than I had. I did not have night sweats or fevers or itching or so many other things that people do sometimes get. My quality of life was fairly good, excepting the lack of energy, that was always a problem.

**Dr. Mascarenhas:** It sounds like there was a net benefit. Can you give us a sense of how long that went on for before things changed?

**Susan:** I would say somewhere between two and a half to three years on ruxolitinib. Then my spleen started to grow again. My blood count started to fail again. I was getting transfusions more and more frequently, and my hematologist decided it was time that we talked about switching to something else.

**Dr. Mascarenhas:** Give us a sense of what that conversation looked like in terms of the decision-making of what that next thing would be or how to proceed.

**Susan:** Well, I had already looked up a lot of clinical trials on the government website, and we talked about some of them. Then my doctor said she's heard of a good one that she knows one patient who's on it and has been helped quite a bit. She thought that might be a good one for me. I read more about it, and that's when I think she sent me to see you.

**Dr. Mascarenhas:** Excellent. During that process, you brought up a good point that I'm going to highlight specifically is ClinicalTrials.gov is a website that anyone can access, and you can put in myelofibrosis, and it will show you the various trials, and that can be a good resource. It's a great resource for physicians looking for trials, and it's an equally great resource for patients.

You obviously took advantage of that. You had this discussion with your physician. It was clear, it sounds like, very clear from your perspective and the physician's perspective that you were no longer garnering the full benefit of ruxolitinib. At two and a half years is around the median time of when we can see patients perhaps losing some of those responses, whether it's blood counts worsen, spleen can get bigger, symptoms can get worse, and a decision was made to pursue a clinical trial.

I think I'll pause here for a second and just point out that in a field like myelofibrosis where it is a complex disease, very heterogeneous and variable in how patients present and how patients behave on therapy and the options that lay ahead of them, there are two broad ways I look at it once you've been on ruxolitinib and are perhaps no longer experiencing benefit.

One is clinical trials, which is always, on a multiple choice question, a correct answer, or commercially available agents. After ruxolitinib failure, commercially available FDA-approved agents that have been evaluated and tested for effects in improving spleen symptom, even in some cases low blood counts, would be two agents that are approved: fedratinib and pacritinib, as well as a third agent that is likely to be approved later on this year in 2023, that's momelotinib. All three are JAK inhibitors. They have similarities to ruxolitinib but some differences and can be used and considered outside of clinical trials to try to impact and improve the disease process in patients who are failing ruxolitinib. Failure of ruxolitinib, I think, Susan, you gave a great example of how failure can be in totality. Blood counts worse, symptoms worse, spleen worse.

Sometimes failure can be worsening side effects. It could simply be toxicity of a drug. Sometimes it is a failure in the sense of one specific aspect might not be well controlled right from the onset. The spleen in some patients may not be adequately controlled even after three to six months of initial therapy. Failure can be primary resistance, but it can also be refractory disease and relapse disease or intolerance.

If I were to just expand on that briefly just so that viewers have a sense that it is very variable, I would say how patients can come off ruxolitinib, I would say that the majority of patients will enjoy benefit from ruxolitinib. It's a minority that have a primary refractory or resistant disease process. Those patients really should be evaluated upfront, in my opinion, for clinical trial options or second-line JAK inhibitors.

I think what's much more common is over time like Susan explained, you do have patients who can have progressive cytopenias, which is lowering of blood counts or

eventually progressive splenomegaly. The median time to discontinuation of ruxolitinib is two to three years. Although there are definitely patients and I've taken care of patients who've been on ruxolitinib for 10-plus years continuing to garner significant benefit.

To get back to you, Susan, the decision was a mutual decision in discussion with your physician that it would be appropriate to seek a clinical trial option. How did that look like in terms of how did you do that? Did you do that? Did she do that? How did you transition to a clinical trial?

**Susan:** Well, I think that my doctor or my hematologist might have contacted your office and got a feel for whether I would fit in with it and then sent me up there to see you. I know you had a lot of questions and did a whole bunch of tests, and you did lay out the criteria for being a participant.

**Dr. Mascarenhas:** To give the audience a sense of what that looked like, did you remain on ruxolitinib and did we add a drug? Did you switch off?

**Susan:** No, I remained on ruxolitinib. That was one part of the trial.

**Dr. Mascarenhas:** Did that make sense to you that you'd remain on a drug that perhaps wasn't working as well and we would try to synergize with another drug, or did you have questions or concerns about that approach?

**Susan:** Well, I did wonder about it, but I thought that these were two different medications, and they worked in two different ways. I thought, "Well, why not? Let's try it. One will do one thing, the other will do something else, and they'll both be helpful, I hope."

**Dr. Mascarenhas:** In brief, that is exactly the concept. Two different drugs with different mechanisms of action can synergize together. We have preclinical that means laboratory data from primary patient cells that these drugs work well together. That's what really drives a lot of the clinical innovation that we see together. What I'm interested to know from you is as a patient, I do this all day long, but as a patient going onto a clinical trial, is it scary?

**Susan:** It's a little scary but not as much as I thought it would be because I figured this drug had already been tested for a variety of things, and I didn't think it would really harm me. There might be some side effects, but I didn't think it would be anything life-threatening. No, I wasn't really nervous, just a little bit.

**Dr. Mascarenhas:** In the process of enrolling on the clinical trial, were you getting your information and your encouragement from your referring physician, your family, from the

receiving physician, where does it come from or does a patient have to navigate this all by themselves?

**Susan:** No. I think you get a lot of information from all your doctors, and you discuss it with your family. All in all, to me, it seemed like a positive step.

**Dr. Mascarenhas:** Was there anyone in your circle that was hesitant or against the idea of participating in a clinical trial?

**Susan:** I don't think so, no. Everyone thought it was a good idea, and nobody was negative about it.

**Dr. Mascarenhas:** It sounds like, in your case, you had a positive experience. You sought that information out. You had a positive experience discussing it with your local physician that the contact was made, the referral was made. You ventured up from the DC area to the New York City area to be evaluated and eventually enrolled in a clinical trial in which the goal was to improve upon your position with myelofibrosis by adding on a study drug to synergize with that. Give us a sense of, did it work as intended? Were there downsides, upsides? Were there toxicities to consider?

**Susan:** No, I think it worked. I think it took a while, a few months before I noticed effects. Mainly, my blood counts went up, and I didn't need transfusions anymore, which was, to me, a very big relief. I was very happy that we achieved that. All in all, I felt better. I can't say I had tremendous energy, and I was able to go traipsing around the world, but I felt somewhat better.

**Dr. Mascarenhas:** Were there any negatives? Did you have any adverse effects of the combination?

**Susan:** I think the only one was a change in my sense of taste, which took getting used to. Everything tasted bitter to me. That's abated somewhat. It's I think something you get used to, and you adapt to it, and it's not an ordeal or anything.

**Dr. Mascarenhas:** When you started out on the clinical trial path to add this drug to your current ruxolitinib treatment, what was the discussion like in terms of your personal expectations, your goals of therapy?

**Susan:** I wasn't expecting miracles. We talked about becoming transfusion-independent, and that was a main goal. Keeping my spleen at a reasonable size was another main goal. Generally feeling better was another main goal, but we didn't have any ideas that this might affect the course of the disease, really. We just thought it would affect mostly the symptoms. I wasn't looking for any miracles.

**Dr. Mascarenhas:** I think you brought up a good point that I'll highlight, which is essential for the physician and the patient to have a very realistic discussion about what the potential goals of any treatment are, whether it's a clinical trial or a commercial drug, what the potential risks and adverse events could be, not guaranteed, but could occur, and to make sure that the treatment plan and the physician's concept of what they're trying to achieve with the patient's disease or for the patient matches the patient's expectations and understanding because if they don't match, that won't be a good outcome in terms of the perception or reality of benefit of any therapy.

It does sound like, thankfully, and of course, it doesn't always happen in every situation, but thankfully, there were benefits that matched, to some extent, the expectations. Those expectations were discussed and were reasonable. How does one look for clinical failure of the current clinical trial? As the patient, what are you looking for expecting to say, "Well," just like you were on interferon or on ruxolitinib, "this is no longer working"?

**Susan:** Well, I do have my spleen checked periodically to see if it's continuing to grow or if it's staying relatively stable. I haven't needed a transfusion [00:28:30] in several years. I keep my eyes on my blood counts. I also pay attention to how I'm feeling. If I suddenly start to have unusual symptoms I've never had before, I would think that might be attributed to the drug.

I think that's about it. I'm just not expecting everything, just I want to stay stable. One thing I do have a slight fear of is transformation to AML. That's something I hope would not happen. I don't think the clinical trial will help with that, but I'm hoping it might have some slight influence on progression.

**Dr. Mascarenhas:** That's a great point to highlight because I think that that's probably a fear that's shared by many patients with myelofibrosis and listeners to this program today. Having a chronic disease and living with a chronic illness and the unknown of what the future may look like in terms of how it may affect, as you pointed out, what your retirement could look like, your life decisions, your partner's life, and then this unknown or concern of "Could this disease progress next month? In three months, could it evolve to leukemia?" is a significant burden for patients with a chronic disease to carry. That takes a toll, an emotional psychological toll, which is often not I think probably acknowledged or discussed enough. Obviously, there is hope that with the therapies that we're looking at, particularly in the clinical trial realm, that we will make these incremental benefits in improving and delaying or stopping the potential progression and evolution of this disease. I totally appreciate how that would be a topic of discussion and something that you would keep an eye out for and be wary of.

**Susan:** There are other things that I always keep my eye out for, and my local hematologist checks me for. She wants to make sure I don't develop any other cancers, so she checks to make sure I'm not developing lymphoma or things that you can feel.

She periodically does unusual blood tests for me, but she's on top of it, and I'm very happy about that. She's proactive. I feel if something's going to happen, the more notice I have, the better off I'll be.

**Dr. Mascarenhas:** You brought up a point that I think rarely gets raised that I'm going to highlight from what you said, which is when you have myelofibrosis, it is frequent that that becomes the absolute center and attention of your healthcare. Sometimes to the neglect of other alternative health-related issues, patients will often disconnect from their primary physicians or their local physicians and not follow up with general health maintenance, whether it's mammograms or colonoscopies, or cardiac care. Those still remain important. One doesn't want to solely focus on myelofibrosis but make sure that the entire general health maintenance and spectrum of conditions is adequately addressed. That is often not done in entirety by a specialist that might be focused on myelofibrosis. Keeping up on those things is really important. I'm glad that you brought that up, and I'm glad that you have a physician that thinks in that manner.

**Susan:** I am, too.

**Dr. Mascarenhas:** I think you've given us a really great sense of how the disease has impacted your quality of life and your functionality, how the treatments have, in some cases, improved certain aspects and ultimately, in the first and second line, have failed continuing to deliver those benefits and the need to move on. Well, can you just highlight for us if you were to rank some of the symptomatology from your myelofibrosis that is most bothersome from highest to least bothersome, what would you put on that list?

**Susan:** The symptom that bothers me the most is fatigue, lack of energy. I'm tired often. I really can't exercise much. I can't walk very long distances or even short distances without it affecting me. It's hard to plan things, and that's mostly because of that inability to exert myself. I don't really have many of the other symptoms now. I'm still anemic, but it's under control. I don't seem to have any bad effects from the medication except my sense of taste, which is tolerable. I don't know if there are other symptoms that other people have, but I haven't had them.

**Dr. Mascarenhas:** For myelofibrosis, there can definitely be a spectrum of symptoms, but I would say that fatigue is the most common. It's often the most severe. We did a patient survey a number of years ago, like a thousand patients with myelofibrosis with Ruben Mesa. The most highly ranked prevalent symptom was fatigue. The most highly ranked severity symptom was fatigue. That is really a challenging symptom to address.

That absolutely can affect your quality of life and your functionality and your planning, your day-to-day planning, or your future planning, vacations, family events, et cetera. It can take a major toll. For many patients, that is absolutely a goal of treatment is to try to

alleviate that fatigue and reinvigorate the patient and get them back into society, into family functions, and in some cases, into work.

As you're going along with this clinical trial, just for patients who may be thinking about going into a clinical trial, what would you advise them in terms of communicating symptoms or adverse events? What is the best way? Should it be passive and you allow the physician to ask you questions? Should you volunteer to answer those questions? How does it work best, in your experience?

**Susan:** I think if something unusual happens, it's best that you say something. You call one of the people involved in the study, or in your next visit, you bring up some topic that may be new. If they're the same old, same old symptoms, everybody knows about them already, that's one thing. If something different happens, I think it's really important to let the team know what's going on.

**Dr. Mascarenhas:** I would add to that I think if a patient has a new symptom on any drug or clinical trial to report it regardless of whether you are sure it's disease-related, therapy-related, or unrelated to a different-- and let the physicians decide because I often will find that patients may assume a symptom could be an unrelated condition or not important. It's really critical for patients to convey to their physicians, as you've pointed out, things that emerge and let that discussion dictate whether it's relevant or actionable.

**Susan:** Yes, I think so.

**Dr. Mascarenhas:** I think we've had a wonderful discussion so far about the importance of understanding and having realistic treatment goals but also appreciating the potential side effects that could occur with any treatment, whether it's commercial or experimental, having the confidence and the openness to disclose those side effects if they were to occur. Patients are in this to help themselves, not to make the physicians happy.

One should be very wary that if they're feeling something, don't be shy, as you pointed out. Make the physician and the team aware of it so that it can be appropriately addressed. That might be a dose modification. That might be discontinuation. That might be adding on an adjunctive medication to address a symptom. Don't sit on things that occur.

If they bother you, let the physician know so they can address it accurately. I would even go as far as saying, if that's not happening, you may want to rethink the relationship with that physician and find a physician who is open to hearing what's going on and have discussions about how to appropriately minimize or mitigate symptomatology and toxicity.

**Susan:** I would like to tell other patients who are thinking of entering a clinical trial to try and find out as much about it as you can. The MPN Research Foundation and the MPN Education Foundation also have information about clinical trials, and the government does, too. There really is a lot out there if you look for it. You have to be proactive. You can't always just wait for someone else to tell you what you should do. You have to bring up any ideas that you have, ask if they would be appropriate, and see what happens.

**Dr. Mascarenhas:** I was just simply going to say that you are a great example of an active participant in your own healthcare and seeking information in the right places, so MPN Education Foundation and Research Foundation, the MPN advocacy groups, ClinicalTrials.gov, in which you searched for clinical trials, and then discussing it with your physician and coming up with a mutually agreed plan is the optimal way to deal with any illness but particularly a rare illness like you have.

I think this has been a fantastic discussion between an involved and, I would say, a proactive patient, in which the ideal model of care would be a patient that is informed, is actively participating in their care, is seeking out referrals and consultations in conjunction with their local physician perhaps, and creating a very open and communicative relationship that allows for identification of adverse events, symptoms, and the ability to adequately address those.

I think the importance of having those discussions with the physician so that the expectations of the patients, the understanding of the disease is conveyed to the patients, the expectations of the patients in terms of their treatment goals, the potential toxicities match what the physician is envisioning in terms of a treatment plan.

That often requires a lot of discussion, thought, and conversation with loved ones. I feel like you've really highlighted what the course could look like. It could look different for different people but what the course could look like for a patient with myelofibrosis in terms of a delayed diagnosis, the use of drugs that might have the potential to modify the disease, knowing when and recognizing when that drug may be failing, when to move on to the next line of therapy, the potential benefits of ruxolitinib, and then for some patients, the eventual failure of the drug and the need to move on to either commercially available JAK inhibitors or clinical trials, which is a whole discussion in itself, in which I really think patients should be aware of and should consider, particularly with rare diseases.

I applaud you for having the courage and the insight to pursue those and to make yourself available. It's not a small thing that you had to travel to a different city to participate in that clinical trial, and obviously, not everyone can do that. When it's a possibility, it's something that patients should consider if they're able to do that. Susan, I

want to really thank you for sharing your story and your time with us today. I've enjoyed talking to you today in a different capacity than what we normally do. I appreciate your insights today.

**Susan:** Well, thank you. Can I say one more thing?

**Dr. Mascarenhas:** Absolutely.

**Susan:** When I first was told I might have myelofibrosis and I went looking to find out, "What is this disease?" I found, as I said, misinformation. Most of the things I read said the survival rate is between two and five years. Now, that could be very daunting. Here I am 15 years later. I'm not terribly energetic but still living, still doing everything I have to do.

I want to tell people when they're newly diagnosed, don't fall for that, that two to five-year survival stuff. That's outdated, very outdated. That could really, I think, affect how they view the whole thing, and they shouldn't be negative about it. They should be as positive as possible.

**Dr. Mascarenhas:** Terrific point.