

Myeloma Matters: A Podcast Series from the Multiple Myeloma Research Foundation

Episode 5: Newly Diagnosed Multiple Myeloma

Transcript

Jennie Shaw: And so, I'm trying, okay, I'm trying to stay fit and healthy, I'm a young mom with two little kids – not a young mom, but a mom with two little kids. And I would go to PT and he would try to manipulate and it would hurt and we just couldn't figure it out. And then, so I took his advice and was doing yoga, doing really gentle yoga, in fact, it was called a gentle yoga class. And in the middle of a class, one day, I was in a plank position and my arm gave out underneath me. And it hurt, I mean, it really hurt when it happened. After the class, I went and spoke to one of the trainers, who wasn't necessarily in that class, but someone I knew well from other exercise classes, and just told her what happened and said, "Could you help me, you know, stretch this out or something? I'm not sure what's going on with my arm." And she looked at me and said, "That shouldn't have happened."

Narrator: Welcome to the *Myeloma Matters* podcast, hosted by the Multiple Myeloma Research Foundation—focusing on patients' experiences with and perspectives on multiple myeloma topics that matter to anyone affected by this blood cancer.

In this episode, you'll learn that there are many paths forward from a multiple myeloma diagnosis and that multiple myeloma can be a highly manageable disease. To understand how a diagnosis of myeloma is reached, you'll hear from three patients, each with their own unique clinical history. These patients will describe the steps they took to get on the right track for management of their myeloma, as well as how the diagnosis has affected their lives.

Please note that every myeloma patient is unique; the information in this podcast is not intended to replace the services or advice of trained health care professionals. Please consult with your health care team or contact the MMRF Patient Navigation Center at 1-888-841-6673 if you have specific questions about your health.

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For most myeloma patients, the first symptoms are usually subtle. Aches and pains are common, and they may be shrugged off as the result of normal daily activities. It may take a while for patients to see a doctor; many need a nudge from a family member or friend before they agree to get checked out.

This was the case for two of our guests today. Jennie Shaw, who you heard from at the top of the program, was 39 years old when she started having symptoms. She'd just started playing tennis and attributed her new pain to muscle strain. Her physical therapist recommended trying a gentler activity, such as yoga, but when her arm gave way during a class one day, her trainer urged her to see an orthopedist.

Jennie Shaw: So I dutifully went home, showered, went to the on-call, like a little sort of ortho on-call we have here, and, you know, explained to the physician my symptoms, and he was, like, "Okay, great." Then he came back and looked a little concerned and said, "I think you're gonna need to see an oncologist." And I'm thinking, "What in the world?"

Jennie's x-rays revealed that she had several lytic lesions in the bone of her upper arm. The orthopedist told her it was not a break as she'd suspected, but possibly cancer.

Jennie Shaw: So, of course, that was an interesting way to find out, lots of calls to my husband, to my parents right away, to be, like, "What the heck is going on?" And then, you know, very quickly, we were able to get appointments scheduled, with my primary care doctor, with oncology, just to sort of figure out, "What are we working with here? And good god, could there be any other reason for this, right, any other explanation?"

Michael Milano also dismissed his symptoms as related to normal wear and tear. He had just retired after 38 years in the field industry doing heavy manual labor and was doing a lot more travel at the time to care for his mother while she was sick. When he started feeling back pain, he chalked it up to age and work.

Michael Milano: I never put really two and two together that it could be anything other. So I muddled through it, I continued to travel back and forth to see my mother and get her situated and work with a team down there for her. And then actually when I was coming back, my wife's goes, well listen, if it doesn't get any better why don't you go see an orthopedist, take a look and we can take it from there. But like anything else, you get busy, and you get caught up and you just really push it, push it away because there was other priorities at the time.

After Michael's mother passed away, he finally met with an orthopedist. Initial x-rays and bloodwork were normal, but after a month his pain was spreading into his lower back and shoulders. He made another appointment, and an M-R-I revealed that something was indeed wrong.

Michael Milano: Once I went for the MRI, actually, probably back three, four hours later after the MRI was done I received a phone call from my

orthopedist saying I see something there that I'm not very happy with. And I want to start moving forward with some tests.

For some patients, symptoms other than pain can cause a medical emergency that leads to a myeloma diagnosis. This can include bone problems such as compression fractures in the spine, also referred to as vertebral collapse, or other effects such as a pulmonary embolism or blood clots in the lungs. This was the case for Steve St. John.

Steve St. John: I had had a complete physical in April and got a clean bill of health, and started to develop pain underneath my right ribs that just was getting progressively worse, mainly in the evening when I would be lying down, it would get almost intolerable. So my wife finally put her foot down and said, "You need to go see somebody."

Steve called his family doctor, described his symptoms, and was scheduled to be seen first thing the following morning.

Steve St. John: He did a full exam, could not find anything, so just out of a precaution, he said, "Let's do a CT, and just to make sure there's nothing going on." And unfortunately, in the CT scan, I sort of lit up like a Christmas tree. So I had two things going on, one was pulmonary embolism, a pretty severe case of PE, and then also a strong presence of lytic lesions in multiple locations on my skeleton. And I remember at the time I was more upset about what am I doing with PE. I was 59 years old, good health, active, traveling, working, so I'm thinking, you know, "What am I doing with blood clots in my lungs?"

Because multiple myeloma is a cancer that starts in the bone marrow, where blood cells are produced, it often causes problems in the bone and blood. These can include bone damage, pain, or fractures, as well as low red blood cell counts—or anemia—and abnormal blood labs.

The effects of multiple myeloma on the blood can lead to other health problems, including an increased risk for infection and reduced kidney function.

Receiving a diagnosis of multiple myeloma is a life-changing event. Multiple myeloma is a rare type of cancer, accounting for only about 1.8% of all cancers and around 10% of blood cancers. Patients and their families often find themselves having to learn a lot about the disease itself and the types of treatments that are available.

Michael Milano: So for me, of course, trying to be healthy in my whole life and working my whole life, not really having any other issues than maybe a wisdom tooth pulled, you get the word that you could have cancer and it's multiple myeloma. Didn't really know much about multiple myeloma, I

can tell you that. But did research and we had a good team and we discussed options at that point in time. And that's really how it all started for me.

Although every myeloma patient is unique with regard to the course and prognosis of their cancer, there are critical steps important for *all* patients to follow on their myeloma journey: seeing the right team, having the right tests—both steps help to confirm the diagnosis—and getting the right treatment.

The first step toward getting the best myeloma care is finding the right team and treatment center. Because myeloma is so rare, community oncologists are unlikely to see the condition very often in their practices, and their experience with and knowledge of myeloma may be limited.

Jennie Shaw: And the first doctor that I saw was incorrectly, I understand now, informed, that she said, "Well, because you're young and because you're a woman, this is much more serious and a worse diagnosis than if you were older or something." And I'm thinking, "Oh, great, well, thank you, 'cause that makes me feel better." But once I saw a true specialist, a true myeloma specialist, he negated that right away and was, like, "Absolutely not. You are young, you are healthy otherwise, and, you know, we're gonna fight this."

For diseases that are rare or particularly complicated, such as multiple myeloma, specialized medical knowledge is important. That's why it's critical to see a myeloma specialist. Myeloma specialists understand better than anyone how myeloma develops, how it progresses, and how and where to look for it at its earliest stages. They're also more likely to have knowledge of and experience with the latest myeloma tests and treatments, which can improve the likelihood of therapeutic success.

Jennie Shaw: This is a very, very specific disease with very different – and even within the disease, so many different indicators and markers and all that kind of stuff. So it became really clear to us that we needed a quarterback who was a pro at myeloma, who really only studied myeloma.

Steve St. John: And I do think it's critical that you have a specialist, and of course that was the first thing that jumped at me when I started spending time on the MMRF website. I'm on there at least once a week, if not daily, you know, since 2016, that's been a real lean-in resource for me. But they were so adamant that if it's available, and I know it's not to everyone, but if it is available, find a specialist that focuses exclusively on this disease.

Myeloma specialists often work out of specialized cancer treatment centers. These centers provide care to greater numbers of myeloma patients and have

been shown to help patients achieve longer remissions and better quality of life compared with centers that manage fewer myeloma patients. Their support staff which includes nurses, radiologists, pathologists, social workers, and pharmacists, also have more experience dealing with multiple myeloma patients and myeloma treatments. Michael and Steve received their myeloma care at a specialized center, which managed all of their treatment and follow-up.

For many people, though, seeing a myeloma specialist for all of their myeloma care isn't an option. If this is the case for you, you may be able to coordinate your care so that you see a community hematologist or oncologist for day-to-day care but arrange in-person or telehealth visits with a myeloma specialist at key points during the course of treatment, such as at diagnosis, upon relapse, or whenever your treatment plan needs to be revised.

This was the case for Jennie, who received most of her care locally in Virginia, with the support of her myeloma specialist located in New York City.

Jennie Shaw: And so, we were able to work with a physician who essentially could set his ego aside, for a moment, and allow Dr. Landgren to be the quarterback. And, you know, it wasn't without a little bit of grumbling, but it happened and it was fine. And I believe that I was able to get started on a more aggressive tract, because he saw that I could.

The second step toward getting the best care is having the right tests performed, as the results of these tests can help your doctor determine the best treatment options for your disease and assess your prognosis. Many of these tests are also used over the course of disease to monitor the effectiveness of treatment.

Tests that are commonly used include blood tests such as a complete blood count—or CBC—a comprehensive metabolic profile, beta-2 microglobulin, quantitative immunoglobulins, serum electrophoresis, serum immunofixation, and a serum free light chain assay. It may also be necessary to have a 24-hour urine collection performed to evaluate for urine total protein, urine electrophoresis, and urine immunofixation.

A bone marrow biopsy is also done to determine the number and percentage of myeloma cells in the bone marrow. Myeloma cells that are collected from the bone marrow can also be used for cytogenetic testing and genomic sequencing, the results of which help determine myeloma subtypes and support risk stratification, both of which may affect treatment decision-making.

Michael Milano: They wanted to wait until after the holidays, right, December we started making decisions. January 2023 I was in the hospital. And here we go, right, we're ready to rock and roll after they did the bone marrow. They came back with all these different observations saying, okay, this is the best thing for you.

A bone marrow biopsy is always done at the time of diagnosis and may be repeated if and when the myeloma relapses.

As multiple myeloma progresses, it causes small holes, known as lytic lesions, to develop in the bones. A number of imaging tests are used to locate and measure lytic lesions, including x-rays, magnetic resonance imaging—or MRI—computed tomography—or CT—and positron emission tomography, also known as a PET scan.

Understanding the role of these tests and interpreting the results can be complicated and overwhelming, especially right after receiving a myeloma diagnosis. The MMRF has several *Learn Your Labs* education resources available for patients and caregivers to help you better understand the role of testing in your myeloma care; to access these, please visit www.theMMRF.org.

The final step toward the best care is getting the right treatment for your disease. There is no cure for multiple myeloma, but there are many treatment options available to manage the disease, with new ones emerging every year. Together, you and your doctor will determine a personalized treatment plan designed around your health and the specifics of your myeloma diagnosis.

The goal in treating newly diagnosed myeloma is to provide symptom relief and reduce the amount of myeloma cells in the body as quickly and safely as possible. Knowing the options that are available to achieve these goals can help you and your care team work together to determine which treatment is right for you.

Jennie Shaw: I mean, I definitely did my due diligence, to try to figure out what was the next step. We thought about it a lot, we read about it a lot, and, you know, ultimately, kind of made a decision together.

The standard of care for newly diagnosed multiple myeloma is induction therapy, typically with a 3- or 4-drug regimen, followed by an autologous stem cell transplant, if you are eligible, and maintenance drug therapy. Revlimid and dexamethasone, plus either Velcade or Kyprolis, are the 3-drug regimens most commonly given to patients with newly diagnosed myeloma. Both Michael and Jennie received this type of up-front treatment for their myeloma, including a stem cell transplant.

Michael Milano: We discussed what was the best outcome so we decided, I decided to go with the stem cell transplant based on my age, based on my health, based on my overall condition. And they felt that was the best direction for me to move forward. So again, you go home, you discuss it with your family. And you put it all out on the table and you try to

figure out what's the best thing for you and your family as you're moving forward.

In certain circumstances, such as for patients with kidney disease, cyclophosphamide may be used in place of Revlimid for induction therapy. This combination is referred to as CyBorD. Steve received the CyBorD regimen for his initial treatment, with good results.

Steve St. John: But I responded right out of the gate, and actually achieved a complete stringent remission just during that 16-week induction therapy. So, and I remember Dr. Anderson telling me those that respond really strongly out of the gate tend to have better longer-term outlooks in terms of how they respond to future treatment. So, immediate response for the induction therapy, and then sort of Phase Two was in October of 2016, I transferred to that team and then they did the PET CT scans, bone marrow biopsies, the FISH workup, and all of that, and started to go through that preparation for the transplant.

After induction therapy, myeloma patients who are eligible based on their overall health will receive an autologous stem cell transplant. The goal of this treatment is to replace healthy bone marrow cells after high-dose chemotherapy. This can improve the chances of prolonged remission, but it is a physically and emotionally intensive process for many patients.

Michael Milano: It's difficult, you're away from your family, your family comes to see you, they have to be fully en-gowned and safe and making sure that you're safe. And so that was probably I have to say one of the biggest challenges that I went through since being diagnosed with this disease.

To learn more about stem cell transplantation in myeloma, be sure to check out the episode on this topic.

Maintenance therapy is given to some patients after induction therapy, and potentially after stem cell transplant, to help prolong the time before the myeloma returns. Maintenance therapy increases the length of time you are in remission and may help improve survival, but it's also associated with side effects. Some common but manageable side effects include diarrhea, nausea, and peripheral neuropathy, a nerve condition that causes a tingling in the hands or feet.

For Michael, Jennie, and Steve, learning about multiple myeloma and finding the right care team gave them the knowledge and confidence they needed to be more involved in making decisions about their care.

Michael Milano: I started learning about the Multiple Myeloma Research and I started looking and digging down into that on my own. And there

was comfort there because also I had the opportunity to speak with other mentors, right, that had it, that went through it. And I felt more comfortable speaking to the individuals that had it that went through it, that are going through what I'm going through versus speaking to somebody that doesn't understand what the Multiple Myeloma or what cancer is.

To learn more about the experiences of patients who have newly diagnosed multiple myeloma, let's turn now to Jennie, Steve, and Michael, who join the MMRF's Mary DeRome to share their perspectives on multiple myeloma diagnosis and treatment, including how living with myeloma has changed their life.

Mary DeRome (MMRF): In hearing your stories, everybody seemed to have been diagnosed after experiencing months of pain, which was brushed off by doctors and others that you consulted as just the normal wear and tear of life, and I think that this is a fairly common thing that many myeloma patients go through. And it does tend to elongate the amount of time between when symptoms are first felt and then when diagnosis comes, which is not necessarily a good thing for patients, because the more time that elapses between when you start feeling symptoms and when you begin treatment, the more opportunity you have for organ damage and bone damage. So, knowing what you guys know now, after you've been diagnosed, would you have done anything differently when you started feeling these symptoms? Is there anything that you think you could have done or that you could have done sooner? Mike, let's start with you.

Michael Milano: Well, that's an interesting question. You know, I thought I was doing everything right. I went to the chiropractor and went to physical therapy, and I work out. I consider myself pretty active. I thought I was on the right track. I was doing everything right, and then the pain never really went away, and it triggered me to move forward.

My wife said, "You know, we've got to go to an orthopedic [doctor] and take it from there," so really, I thought I was doing everything on the proper channel. Would I change anything? Probably not, because I never realized that I had anything. I thought it was just wear and tear and part of life, right? I was always physical. I always worked, and I figured that's what it was, but when the pain became too much, it triggered me to move forward, and like I said, I went to the orthopedic [doctor], and from there, the orthopedic [doctor] triggered me to go for some MRIs, which, at that point in time, spurred on other things that alerted me that it could have been something more severe than what I was thinking.

Mary DeRome (MMRF): Jennie, you had an experience where I think that you were speaking to a number of people about the symptoms that you were feeling, and really, you weren't getting much satisfaction from anyone that you spoke to about why you were feeling this pain, until you were in a yoga class and injured your shoulder or your arm when you were doing gentle yoga. So, thinking back

on that experience, is there any way that you think that this could have been handled differently, either by you maybe being more forceful with the people that you were talking to or if they had actually paid better attention to what you were actually trying to tell them?

Jennie Shaw: Yes, it's hard to say. I went, just like Mike, to physical therapy, and I think, in the manipulation with the physical therapist, I got more injured because he was so aggressive. And also like Mike, I'm pretty fit and active. I had taken up tennis recently. And [the physical therapist] said, "Well, that might be just a little much for you right now. How about you don't take up a new sport right now. Let's just focus on swimming and yoga," which is what put me in that gentle yoga class. I think that because I was not a typical myeloma patient (I didn't look like the typical myeloma patient, I was young, I'm female, I'm thin, all of those factors), it was not on the radar. And so, it was just a huge shock to everybody, including the poor doctor who saw me in the on-call orthopedics clinic when I came in after the yoga class. He was a little surprised to share with me that was the issue.

Mary DeRome (MMRF): Okay, Steve. Let's hear about your situation, and when you were diagnosed. You had pain in your ribs?

Steve St. John: My pathway, I guess, was a little unique. In April of 2016, I'd had my annual physical and received a clean bill of health, and I was diagnosed with myeloma in June. What transpired was that I started to develop pain underneath my right ribcage that was a low, throbbing pain. It just got progressively worse.

It bothered me at night, lying down, but when I would get up, I felt fine, so this is the type of scenario that you continue to put off, and I finally went back in to see the family doctor. Actually, I left him a message and said, "Here's what these symptoms are," and he called me at home that night and said, "I want you in the office first thing in the morning, 7:00 AM, when I unlock the door," so he obviously was concerned about that. [He] could not really find anything, but he requested that I do a CT scan, just to cover all the bases, and unfortunately, I lit up like a Christmas tree during the CT scan. I had significant pulmonary embolisms, which are blood clots in your lungs, and a significant presence of lytic lesions on my bone structure. [Like] other two patients on the call here, I was in great physical condition. I was 59 when I was diagnosed, but very active, a nonsmoker, moderate drinking, all that. I was in really good physical condition, so I was most shocked. What am I doing with blood clots in my lungs, being this healthy and at this age? And by that afternoon, I was being informed that I had bone marrow cancer, and it was multiple myeloma.

So, what could I have done differently? Nothing, in that respect, but I did have significant fatigue for about nine months leading into that diagnosis, and I travel extensively. At the time, you just figure, "Well, I'm just wearing myself out. I need to rest more. Maybe don't exercise so hard," but the fatigue was getting really

bad, where I would be sitting at a meeting, and I would literally be thinking, “If I don’t stand up, I’m going to fall asleep,” and that’s not the way I’ve ever been. That was really the only symptom, and a lot of people, colleagues, asked me about that, postdiagnosis: “Was there anything you saw or could’ve known?” And for me, I probably should’ve been more aggressive with my doctor that this fatigue was a significant issue. I just put it off to overwork, too much travel, that sort of thing, so the blood clots are really what got me in there and got me diagnosed before this disease got too far along.

Mary DeRome (MMRF): I guess, in a way, that’s good, right? Your diagnosis wasn’t prolonged, and some people go for half a year or a year with these terrible symptoms before they get diagnosed. The issue there is that myeloma is such a rare cancer. It’s only 1.8% of all cancers, and when a patient steps into your office, and you have testing done, and you have anemia, and you’ve got bone pain, and maybe your renal function is not that great, it’s seldom the first diagnosis to pop to the top of the mind of the physician that you’re seeing, because many of them see very few patients, if any, especially if you’re just going to your primary care provider. They just don’t have experience with the disease.

Let’s talk about finding a myeloma specialist and a care team once you have been diagnosed. Jennie, how complicated or how easy was it for you to transition from your community care doctor to your specialist?

Jennie Shaw: I was very fortunate that I had an aunt who was working at Memorial Sloan Kettering in New York at the time of my diagnosis. We were getting very gloomy information from my local doctor that I had sort of been thrown out to once I got this diagnosis. We knew that we needed to seek other opinions, and so I was very fortunate to get in very quickly with Dr. Ola Landgren, who’s now in Miami, and we were able to get a workup with him and start learning about my options. I also was able to see a specialist in Boston. I live in Virginia, so it was a lot of travel and some exhausting days.

But once I decided that I wanted to have Dr. Landgren “quarterback” the whole process, it was pretty good to work with my doctors in town in terms of having Dr. Landgren be the quarterback and letting them help run the plays. It wasn’t always easy. There was some pushback, but I think that most of the doctors I’ve had and worked with in Virginia understand that it’s a complicated disease and that they don’t know everything about it. Especially this last [doctor] I had was really looking at it [with the perspective] that they could learn a lot from him and from the ideas that he had and the drugs that he recommended. The protocols that he was running were different than what they had heard of and the antiquated ways of handling myeloma.

Mary DeRome (MMRF): Believe it or not, that’s still fairly common that people will go to the doctor and get diagnosed with myeloma, and the standard-of-care

therapy is taking either a triplet therapy or a quadruplet therapy, and they'll be given a doublet therapy. That happens, unfortunately, all too frequently, so this is one of the reasons why it's so important to consult with a specialist. Steve, what about your story, and when you were diagnosed and transferred over to UT Southwestern?

Steve St. John: I love the woman that diagnosed me, but unfortunately, she was not a myeloma specialist. I did stay with her right up until the transplant, and then her advice at diagnosis was, "I don't think you need a second opinion with respect to what you have. We have a pretty good handle on that, but you might want to consider meeting with a team that specializes in myeloma." She was very open about that, so she worked with me up until that transition. At the transplant date, I moved over to Dr. Anderson at UT Southwestern, who's an absolute wonder in terms of myeloma care, and I've been with his team the entire time. But [the first doctor] did a great job getting me ready for the transplant, and I think it's so critical.

She was very vocal about spending time on the MMRF website. That's how I got turned onto that, through the original oncologist that diagnosed me, and that's where I got this mindset that I don't need so much a second opinion, I need to look at someone who specializes in this disease. And myeloma is so complicated. And the other issue for me is that the treatment landscape is so rapidly changing. I thought it was rapidly changing in 2016 when I was diagnosed. It is crazy right now not only with what is only approved, but what is in the trial phase, and I like to do research and keep up with this, and it's just out of reach to get a handle on all of that. But [based on] those two dynamics alone, if accessibility is available to you, to have a specialist, even if you have to commute, I would strongly urge you to take that path if you can.

Mary DeRome (MMRF): Mike, what about your story?

Michael Milano: It's pretty much the same as everyone else's. When I went to the orthopedist and the MRI came back, my primary doctor called me, and I was on the road with my wife, and we had to pull over to the side of the road because I couldn't really make out what the conversation was. And then I was on the side of the road probably for a good half an hour as he was explaining what he thought it was, and we said, "It's cancer?" And he said, "Yes. I believe this is what it is, and I believe it's multiple myeloma," and the whole nine yards, and we were just looking at one another like, "Oh. What is that? I've never heard of it." He referred us to a blood specialist, and within two days, we received a phone call from Northwell Health group, and I was lucky enough that there really wasn't much travel involved. It was close to my home, so I was able to meet the team from Northwell that specialized [in myeloma]. Like everybody else [said], there's so much that is dynamic about this. It's moving. And what's the next step? I went through the induction therapy with the three drugs, which they thought was the best to do. We didn't want to waste any time, based on my age and my health, so

we were on the fast track to try to work with this and keep everything at bay. We set up PET scans. We set up everything. Everything was just quickly moving. I can't even explain it, because from when it started back in June to where we are today, it's just unbelievable the movement of everything. I've been lucky. I had a good, solid team around me looking at the bloodwork, giving me direction and thoughts of what was the best direction to go, the planning. That's pretty much where I am at, at this point. It's just that you scratch your head because, like Steve says, there's so much technology out there. It's like, "Oh, we're going to do this. We're going to do that," and then you're staying on track with the three drugs that I was given. It seemed to help me to get to where I am today.

Mary DeRome (MMRF): Good. I think it's an extremely common occurrence that when people are diagnosed with multiple myeloma, their first question is, "What's that?" No one's heard of it. And yes, people can tell you it's a cancer, but it has very little in common with the most common cancers like lung cancer, breast cancer, colon cancer, or prostate cancer, because it's a blood cancer, which is extremely different. Mike, when you were diagnosed with this, did you then decide that you really needed to learn about it and really educate yourself about the disease, or did you just leave that to your physicians?

Michael Milano: No, I didn't. As soon as I found out about multiple myeloma, I started doing my research. It's not always a good thing to do your own research. You're reading some stuff that you really don't want to read about, but I wanted to get the basics. I wanted to get the knowledge of what it was and what could be done, probably like everybody else on this call. What could we do to resolve it? What could we do to work with it? I'm not the type of person that sits back, waiting for the results to happen. I'm all in. What do we need to do? I listen to my team. What's the next step? Does it make sense? I felt I didn't need a second opinion, because I did a lot of the research myself, and I knew what was going to take place, what would have happened at Sloan's and would have happened at some of these other locations as well. They were on that myeloma track. So, I felt comfortable with that, and then I was lucky enough to get turned onto the MMRF, which was very helpful: the websites and talking to other patients and other mentors out there. Those are real-life people that you want to talk to, not listening to something on a webcast that is not up front. That made me feel comfortable and that we were heading on the right path.

Mary DeRome (MMRF): Certainly, there are places to get information that are not so great, as you mentioned, so it's always good to do your research and touch base with an organization who knows a lot about multiple myeloma to get the best and most trusted information. Steve, tell us about how you learned more about myeloma once you were diagnosed.

Steve St. John: To second what Mike said, I dove right in. I want to know everything about what I'm facing. My wife's the exact opposite: "I don't want to know anything. Just let the doctor run things." I want to know, and I want to be

empowered with that knowledge, so I initiated extensive research, which I do to this day. I did get some good advice right out of the gate, which is to be really careful on the internet. I remember back in 2016, when you would go in and google 'myeloma,' you would see that one-to-three-year death sentence, and I was stage III at diagnosis, so I was thinking, "Well, I've got a year to a year and a half to live, based on some of these websites." And I knew that wasn't the case, because they had forewarned me that I was going to see that type of data. And so much cancer data can be stale, as well, depending on the website you're on. I've started to leverage the MMRF and the Leukemia & Lymphoma Society of America, sites that I know are safe to use, and some of the treatment centers, like UT Southwestern, Sloan Kettering, or MD Anderson. You can find very good, valid research data on myeloma there, as well, but I think it's important to look at reliable sources. I just wanted to know everything I could about the disease: what the outlook is, good or bad. That's how I psychologically prepare for treatment, and that's how I psych up, so I want the doctors to have an open line of communication with me every time I go in. What's the status? What are we looking at? What signs are you seeing? What do we see going forward? I'm all about being empowered through research, but just be careful with the resources you use, because you can find some misinformation out there that will scare you that's unnecessary. There's such progress right now. If you're on any legitimate myeloma website, I would think there is some pretty favorable and positive information on there right now from a treatment perspective as well as a diagnosis perspective that wasn't there in 2016. A lot changes quickly.

Mary DeRome (MMRF): That's very true. As an organization that tries to keep patients updated with everything that's happening in myeloma, we have to literally refresh our materials every year. That's how rapidly this field is evolving, and there are so many great new therapies that are in development or have been developed for patients that are really making a difference. Jennie, can you tell us your story? Once you were diagnosed, did you try to learn more about myeloma, and what sources did you use to get your information?

Jennie Shaw: Sadly, the concept of myeloma was not news to us. My husband's father had died about six months before from myeloma, which made us have more information than we really wanted at the time, to be honest. He was in his 70's. I was 39, so that was a really scary thing, to know a lot about it and to have had my husband watch his dad go through two stem cell transplants over the last 15 years. So, we knew a lot going into it, but I think what gave us the most hope was the new things we were learning. We were realizing that the myeloma of 2015 was really different than it was when my father-in-law had been diagnosed. We really latched onto that and tried to get as much information as we could.

Mary DeRome (MMRF): Let's talk a little bit about having the right tests done when you were first diagnosed. Mike, can you tell us a little bit about the testing that you had when you were first diagnosed, like the bone marrow test, imaging test, blood test, and things like that?

Michael Milano: Yes. I pretty much did all that. I did the bone marrow test. I went in for the bone marrow, and that came back showing me that there were definitely traces of multiple myeloma in my blood. Then we did the 24-hour urine test to make sure where we were with that. All of those tests came back with positive results for multiple myeloma, and that's [what] triggered me to ask, "What's the next step? Where are we heading down the road? What's going to happen at this point in time?" It was all new to me. It's like talking another language.

Even to this day, when I'm hearing certain things, it's still unbelievable to me that I'm going through this. A year and a half ago, I never thought that I was going to have any issues in life. You hear about other people with cancer, friends and family, but you never think, "It's going to be me." So, instead of sitting there in the corner, [I ask,] "What's our next step?" I was thankful that I had a good team and that they put me through these different types of testings and put me through the autologous transplant. We talk about it today, that there are so many different opportunities out there. That's basically where I'm at, Mary.

Mary DeRome (MMRF): Did you feel, when you were undergoing this testing and you were getting the results of the tests from your care team, that they explained it to you in a way that was easy to understand so you got the gist of what was happening?

Michael Milano: Yes. Me and my wife, we want to put it in vanilla terms, because we don't know the [terminology] of "kappa light chain." What's a kappa light chain? I'd never heard of it. When we talked to our doctors and we talked to the team, we had them explain it to us in such a way that, if I had to talk to my neighbor, they would understand it. And that made me understand it. What does it affect? Why does it happen? We put that into terms that were more vanilla, so it was understandable, which made me feel more comfortable.

Mary DeRome (MMRF): Yes. That's great. The ability to communicate with your care team and their ability to communicate back to you in ways that you can understand is vitally important to make you feel like you have some control and some knowledge of the situation. Especially when people ask you, "So, how are you? How are things going with your treatment?" and you can actually answer them in ways that they can understand.

Michael Milano: That's the most important piece out of it, making sure that you understand and you're getting the proper knowledge back from your team. Because you hear it all the time on a lot of these calls that I hear you on, Mary, with some of these doctors. I get off [the calls] sometimes, and I'm shaking my head because they're so highly intelligent that they're speaking at levels where, it's all good stuff, but if I had to re-explain it, I couldn't do it.

Mary DeRome (MMRF): I agree, and some of them are better at speaking at a patient level than others. Some of them find it difficult to come down to the level that they need to, to make sure that the point that they're trying to make is actually getting across to the patient in a way that the patient can understand it. Sometimes, when maybe the doctor's not the best person to talk to, you talk to the research nurse or somebody like that, and they can actually talk to you in ways that you can understand, better than the doctor.

Michael Milano: Yes, but you know what? I think, through educating myself on the terminology, when I go back for bloodwork and I meet with my doctor, I have some notes [so] that I'm able to talk to them and bring up some things that I see on my chart. I'm becoming more educated in something that's affecting me.

Mary DeRome (MMRF): Yes, exactly. Jennie, when you were undergoing your first battery of tests when you were first diagnosed, does anything stand out to you as something that you found surprising or shocking, or did you have an easy time talking to your care team and understanding what they were trying to get across to you?

Jennie Shaw: The whole time, I kept thinking, "Okay, the next test is going to say this is not cancer. One of these tests is going to throw this whole thing off." Because, we did not sign up for this, and so, with each test coming back positive, [I realized] this is it. This is really myeloma. It's really myeloma. I just remember being so surprised and confused by it all and trying to figure out what the lytic lesions in my arms and my ribs had to do with the elevated levels in my blood, and learning all about it. It's complicated stuff.

Mary DeRome (MMRF): Steve, tell us about some of the testing that you have done and what you thought about that, and did you understand it, and how your care team was about explaining it to you.

Steve St. John: It happened at such a fast pace. I went in and did the CAT scan, and I ended up being hospitalized for the pulmonary issues. And then that afternoon, probably about 4:30, [the doctor] came into the hospital room and said, "Let's clear the room out so I can have a visit with you and your wife," and you know that's not a good sign.

So, we're thinking, "Here comes a very heavy conversation," and I remember her walking over and saying, "You have bone marrow cancer. This is multiple myeloma, and we haven't done a single test yet to validate any of this, but I'm looking at a healthy male presenting with blood clots in his lungs and lytic lesions on his skeleton structure. That's what you have." She even went so far as to say, "I think you have what is known as Bence-Jones myeloma," which turned out to be the case, which is kappa light chain myeloma, which is 15% to 20%, I believe, of cases that are diagnosed.

I remember her telling me, “You’ve sort of hit the cancer lottery here, but the good news is there are a lot of people in the oncology community that are going to want to spend time poking and prodding and looking at you, depending on who’s in charge of your care.” She put me in surgery the next morning to do some extensive biopsy testing. So, I got to sleep through my first bone marrow biopsy, which was great, and then I got to celebrate the real deal later. I was in the hospital over the weekend, and then that Monday was a barrage of tests. I was relatively clueless about the FISH (fluorescence in situ hybridization) panel, the light chain assay, and all these various tests they were doing.

I was just waiting to hear from them, have we positively validated that that’s what you already know I have? That was the case that following week. So, it occurred fairly quickly. But the PET scan, the full body x-rays, the whole array of tests that they do, was really just done to validate what she already had her head set on that I had. I was always amazed that she was able to make this call, just observing me there in the hospital, but she’s a renowned hematologist, and she was spot-on. And then we reached out to Dr. Anderson’s team at UT Southwestern. They did the test themselves pretransplant, just to make sure they validated exactly what we were contending with, and I did proceed with the autologous transplant in November of 2016.

Mary DeRome (MMRF): Steve, did you say that when you were diagnosed, you were stage III?

Steve St. John: That’s what I was, because of the lytic lesions. Under the original Durie system, if you have the lytic lesion presence to the degree I had, that automatically put me in that category, and then my light chain count. I don’t show anything on the New International System, the beta-2 [microglobulin], all of those, I don’t have any markers. I don’t have the M spike. So with the Bence-Jones, the only thing that they really can confirm or track are the light chains, and thankfully there’s a blood test that they can do that will tell you within 24 hours where those chains are. Are they going up? Going down? I anxiously await that result once a month just to see the directional trend in my light chains.

Mary DeRome (MMRF): Do you know whether your myeloma is categorized as high-risk?

Steve St. John: I’m considered standard risk. I did ask them that. I have the KRAS [mutation] and, I think, the CD56 marker. I can’t believe I throw these terms out. It’s amazing what we are educated with as we go through this process. I went from not knowing anything, but as of last week, I’ve been seven years since diagnosis. I learned a lot about cancer and certainly a lot about myeloma over those seven years.

Mary DeRome (MMRF): Jennie, was your myeloma staged when you were diagnosed? Did they tell you what stage you were?

Jennie Shaw: I'm not sure that they did. I definitely had lytic lesions. I'm not sure that they said or that I asked. I don't know. I had lytic lesions everywhere, throughout my arms, my legs, my pelvis, my ribs. It was not brand new, let's put it that way. It had been around for a while before it was detected, but I don't remember them giving it a number.

Mary DeRome (MMRF): It's a little bit different in myeloma than in other cancers, right? Were you staged, Mike, when you were diagnosed?

Michael Milano: No. I was pretty much on the same page. They didn't really stage me. They just called it multiple myeloma. It wasn't really a staging process. They could've told me it was stage 15, and it wouldn't have mattered, because [I] was [just thinking], "What are we doing? What's our next step? Just let's do it." Whatever we have to do to get better and move forward, that's what I wanted to do. To me, I don't think it really mattered. If they would've told me the stage, it would've probably not mattered at that point in time. But as I hear Steve and what he was up against, it's good to hear that it's seven years, and that's what I want to hear, and that's my direction.

Mary DeRome (MMRF): Do you know, Mike, whether or not they'd done a bone marrow biopsy on you? Have they tested your cells for any genomic abnormalities? Have they talked to you about being high risk or standard risk?

Michael Milano: I don't remember hearing our conversation. I might have heard it, but I'd been on this fast track since it was diagnosed, and it might have been said to me, but me and my wife both left there asking, "Did we get everything? Did we get all the conversation? Did we get all of the knowledge that we need?" It might have been said. I'm from the school of, "Okay, I believe it. Let's just move forward." Maybe I should, like Steve, dig into it a little bit deeper, but I go by how I feel. I go by how the testing is, and then just continue to move forward [from] where we're at.

Mary DeRome (MMRF): Jennie, when you were diagnosed, or even since you were diagnosed, do you remember anybody talking to you about whether or not you're high risk or standard risk?

Jennie Shaw: It must have been pretty advanced by the time it was diagnosed. I don't know that they called it high-risk, but they were able to start me on a drug that's typically for the refractory setting, thinking that I probably had had smoldering myeloma for a while and didn't know it. So, I got started immediately on carfilzomib (Kyprolis). Literally, after one infusion of it, my numbers plummeted. It was amazing. We were celebrating big time, and that was part of the whole idea of having a specialist, because my doctors in town were just like, "Okay, this is what we're going to do. We're going to do the VRd (bortezomib [Velcade], lenalidomide [Revlimid], dexamethasone) regimen," and the specialist

said, “Nope. Let’s try this instead, and let’s make this work,” and we were so grateful that we were able to.

Mary DeRome (MMRF): Mike, you’re on RVd, right? Are you still on that?

Michael Milano: When I started induction therapy, I was on Revlimid, I was on a steroid, and I was on the Velcade. They started me on that. It was approximately five total sessions prior to my transplant. It was 28 days on, and then you had a couple days off, prior to my transplant, and everything was looking good at that point in time. I was on a three-drug regimen.

Mary DeRome (MMRF): Steve, it looks like you were on CyBorD (cyclophosphamide [Cytosan], bortezomib, and dexamethasone). That was your initial treatment, and that probably had something to do with the fact that you have light-chain–only myeloma, which affects your kidneys more. CyBorD is usually a therapy choice for people who have renal insufficiency. Did your doctor say something like that to you?

Steve St. John: Yes, and I didn’t have any renal issues, but I think, given the diagnosis, they opted to use Cytosan in lieu of having Revlimid there with the Velcade. And to Jennie’s point, I responded immediately. My counts plummeted after the first week or two of that induction regimen. So, by the time I got to transplant, I was in stringent complete remission. It’s always good to respond coming out of the gate, because that tends to show a better [prognosis] of responding to treatment down the road as well. I’ve always responded very well to what they’ve put together and thrown at me, and that continues to this date.

Mary DeRome (MMRF): Did any of the three of you feel that you needed to have a second opinion when you were first diagnosed, and you wanted to have another doctor look at your case? Steve, you were saying that you’d had all the testing done with your primary doctor, and then you went to UT Southwestern, and they did all the same testing again and were able to confirm the same information. Jennie and Mike, did you have that same process, or did you just basically go to the doctor and do what they were telling you to do?

Jennie Shaw: I did seek out separate opinions from two different institutions other than our local hospital. Not necessarily to confirm. I knew the diagnosis was what it was. Unfortunately, even though we wished that it was going to be something different, we knew what it was, and we knew we needed to deal with it. Really, the consultations I wanted to have were to find a doctor who I felt like I could really trust, who is a specialist, and also to decide if I needed to do a transplant. I [was wondering if] that was really necessary. That was going to be a lot. As I said before, my husband watched his father go through it twice, and I knew how hard that was on him physically and emotionally. Our kids were ages four and six years at the time. They needed their mom, and so we weren’t really excited about the idea of doing a transplant. That was really my reasoning for

going to get multiple opinions, to make sure that people really thought that was necessary. And the answer was yes, they thought it was, and so we did it.

Mary DeRome (MMRF): There's a lot of work going on to determine whether or not people can do a transplant upfront, right after they finish induction, or do induction and then go on consolidation, go on maintenance, and then when they start to perhaps relapse after being on maintenance for a period of time, then do the transplant.

Jennie Shaw: Right.

Mary DeRome (MMRF): But I think that the data have shown that it really is still standard of care to do induction, and then do the stem cell transplant, if you're a candidate for that, and basically that's what all three of you did. You had your induction therapy, and then you had your transplant. When I think about going through something like that, it just seems that it's got to be hard. It's got to be hard to go through a transplant. Who wants to tell me about their transplant experience?

Michael Milano: I could definitely jump in and speak to it. It's mind blowing just because of the documentation that you have to read and understand, you and your family, and what you're up against, and what the complications can be. It was made very clear to me that there could be complications. There's no guarantee. When you start hearing words like that, you start looking at yourself. You start looking at your wife. You're looking at your family. It's a lot that goes through your mind, but I knew, based on the direction that I needed to go, and based on my team, that it was the way to go, and I didn't want to wait. So, yes, I went through the procedures. I went through the induction therapy. I went through all that. My numbers were looking good. My numbers were getting better.

January of this year is when we went through it. I went to North Shore University in Manhasset, to the great team over there. I have to tell you, it was definitely an experience that is very difficult to go through. You're there, and the team is around you constantly, and you're in a room by yourself. You're isolated. My wife would come, and my daughter would come, and you're dressed up to protect yourself. You have to be protected, and that alone is difficult, between the bloodwork and preparing and going to the chemotherapy. I went to two rounds of heavy-dose chemotherapy. That's what I needed to do for my particular case. It was 30 minutes of chemotherapy on day one, and 30 minutes of chemotherapy on day two. You take a break, after they take your stem cells out from you, and then, a couple of days later, your stem cells are transplanted back into your system again. And you can only hope that they start doing their thing and they start finding where they need to go back into your bone marrow and start to grow, and start to seed. It's just remarkable what happens to your system and what takes place. It's hard to put into words, but it's just amazing that stem cells come out of you and they know where to go. By giving you injections, it's like fertilizer,

to get them motivated, to get them [to say], “Let’s go. We’ve got to get back into our positions. We’ve got to get out there and start fighting the bad guys.” And that’s what happens.

Mary DeRome (MMRF): When they developed these procedures, years and years ago, how did somebody ever figure out that this was going to work?

Michael Milano: Yes. It’s just crazy. And then, once they start growing and they started doing what they need to do, I think it was around the 6th of January when they started to do their thing, it was like a new birth, they called it, for me. That was like a new birthday, which was great. They come in. They celebrate. And I’m still there. My goal was to make sure that my white cells were coming back and that my red cells were doing their job. I was in North Shore University for 17 days total before I was released. I can’t speak on behalf of Steve or anybody else, but I could tell you, it was definitely a trying 17 days. Going through this and the chemotherapy was a difficult task. But [there is] a great team, solid people around you. Every day, every hour, they check in on you, and they’re making sure you’re good, and if it wasn’t for them, the conversation might be a little bit different where we are today. It was just great, knowing that the team around you was definitely on target.

Mary DeRome (MMRF): Jennie, I know you had a transplant as well. Thinking about the fact that your father-in-law had two of them, were there differences between your transplant and the two transplants that your father-in-law had gone through?

Jennie Shaw: Yes, I think so. I was younger. I was in better physical health than he was at that time, and so I was a little stronger going into it. A few days before I was supposed to go in to do everything, I remember sitting at one of my kids’ basketball games, and one of the other parents, whom I was close with, said to me, “I can’t believe [it]. You look fine. You seem fine, and you feel pretty good right now.” And I said, “Yes, I feel great right now. All the pain’s gone.” He said to me, “It seems kind of weird that you’re about to go in and do this really aggressive procedure, you know?” And I remember thinking, “Yes, you’re kind of right. What am I doing with this?” But it felt good to feel good going into it and to feel strong enough that I felt like, “Okay, I’m going to be able to do this.”

And then I was in the hospital, I don’t know [for how long, maybe] three or four weeks. I had a few infections while I was there that kept me in, and I was very sick. I got a lot of gastrointestinal stuff while I was there, and that was really hard. I lost a lot of weight, which was concerning, but honestly, when I look back on it now, once I wasn’t feeling terribly sick, I was just so bored. I am a very busy person, and having to sit in that room all day long was just mind numbing. And people kept giving me coloring books and all this stuff, and I thought, “I don’t want to color. I want to go outside. I want to take a walk.” I just needed to get out of that room. That was honestly the hardest part for me.

Mary DeRome (MMRF): Steve, tell us what your transplant experience was like.

Steve St. John: I spent the entire 16 weeks of my induction researching transplants, tracking down everybody I could that had had one, just to seek advice and maybe a game plan. For lack of a better phrase, I sort of trained for my transplant. I tried to physically get in good shape, and I tried to have a game plan going in, which I put together from a couple of MDs I had tracked down that had actually gone through the process. So, I had a game plan sort of set once I got in there. For me, the overall experience was nowhere near as negative as I thought it was going to be. I was a bit of an outlier. I had very few issues with nausea, or side effects, or mouth sores, or the diarrhea, or any of those things that they tell you you're going to have with the melphalan [Evomela] and what that does to your body.

My experience overall was not that bad. It's not something I would want to have to do again unless it was necessary, but I was in a state-of-the-art facility, so my room was filtered, as were the hallways, so I was able to walk. One of my plans every day was to get up and walk around the transplant unit and do three laps, so I would get out of bed. That was difficult after about a week, once the melphalan set in and I was neutropenic.

It was a little more difficult to get out of bed, so my wife was a motivating factor there, saying, "Let's get up. Let's walk," but that kept my optimism up at a high level to do that walking three times a day. I would meet the staff in the hallway and run into the other oncology teams, and they would cheer me on. That was my game plan. And I had plans to eat and make sure I ate my meals. My appetite was fairly stable throughout the transplant, which is not the case for everybody. I got a good breakfast, a not-so-good lunch, and then in the evening, it was a challenge to eat, but I would do a milkshake in lieu of dinner. I was told that if you want to get out of the hospital sooner, get out of the bed and make sure you eat food. Don't let them feed you through the IV. Make sure you eat. If you get sick, eat again. If you get sick, eat again.

So, I had that game plan, but in terms of side effects, I was pretty blessed, overall, and I grafted very aggressively on day 11. It literally felt like they had hit me with a narcotic. It was kind of late in the evening, and I could just tell. I said, "I just don't feel that bad tonight," and the night nurse who was on shift said, "I heard a rumor that somebody might be getting released tomorrow." I was in this euphoric mood.

You literally can tell once those stem cells do their thing and they graft in there. It was an immediate uplift from that heavy, heavy fatigue. I describe it as feeling like a rag lying on wet cement. You're just sort of flopped there. You don't really want to do anything, so you have to make yourself get up. But again, I think that procedure is getting better and better as we go forward.

So, again, be careful researching transplants. My initial research was that it was just going to be this horrible, horrible experience that I would regret the rest of my life, and that was anything but the case for me and most of the people that I talked to. It was not something they would want to go through, but certainly something you can get through, and I think the benefits of it are worth whatever suffering you have to put up with to get through that.

Mary DeRome (MMRF): Certainly, things have progressed amazingly since the early days. There was a time in myeloma where transplant was literally the only thing that they had to treat the disease, and people would go through two of them, three of them, sometimes four of them, depending on where you were being treated, because there was really no other choice. Luckily, we've come a long way from those days.

So, all of you had your induction therapy, then you had your transplant, and now everybody's on maintenance. It looks like everybody is taking Revlimid maintenance with the exception of you, Jennie. It looks like you've had a little bit of a different path than the rest of the folks here. Can tell us a little bit more about where you are in your maintenance? You were on a clinical study for maintenance for a period of time.

Jennie Shaw: Yes. I was on a clinical study for Revlimid right after my transplant and I stayed on that study for about two to three years, at which point my light chain numbers started to rise again and I was no longer eligible for that study. So, I kind of got kicked out of that study, which was a good thing, because my doctor said, "I don't want you in this study if it's not helping you anymore," and so it really fast paced us to get onto something different. He recommended that I start on daratumumab (Darzalex), which I started in, probably, 2018, so five years ago almost. That started out with infusion, and now it's a subcutaneous shot in my belly.

Mary DeRome (MMRF): A five-minute shot, right? So, easy.

Jennie Shaw: You think, "Yes," except with the waiting time before and after of getting in the clinic. I joke that it's a five-minute procedure that takes two hours.

Mary DeRome (MMRF): How often do you get the daratumumab?

Jennie Shaw: Once a month. And now there's discussion with my doctor about — I don't know that there's any research that says for sure that you could go longer, but it seems like there's a pretty long half-life, and so it's possible that we could start to extend the period between getting the daratumumab to six weeks or two months.

Mary DeRome (MMRF): That's a really interesting story, that you were on a clinical study. Steve, you were also on Revlimid, and you relapsed after that within a period of years, right?

Steve St. John: Yes. I'm technically on my third relapse. Currently, I'm on Darzalex, pomalidomide (Pomalyst), and dexamethasone. I'm on that triplet regimen, coming up on 24 months of being on that regimen. That's worked really well, so that's a pretty good time frame to be on that one.

Jennie Shaw: I was on those three, and then at one point, I was having really bad peripheral neuropathy in my feet, and so the doctors decided to pull away the Pomalyst and the dexamethasone, mostly the dexamethasone, just because it made me crazy. Now all I do is the daratumumab.

Mary DeRome (MMRF): Mike, you just had your transplant six months ago, right?

Michael Milano: Yes. I had it probably close to six months ago, and now I'm on maintenance, and I'm going on my second month right now of maintenance.

Mary DeRome (MMRF): How has that been working out?

Michael Milano: So far, it's good. In the first month, I had some diarrhea issues that I was working through. It's still a little tricky, but it's been a lot better in my second month. I keep my fingers crossed, just listening to everybody on the call here, that as we continue to move forward there are other things on the horizon if this doesn't work out. I'm positive and keep solid, keep strong. I work out. I try to eat right, and I try to stay physical, on the track, and learn more about it every day. I feel good. My pain is probably a zero at this point in time, so I'm just on that solid track right now, and I'm feeling good, so I just want to continue in that direction.

Mary DeRome (MMRF): Let's talk a little bit about the importance of being able to speak plainly to your healthcare team and have your healthcare team speak plainly to you in ways that you can understand. It's really important that when you talk to your healthcare team, you communicate your needs to them and you are heard by them. That is, you tell them what your concerns are, and they help you with whatever your concerns are, and you talk to them about what choices you have for treatment where you are in your disease journey, about the side effects you're feeling, and how they can help with that, and maybe how they can help with stress and anxiety that you might have from this diagnosis, which is totally understandable.

Mike, you've also talked a lot about having your wife by your side through all of this. Talk to us a little bit about your relationship with your care team and how your wife has played a role in where you are.

Michael Milano: It just means a lot that you have somebody in your corner. That you can pick up the phone and you could speak to [them]. When I was in the hospital, I was able to pick up the phone and make a conversation. My wife would be there. My kids would be there. It's important that you have that support team around you.

And we get phone calls from Northwell. They would call up, asking, "How you doing? How are you making out? I just want to check up on you. Do you have any questions?" And that makes you feel that much more present in that moment.

It's so important to have a team around you that you can talk openly to, whether it's a neighbor or whether it's somebody [else] that you feel comfortable with. It's so important that you have that team around you and not take it in all by yourself, because you can't. You just can't do that. It's way too much. From Northwell, calling, making sure I'm okay, and [my] children, it's just a phenomenal feeling that you know you're going to get better and you have them around to support that.

Mary DeRome (MMRF): Talking to other patients is always very useful as well and hearing their stories and what they've been through, right? It helps you really understand some of the things that you're going through as well. It's always great to talk to somebody who has been through or is going through the same thing that you are going through.

Michael Milano: Yes, and you know what, Mary? That's why I'm on the MMRF site. I talk to people. I listen to the webinars. I find [it] very comforting to hear doctors and other patients talk about that there are good things on the horizon and they're looking for a cure. When I hear that, that just perks you up. I heard one of your webinars, and I forget who the doctor was, and the bottom line was, "There's going to be a cure for this." And when you hear that, it just makes you feel like you've got to continue your crusade. You've got to move forward. You've got to be strong, because you have kids. My son just got married, and it's important, right? And when you hear that there's going to be a cure, it just makes you, every day, have a little bit more skip in your step.

Mary DeRome (MMRF): Absolutely. I started working in the myeloma field in 2014, and at that time, nobody was talking about a cure. But now, since we have these newer therapies, like these chimeric antigen receptor (CAR) T-cell therapies and bispecifics and other things that people are developing for myeloma. This is the world that everybody is talking about now. Over the last couple of years, it's been really amazing that, from a disease that literally had a terrible, terrible prognosis not that long ago, the prognosis now is much better, and it's really almost become a chronic illness. And there are many, many other choices for therapies if you begin to relapse from whatever you're on currently.

There's always something new to go to, so I think there's really a lot of hope these days in the myeloma field that we will eventually achieve a cure. How that will be done, we don't really know yet, but we're inching closer and closer all the time, which is really a good feeling. Jennie, I know that when you were first diagnosed, you got opinions from a number of people, and then you were going to Memorial Sloan, and Dr. Landgren was your doctor, and he is the quarterback of your team, making sure that everything with you is going smoothly. How important was it for you to be able to talk to your care team and get the information from them so that you could feel like they were doing the right thing and that they were doing what you wanted them to do and meeting the goals that you had for your treatment?

Jennie Shaw: I really trusted Dr. Landgren so much because he's just like a wizard and knows everything, and I just trusted him, and he also was very kind to me, and I could tell he [had the attitude of], "You are not going to die from this. You're going to get through this." He had confidence in the science and in what could happen, and I felt so supported by that.

Really, the most challenging part for me was to be able to have him be able to communicate with my team in Virginia, which had some challenges, but for the most part, it was relatively smooth. And I had to stay strong [and say], "No, this is how we're doing it. We are going to have him as the quarterback, and we're going to have the team here in Virginia to implement the strategies," and it worked well.

Mary DeRome (MMRF): So, clearly, you told them what you wanted, and they heard what you said.

Jennie Shaw: Yes.

Mary DeRome (MMRF): It's a great example of how patients should be able to communicate and cooperate with the care teams and vice versa.

Jennie Shaw: I think you really do have to advocate for yourself though, because I did have to push back on it a few times when [they would say], "Well, now we can do this and that." "No. Nope. This is what we're going to do." My husband and I felt really strongly about it, and we felt like we were getting the best advice from someone who's truly a myeloma specialist. There were none in our area at the time, and so we felt adamant that that's what we needed.

Mary DeRome (MMRF): That's some good advice. Steve, how about your experience with your care team? I know that you're being seen at UT Southwestern, which is a great center for myeloma specialists. Dr. Anderson is amazing, and he has a couple of other great myeloma physicians on his team as

well, so tell us a little bit about your relationship with them, and your communication with them.

Steve St. John: Yes, I do think it's important that you're comfortable with your team, but I also think you have to make sure you have a voice. Sometimes they may just take for granted that you understand what the procedures are, or what the regimen is, and so I have a list of questions for Dr. Anderson every time I go in every month. They're on my phone, and he'll finish and say, "Okay. I know you have questions," and just during that month, things [have come up] that I'm concerned about, or just want to be empowered [about], or want to know, or maybe push back [on], or challenge.

I always go in with those questions, and he's usually able to defuse those to my satisfaction without any angst on my part, but I think it's important that you do have a voice, and I think they want you to have a voice. If you just sit back, they'll let you sit back, and they'll give you good care, but I think it's important that that be interactive, and you do have a choice. As I move forward and start to look at potentially going to a trial or some of these other treatments, then I'm going to do some research, and I'm going to want some pretty definitive feedback, and usually I put the ball back in their court. "If it were you personally, what decision would you make?" And I start with that. "If you were in my shoes with this disease at this stage, what would you do?" They're usually pretty straightforward about that: "If it were me, this is what I would do." Not that I'd necessarily go that direction, but I'd say nine times out of ten, I'm going to lean that way.

Mary DeRome (MMRF): Yes. I think that it's so important for myeloma patients to advocate for themselves. It's almost like being a consumer of your own healthcare. You need to know what you need, and then you need to be able to ask your doctor what you need and what your goals are. There are people that really want to treat their disease very, very strongly, and they're worried less about quality of life, but then there are other people who may be at different stages of their life where they're more interested in quality of life and being treated with something that's not going to give them too many side effects. Everybody has different treatment goals, but the most important thing is to speak plainly and communicate with your care team. Tell them what you're feeling. Tell them the side effects that you're having, because if they don't know what's happening with you, then they can't help you. That's a really important point.

I would really like to thank our three patients, Steve, Michael, and Jennie, for being with us today and talking to us about their experience as newly diagnosed patients. It was a great conversation. Thank you so much.

Narrator: Thank you for listening to this episode of the *Myeloma Matters* podcast on newly diagnosed multiple myeloma, hosted by the Multiple Myeloma Research Foundation. The MMRF thanks Jennie Shaw, Steve St. John, and Michael Milano for sharing their stories and unique perspectives on their

experiences with myeloma diagnosis and treatment. The MMRF also thanks AbbVie, BMS, CURE, Genentech, GSK, Janssen, Karyopharm, and Takeda Oncology for their generous support of this podcast. If you have additional questions about what you heard today, please call the MMRF Patient Navigation Center at 1-888-841-6673.

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