LEUKEMIA & LYMPHOMA SOCIETY®

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Choosing the Path Forward: Shared Decisions in Myelofibrosis Care'

Description:

In this episode, we speak with Mary Wells, who was diagnosed with primary myelofibrosis in 2018, a rare blood cancer that falls under the umbrella of myeloproliferative neoplasms (MPN). Mary walks us through her journey, from the side effects and emotional toll of cancer to finding the right treatment that allowed her to reclaim her life.

Mary shares the ups and downs of watch-and-wait periods, switching medications, and navigating side effects. Along the way, she advocated for her own care and partnered closely with her doctor, making shared decisions that ultimately led her to a treatment that works best for her.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Elissa: Today, we will be speaking to Mary Wells who was diagnosed with primary myelofibrosis in 2018, which is a type of blood cancer that falls under the broader diagnosis of myeloproliferative neoplasms, or MPNs. Since that time, she has gone through various periods of watch and wait and two different medications, the latest one having made a tremendous difference in her life. She is now living an active life with cancer, traveling around the world with friends, and working on home remodeling projects. Welcome, Mary.

Mary Wells: Thank you very much. Happy to join.

Elissa: Happy to have you here. So, let's start with your diagnosis of primary myelofibrosis. Can you tell us a little bit about what that is and then how you were diagnosed?

Mary: Well, it is a blood cancer that causes extreme fatigue. It is mostly defined by the fact that your red blood cells are too large. They're like twice the size of normal blood cells and yet they carry far less oxygen in each cell. So, fatigue is very common; and I would say that's what I started out with was in the summer of 2018, I was having fun. I was actually working as an Uber driver at the time-

Elissa: Oh!

Mary: -and did the early morning shift. I would be up at four in the morning and chauffeuring people from the airport to Silicon Valley or whatever and having a great time. It was very interesting to me. It was a lot of fun. But I noticed that in June, July that I was getting more and more tired; and I couldn't understand why and kept thinking, eh, it's something. It'll pass.

And it didn't, and by Labor Day weekend, I was really feeling terrible; and I actually had a colonoscopy scheduled for the Monday of Labor Day; and I've seen this doctor for years, good friend. And I showed up for this colonoscopy saying, "Something is terribly wrong."; and she's like, "Well, we'll look and see what's going on." And she came back afterwards and said, "That's not the problem. Come see me in my office later on this afternoon."

Elissa: Oh.

Mary: And I did, and she scheduled an endoscopy; and that wasn't the problem. So, then she got bloodwork back and said, "Oh, you don't need to see me, you need to see a hematologist." And I didn't even really know what that was. I know hema means blood, but I was like, "What?" And she said, "You need to see a hematologist, and there's one in our practice. Go see this person."

And I was stunned. I had no idea. I'd had mono as a teenager, and this was worse than mono. I was very tired when I had mono, but this was worse. So, I had to go see this other doctor and learned about the world of blood cancers. I mean, I'd heard of leukemia. I had a friend in Italy that had leukemia, but I had never heard of all the various types of blood cancer that existed. So, it was a real learning curve for me to understand that that's what I had. And because other factors for my age – at the time I was 68 – I was very healthy in terms of I didn't have the usual litany of problems that older people developed – the high blood pressure, high cholesterol, or whatever. And so, they said, "Let's wait and see what happens."

This first doctor suggested that I start on hydroxyurea, but I chose not to for a variety of reasons. And so, we agreed to a wait and see, and that lasted about a year or so. And then my spleen started swelling to the point that I could no longer eat a lot. And they call it "four bites and you're full," and I could barely get down three bites, and I lost about 50 pounds. And so they said, "You need to go on a drug to keep your spleen in control."

And so, I started on Jakafi®. And I did fine on that for a year or so. And I had what I'd call minor side effects. You get the itchies. Your skin starts to itch in strange places, but my spleen was definitely reduced. But then, after a year or so, the itching got to the point that for some reason it attacked my forearms; and they were on fire. And I ended up in the Emergency Room and had to get off the drug. You can't do cold turkey, so I had to taper off. And I was so relieved when the itching on my forearms stopped; but to this day, they're scarred. The skin is. It's like permanent damage on my forearms.

We waited another six months or so, trying to let my skin recover. And then, again, my spleen started to enlarge; and so I actually now have two doctors, one at Stanford and one in San Francisco. And the Stanford doc said, "You have to hold off. There's a drug coming out like literally any day now-

Elissa: Oh!

Mary: -called OJJAARA®." And that drug is meant for you. You're the perfect patient to be on that drug. Because, in addition to the myelofibrosis, I have a very rare form of autoimmune anemia and getting iron-deficient anemia off and on through this blood cancer. And so he was like, "No, you've got to hold on. Wait, wait, it's coming. It's coming."

And the drug was approved in October of 2023, and it took me until December being on the phone literally eight hours a day trying to get it put onto the Medicare formulary, trying to get it put onto my insurance's formulary to accelerate my accessibility to the drug. And so, in December of 2023, I finally got my hands on it and started taking it. And I have had side effects that we're trying to manage and deal with in different doses. It's still considered a somewhat experimental drug. There's not a lot of people taking it.

It's amazing how changing the dosage can change the side effects. And yet, my blood numbers have stayed rock steady throughout this year and a half. But at first, I was having constant UTIs (urinary tract infections), and I didn't have a history of UTIs. But still, you have to go through the scientific process of eliminating any possible other reason for it.

Elissa: Right.

Mary: And so I went through ten months of UTIs, and we adjusted the dose. And when I ended up from 200 milligrams down to 150, nothing happened. But when I went to 100, the UTIs stopped immediately. So, they came to the conclusion that the dosage does affect the outcome. And so, then I was fine on 100 milligrams for a few months, and then I started having bone pain, which is the second most common side effect of the disease. First is fatigue and then it's the bone pain. And my Stanford doc said, "That's because of the lower dose." And so what we're trying to do now is

experiment. And the reason I tell this whole sort of boring saga is that it's important for the patient to take an active role-

Elissa: Right.

Mary: -in deciding what works for them personally. And I said to my Stanford doc one day, "Why am I having these problems – whether it's UTIs or bone pain – but my numbers stay the same?" And he looked at me in amazement, and he said, "Because the numbers really have nothing to do with what the patient is experiencing."

And, I go, "Oh, okay, so I'm not crazy." And he's like, "No." But, he said, "You have to do this work. I'm perfectly happy not to see you for six months because I know you're stable. But it's going to take a long time to figure out exactly when to bump up the dose, and only you can do that."

And so, we're in the process of that part of the solution at this point because the complication is that, for example, when you have constant UTIs, it's difficult to leave the house. I had to start finding out about all the leak-proof underwear and stuff because-

Lizette: Yes.

Mary: -suddenly I had a problem I'd never had in my life.

Elissa: Yeah.

Mary: And that's behind me. But now with the bone aches, it's like, it's hard to feel excited about going for a long walk if it's going to hurt. And so, there's definitely struggles. But it's still so much better than what it used to be.

Elissa: Yeah. So, right now then, they're just adjusting the dose essentially to try to find just the right thing for you so that you have hopefully minimal side effects but that your numbers are still staying steady?

Mary: Right. And, they've pretty well established that any of the dosages work as far as keeping my numbers steady.

Elissa: Okay.

Mary: What we're experimenting with is getting rid of the symptom that seems to be independent of what the blood numbers are. So, and it's up to me; and this is where I say the patient has to learn, especially these types of rare diseases, has to be their own best advocate-

Elissa: Yes.

Mary: -and has to really pay attention. And I'm not a scientist at all. I didn't even pass Biology in high school. I mean I'm a linguist, I've been forced to be my own best advocate; and while I might not thoroughly understand the science, I do understand my own body.

Elissa: Yeah.

Mary: And I do understand when I'm not feeling well, suddenly there's something wrong that was never wrong before, but yet I've been taking a new drug. And you have to do that work to figure out what will work for you.

Elissa: Yeah, being your own best advocate definitely includes making sure that you're communicating those things with your doctor on a regular basis when they're happening so that they know these things and they can, hopefully, adjust things for you to make that better.

Mary: Absolutely.

Elissa: Just to recap so we know how the process worked for you, so after your diagnosis, you were on watch and wait for a little bit. Then you went on Jakafi. And then after the side effects went back to watch and wait for a little bit, up until OJJAARA or momelotinib came out, correct?

Mary: Yes.

Lizette: Wow. Now, I just want to highlight that you said that you were on the phone for such a long time, being such a great self-advocate. And you did have the doctors and your treatment team to assist you, but you still went and really knew that this was something that could really assist you. I mean it sounds really exciting when you said that the doctor said, "Oh, there's something coming out just for you. It's going to be so good for you."

Mary: And I believe in him in terms of he's one of the top doctors in the nation for MPNs; and I like the man very much. Very human, very accessible; and he believes in this drug and inspired me to believe in it. And so I'm fighting to stay on it. It's possible that the bone pain is simply coming from progression of the disease. After eight years, it might be understandable.

This Stanford doctor really believes in the drug and inspired me to believe in it enough, but they don't have the time to do the lobbying that is necessary to ensure that each patient gets the drug. And I was, I guess, the first that was proactive enough to find out that unless it's on the formulary, it doesn't exist for an insurance company or for Medicare. And I thought once the FDA approved something, it was just magically there. But it's not. There's a whole process that they have to go through to get it on their formulary. And, so, there was nobody to do the work but me in terms of calling.

Elissa: Sometimes that's what you've got to do.

Lizette: Yeah. I mean it's like you said, there's many drugs that are being approved by the FDA in the United States; but there's that issue of actually being able to get that drug for the people who need that drug. So, I am glad that you were able to get the drug. I'm glad that you're talking about access because access is an issue, and part of that is the advocacy.

Mary: Yes.

Lizette: LLS, we have a great advocacy team, and we really do implore everybody to join so we can raise our voices and be heard.

Mary: I see so many patients that just sort of say like, "Oh, this is what my doctor told me to take." And I think, the doctor means well; but the doctor's got thousands of other patients. You've got to advocate for yourself. And if you're having side effects, speak up.

Lizette: One of the other things that you were mentioning was that you were making decisions with the doctor as a team. So, kind of that shared decision-making model that we always speak to where you are a vital part of your treatment team. Many patients don't feel that way.

Mary: Yeah. All of my doctors have always been the type that say, "What's your opinion or how do you feel about doing this?" And I've always appreciated that because while I'm not a scientist, I do know what's going on in my body and what I react well to or don't.

Lizette: Right, exactly, exactly. Now, did your doctors speak to you in regard to myelofibrosis being more of a chronic type of cancer, a cancer that you want to manage with your medication?

Mary: Oh, definitely. I believe the average lifespan is seven years; but it's extended more and more as medications advance. And so, people can live successfully with these diseases for 10, 20 years and still have quite productive lives.

Generally, it happens in your 60s, although they believe that the gene defect started in your 20s or 30s. But the effects of it don't happen until you're in your 60s. So, it doesn't tend to impact your quality of life or your career. But you can still have very good quality of life into your 70s or 80s with these diseases.

Elissa: Right. So, let's talk about then living with cancer. So, I mentioned in the introduction that you have a pretty active life. Would you tell us a little bit about it?

Mary: Well, first of all, I'd like to clarify that it's not quite as active as you said in the introduction. I spent my life traveling. I was raised in London and went to college in Italy, and so I have friends from overseas. I used to go quite a lot, but especially since COVID, which happened shortly after I was diagnosed, as I still wear a mask when I'm in public and, because of a diminished immune system. And so, it has limited my lifestyle and some of the choices that I make.

Elissa: Yeah.

Mary: But I still, I wish I could go back to driving for Uber. I really enjoyed it. It was a lot of fun.

Elissa: Yeah.

Mary: I've always liked driving anyway, but I was picking up international passengers and taking them to big meetings and in Silicon Valley and all this. It was fun. But I don't have quite the stamina to do that anymore and, quite truthfully, there's not as much international travel for business anymore. Everyone's discovered Zoom.

Elissa: Right.

Mary: So, it's very different. But I'm just grateful at this point and at 75 years of age that I can live independently. I live alone and take care of myself and my home and now I use Instacart® for grocery shopping, just because I feel like I don't want to exhaust myself going to the grocery store when there's an alternative.

Elissa: Right.

Mary: But I can still go and travel within a limited area and see friends, go to lunch, go to dinner, go to a play, things like that that I would not be able to do if I were not taking the drug.

Elissa: Right, yeah. So, it does allow you to still live at least a somewhat normal life, even if you're a little fatigued maybe sometimes or have that bone pain or deal with

being immuno-compromised and having those restrictions to keep yourself safe but within those parameters still can live a fairly normal life.

Mary: Absolutely. Absolutely. I'm grateful for that. And for example, I did this little movie and it was two days of being picked up at 7:30 in the morning and dropped off at 7 in the evening. So, those were long days for me where I was the star, kind of always on. And the first day I came home so tired, I hadn't had a 12-hour day in a long time.

Elissa: Yeah.

Mary: And I thought I'm not sure if I'm going to make it tomorrow. And I just said don't think about it; just go to bed. And I woke up the next morning and thought, well, I'm still here. And to me, this is the difference with the drug in terms of that incredible crushing fatigue is gone.

Fatigue is like imagine living your life walking through mud up to your waist, whether you just have to get up to go to the bathroom or you want to walk a mile. Walking through mud up to your waist just makes every step so hard, and that's completely gone. I just don't have that anymore. And it's better living through chemistry; but it's working.

Elissa: That's great. And to give you some credit, I would think that older adults have some difficulty with 12-hour days all by itself. I mean, I'm in my 40s, and I have difficulty with 12-hour days. I would be very tired at the end of the day. So, I think that is completely normal. But I'm glad that you're still able to go see friends and go see plays and everything while you're on this drug, while you're living with cancer.

Mary: This is not a short battle. This is a long war. And it takes a lot of fortitude to fight for yourself in terms of the system. People have to be their own advocates, and it requires a lot of hours just to get accomplished what you want to accomplish.

Lizette: So, to manage your medication, how often do you go see your physician?

Mary: I see my hematologist here in San Francisco about every 6 to 12 weeks.

Lizette: And do you have worries about progression? Folks see you and they see someone that looks healthy. How does that affect you?

Mary: Well, it's frustrating at times, but I just decided from the get-go that I have to be open and honest about it in terms of if I'm like I can't stand in line for a long time. And they're like, "Why? You look like you're fine." And I'm like, "I have blood cancer." And even though they don't really understand what that means, that seems to, "Oh, okay." That will shut them up. And I'm just grateful that I have access to good doctors. I happen to live in a major city. My hematologist is literally eight blocks from my door, and most of my other doctors are as well. I have asthma, so I see a pulmonologist; and I have a whole bunch of autoimmune diseases and see other doctors, but they're all within eight, ten blocks of my house.

And aside from occasional anemia coming up in my bloodwork, and then they have to give me infusions, that's the only bad news that there's been in terms of my blood.. And if it's true that the bone pain is now because of disease progression rather than dosage of the drug, it's inevitable that that's going to happen at some point. Is it now? Nobody knows. So, I don't worry about it. If that's what it is, that's what it is. But in the meantime, I've been given an incredible opportunity to enjoy many extra years.

Elissa: And it sounds like you are really making a difference on your own for yourself and for other patients as well.

Mary: Yeah, that's become important to me. I've had other health issues in the past that were common. But when you get a rare disease, it's so unusual to find anybody that shares that, that it can be very lonely. And so, I'm all for sharing the experience and the wisdom that I have gained to say what I know might not work for you, but here's how you can talk to somebody who might help you find out what works for you.

Lizette: Right. I know that with many of our programs, we talk about community and how do you find your community? So, how have you found your community?

Mary: Well, I had breast cancer 14 years ago. And I learned through that about community; and I'm still in a cancer survivor's yoga class.

Elissa: Oh.

Mary: And over the years I have found that to be so sustaining. Through that, I learned about the importance of community in shared experiences.

So, when I was diagnosed with this, I googled support groups and the hospital system that I belong to has all sorts of cancer support groups, but it's for what I would call common cancers. They couldn't put together groups for blood cancer, so I had to cast a wider net and go online. And I found some groups within the Bay Area, and then I found organizations such as The Leukemia & Lymphoma Society, which does such good work and has the chat groups. And I found that very helpful because it's a wider net, and it's always good to hear what's going on in different parts of the country.

Elissa: Yes, the chat groups are wonderful; and we do have an MPN chat, and so we'll make sure to include that in the show notes, as well.

So, that actually leads me to my last question for you today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to your fellow patients and caregivers to give them hope after a diagnosis of myelofibrosis?

Mary: I would say hope for fortitude because it requires fortitude to fight a long battle and to fight it well and to have that strength, emotional strength, not the physical strength, but the emotional strength to carry on a good fight.

Elissa: Well, thank you so much, Mary. You have been such a wonderful example of a patient really advocating for themselves and advocating for others as well as you did

with getting this medication on the formulary. And so, we really appreciate you sharing your story. I think it was great to show others, other myelofibrosis patients, other MPN patients that there is hope. And so again, thank you so much for joining us today.

Mary: Oh, thank you so much for the opportunity.

Elissa: Thank you.

Lizette: Thank you.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

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We would also like to know about you, and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact LLS staff, please email TheBloodline@LLS.org.

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Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. For more information on myelofibrosis, please visit LLS.org/MPN. These links and more will be found in the show notes or at TheBloodline.org.

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