THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Pushing for a Diagnosis: A Polycythemia Vera (PV) Story'

Description:

Join us as we speak with David Wallace, a polycythemia vera (PV) patient and advocate. In this episode, David shares how he struggled to get his diagnosis, advocated to get the treatment he needed, and finally how he found a specialist that was able to treat his PV. He used his struggles to create the website, *PV Reporter* and nonprofit, MPN Cancer Connection, to educate patients about their disease, help them find resources, and increase awareness of MPNs. David encourages all patients to become their own advocates and to actively participate in their cancer journey.

Transcript:

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

Edith: I'm Edith.

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

Elissa: Today we will be speaking with David Wallace, a polycythemia vera, or PV, patient and advocate. Diagnosed in 2009 and finding minimal information about PV, which is one of a related group of blood cancers known as myeloproliferative neoplasms, or MPNs, he found that advocating for himself was the best way to manage his disease. David found support in the MPN community and wanted to give back, which led him to create the website *PV Reporter*, a comprehensive, patient-focused website for MPNs. Later, in 2015, he founded the nonprofit, MPN Cancer Connection, to increase awareness and access to local and national cancer programs. David is educating patients to become their own advocates and make informed decisions on their treatment.

Welcome, David.

David Wallace: Thank you for having me. Looking forward to the episode.

Elissa: So, let's start with your diagnosis. What is polycythemia vera, or PV?

David: PV is a chronic blood cancer where the bone marrow produces too many red blood cells, and it causes the blood to thicken, and the blood flow becomes slow.

Elissa: As I mentioned in our introduction, PV is a group of blood cancers called myeloproliferative neoplasms, or MPNs. Can you tell our listeners what that is?

David: Sure. MPNs are chronic blood cancers that cause the bone marrow to produce too many red blood cells, which is PV, white blood cells or platelets, and too many platelets as ET [Essential Thrombocythemia].

Elissa: Now what were your signs and symptoms leading up to your diagnosis?

David: Oh Lord, I had a lot of them. I had intense itching episodes. Fatigue was really bad. I had chest pain, which was a concern, shortness of breath, trouble concentrating, and red eyes and a red face.

Elissa: A lot of those symptoms can be attributed to so many other different diseases or disorders or injuries, but the itching is something that seems to be a little bit more unique. So, was the itching itself bringing the doctors a little bit closer to thinking, hey, this might be PV or something else similar?

David: You know, that's a great question. It actually was not recognized by my local physician or general practitioner. So, the situation I had with him was every time I would mention a symptom, he would kind of spin a little story and throw a negative feedback to me. So, when I talked about itching after showers and whatnot, he said, "Have you had your water checked?" And I said, "Yeah, I've had my water checked and that wasn't an issue." When I mentioned problems with pain in my big toe just being tremendous, he said, "Do you drink?" I said, "Yeah, I drink a couple beers during the week." He said, "Well maybe you ought to lay off the sauce." And everything that I would mention as far as a symptom, he had an excuse for but no answers.

Elissa: What was then the process that led you to finally getting diagnosed? How long did that take?

David: Yeah. I probably had PV for I would guess four to five years before I was diagnosed. I was someone who was very active. I worked out at the gym three times a week, rode motorcycles, went skiing, scuba dived, and whatnot. And I recall prior to my diagnosis a couple things – taking a motorcycle trip to the mountains and just having difficulty kind of gasping for air, and I'm like, "Gosh, that's strange. That's not good." And, going out skiing with my buddies in Utah and we were just about equal as far as how well we skied, but a couple of my buddies, they could make it all the way down the mountain, and I had to stop probably six or eight times along the way before I could make it down to rest. So that was an issue.

So, the night before I was diagnosed, in 2009, went out to hear a band and have a few beers with some friends, and it was a good night. But during the course of the night, I was having some serious chest pains. And when I came home, it started to get worse. And at that time, I'm like, "Well, I'm not ready to go to the ER," even though I kind of knew that's what I needed to do, but I said, "I'll sleep it off, and if I'm having the same issue in the morning, I'm going to go straight to the walk-in clinic."

So long story short, after several years of not being diagnosed, I go to the local walk-in clinic, which is literally three miles from my house, the next morning, and the doctor ran a blood test on me. And she came back and said, "I'm sorry, Mr. Wallace, we're going to have to take another blood test." And I said, "Well, why is that? I don't really care for needles and what's up?" She said, "Well, we just got a bad reading, so we need to make sure what's going on."

Anyway, so she came back after the second blood test and sat down with me with I guess you'd say kind of a serious look on her face and it, it didn't look encouraging to me, and she said, "You have a rare illness called polycythemia vera, and you need to go to the ER immediately. Your hematocrit is 69," which really none of that meant anything to me. All I knew that it wasn't good knowing that I had to go to the ER.

So, I actually went home first and had dinner and, quite frankly, a glass of wine because I knew I was going to be in for a long evening. And when I went to the ER, they did numerous tests – blood test, heart test, all kinds of things that at the time I really didn't even know what was going on. I was just panicked; I was frightened; I didn't know what all this meant, and they didn't use the word cancer in the ER. They told me "You have a blood disorder and, quite frankly, if you have to have a blood disorder, this is a good one to have." And I thought, wow, really! I've been healthy all my life, and this is good? I didn't leave happy with that, but they left me with instructions and said, "You need to follow up with your local doctor and have them get you an appointment at a hematologist for treatment."

So, I called my local physician and mentioned to them that I was in pain and having been to the Emergency Room and had the diagnosis of polycythemia vera and would they please get me an appointment with a hematologist immediately. I spoke with the nurse and she said, "Yes, Mr. Wallace, we'll get back to you shortly with that appointment." And I didn't hear from them that day. Really wasn't expecting to, but I waited until the next morning and called about 12 noon, and I said, "Have you got me an appointment with a hematologist?"

I felt like my chest was just hurting so bad that I needed to be looked at right away and I need help. So, they said, "I'm sorry, Mr. Wallace, we're still working on getting you appointment." And at that point, I said, "You know what, the heck with it. I'll find my own hematologist." And at that point, I got on the phone and I started calling. Literally, I just typed in hematologist on Google, and I said, "I'm going to find the first hematologist locally that can see me tomorrow." And there started my journey.

And in going through that experience, I learned that if you don't advocate for yourself and you don't push, things are not important to all medical staff like they should be, and you can easily be either forgotten about or kind of put on the back burner. So, I really feel like I learned to speak up very early on.

Elissa: I'm curious, thrombosis or blood clots can be a common thing to happen with PV. Is that something that you had experienced in that four or five years prior to diagnosis?

David: No. So that's a good point. I never had a blood clot and never had thrombosis, but I was at the point where once I had my diagnosis, I felt like if I didn’t get treatment immediately that I was going to have a heart attack or a stroke. That's the point I was at.

Lizette: Wow! Did you feel that after all these years when they did give you a diagnosis, which isn't something that, of course, you expected, but when you did get the diagnosis, did you feel a sense of relief for knowing that you knew you had something all these years?

David: So, I didn't really feel that relief, to be honest with you. I know that some people do. And I have kind of my own theory on that. I think that some patients that are, shall we say, birthed into the MPN world, if they hadn't had a lot of symptoms and are diagnosed via blood test, it's kind of a smooth transition and they're not going to be freaked out. They may be okay with the diagnosis coming that way. But for me, my life was in so much turmoil that I just looked at it like, oh gosh, here is a big challenge coming up. So yes, it did help to have that diagnosis, but I was also very scared of the challenges that lay ahead.

Lizette: I'm curious, were you able to get an appointment the next day with a hematologist?

David: I was not able to get an appointment the next day; it was actually the day after. And because of that delay, my chest was hurting so bad, and my symptoms were just out of control that I ended up going back to the ER for a second time. And in the ER, the doctors told me, "Look, we see that you've got an appointment with a hematologist tomorrow, so we feel like your situation would best be handled in the office of a trained hematologist." And I said, "You know what, this is an emergency, and I need treatment right away. Can you do a phlebotomy here in the ER?" And they said, "Well, we don't generally do phlebotomies here." And I said, "Well, you don't generally, but if it's an emergency, you can, right?" They said, "Yes, we can, but we'd have to do the phlebotomy through your hand." And I'm like, "You know what, whatever it takes let's get this done."

And so, they proceeded to give me a very painful phlebotomy by sticking this large horse needle in the vein in my hand. And my blood was so thick that they were squeezing the bag and moving the needle 100 times during the course of that procedure. And it was a very frightening experience, but that was my initial phlebotomy, and then the next day I had the appointment with the hematologist.

Elissa: Ouch! Can you explain to our listeners what a phlebotomy is?

David: Yeah. So, a phlebotomy is a removal of blood typically, I believe, a 500-cc bag. A large needle is inserted into a vein in the arm, and the phlebotomist removes blood from the patient and because the blood is from a PV patient, the blood is tossed.

Elissa: So then after they remove the blood, the reason that they're removing it is because they want to thin it out, correct? Because you tend to have very high levels of red blood cells and often then some high levels of white blood cells and platelets?

David: So, the removal of blood during the course of a phlebotomy reduces the volume of blood that's in a patient's system, and by having less blood in the system, that typically helps reduce some of the symptoms. And as long as the hematocrit, which is a measure of the red blood cells in your blood, is kept at 45 or below, that helps to reduce the likelihood of thrombotic symptoms.

My test came back at 69, the folks in the ER said that was the highest they had ever seen, which, of course, was a-

Elissa: Wow!

David: -bit of a red- yeah. Kind of scary.

Lizette: So, when you went to the hematologist, is that when you found out that it was truly a blood cancer?

David: You know, I don't recall being told that it was a blood cancer. I actually referred to online resources, and during the course of my research, at the time, they were calling it a blood disorder, but in digging deeper and as well as being connected with patients who were knowledgeable about PV, at that time is when I learned that PV, polycythemia vera, is, in fact, a blood cancer.

Lizette: And was it frustrating and confusing not to find a lot of information or did the doctor explain that polycythemia vera was under the umbrella term of myeloproliferative neoplasms?

David: Yeah, so, quite frankly, some of the doctors that I had early on did not really provide a lot of background information for me. They did mention that it was an MPN, but they didn't really have a grip on, you know, what were the treatment options, what should our plan be moving forward to take care of me so that perhaps I don't progress or get worse. So, the amount of information that they had, honestly, they were puzzled by the illness, and I think what they had was what they had read in the medical books many years ago. So, at the early stages, I was not seeing a specialist. I was just seeing a local hematologist who might've had to treat 50 different blood diseases, and how could that person really be very knowledgeable on PV.

Lizette: How did you come to see a specialist or come up with a treatment plan if the doctors that you were with weren't really sure at that point?

David: During the course of visiting with multiple doctors in our local healthcare system, I really reached a point of frustration. I had learned from patients in the community that Pegasys® was a drug that was available that would have the best likelihood of helping keep the disease at bay and perhaps keeping the disease from progressing to a more serious form of either myelofibrosis or perhaps AML. So, with that in mind, I set an appointment with the chief of hematology at my local healthcare system.

And on our first meeting, I think he had gone over my chart in some good detail and was probably frustrated and said, "Mr. Wallace, you've seen five local hematologists here. What could we do for you today?" And I have a tendency to be kind of chatty, and in this case, I decided that short and sweet answer would suffice. And I said, "Dr. I'm just looking for another doctor who knows more about PV than I do."

He looked at me and he was really taken aback by that statement, and he paused for a minute and said, "Do you mind waiting here? It might be 10 or 15 minutes." And I said, "No, I am totally cool with that." And about 10 minutes later he came into the room and he said, "We do have an MPN specialist here, and I think that you're really going to like this doctor," and "We'd like to go ahead and schedule you an appointment with this physician who is an MPN specialist." So, a week later I had an appointment with an MPN specialist.

And I came to the first appointed armed if you will. And by that, I mean, you know, I had been a patient advocate for some years. I had been attending the largest hematology conference in the world called the American Society of Hematology, also referred to as ASH. And so, I had reporter credentials and was interviewing doctors and attending presentations that were very high level.

And in 2015, there was a presentation that was given by a group of Danish physicians, and they were discussing the positive results that they had in treating PV and MF using the combination therapy of Pegasys, interferon, as well as Jakafi®. And one thing that I probably forgot to mention was I had been on Pegasys for about two years and increasing dosage. So Pegasys is typically started at 45 mcg weekly and then it needs to be increased until the patient reaches a level where their counts are under control. And over the course of two years, I was up to 135 mcg dose of Pegasys every week, and that medicine was killing me. I was having really bad peripheral neuropathy, which is pain and tingling, really pain in my case, in my hands just very debilitating, as well as depression also came into play. At that point, I'm like, "I want to stay on this drug, but I can't tolerate it." And so that's when I decided I need to find another method that will keep this as part of my treatment plan but help me battle PV.

And so that's when I kind of put two and two together, and when I saw the presentation on the combo treatment at ASH, I took note of the presentation. I actually took pictures of every screen and was able to take copious notes. And on the first visit with my new hematologist, I said, "I've been on this Pegasys for two years. It's not keeping my counts under control." And I saw a very impressive clinical trial that was done from the Danish team, and I presented him with a printout of the abstract, which essentially is the background research supporting the clinical trial. And I said, "And by the way, a lady that I'm friends with, in Chicago is on the same treatment and her doctor is Dr. X." And he said, "Oh, I know that doctor."

And immediately is sending an email to that doctor inquiring about the treatment and, apparently, he got an answer back very quickly. Did some due diligence while we were in the treatment room during the visit. So, it was a long first visit. And at the end of the visit, he said to me, "Mr. Wallace, I'll be okay with working with you on this treatment of combination Pegasys and Jakafi as long as you don't mind coming in for a blood test every week because this is a new therapy, there's no trial in the US on it, and I really want to monitor your counts." And I'm like, "Absolutely. I'm totally cool with that. I think that's a great idea."

And from that point on, I knew that I had a doctor who was not only extremely smart, but he was very patient-friendly. So, he was able to kind of realize that I had a good background in PV and work with me to come up with a treatment plan that would help me move forward with PV in the best fashion possible.

Elissa: That's great. What an impressive way to advocate for yourself and be able to bring that back to your specialist. I am a little surprised that it took two years of treatment to get to a specialist in the same clinic.

David: Yes. So, I was diagnosed in 2009, and I was not able to get to a specialist until 2016. And the way that that occurred, I think there's actually a lesson here and that lesson is Charlotte is a fairly good-sized city. And when I started my treatment journey with other hematologists, I really wanted an office that was closest to me. At that point I'm like "I don't want to drive downtown." And that's where the best office was.

So, the lesson for me was instead of just going to the closest office, why not find out who the best hematologist is in your city and pursue that hematologist. And they may be located a half hour, hour; even if it's two hours away, it's worth that trip to see somebody who truly knows about your illness. And if you don't have a specialist who's local, probably one of the biggest words of advice that I'll share with a new patient is, please be sure and see an MPN specialist and don't wait five years like I did. It will definitely help you to get on the right treatment plan and to have a doctor that you can collaborate with and work together on, improving your symptoms and improving your counts and, hopefully, improving your prognosis.

Elissa: That's just such good advice for patients. I think particularly with blood cancer patients, seeing a specialist is so important that knows about your type of cancer.

Lizette: Right, because the blood cancers aren't the most prevalent type of cancer, and even PV and myeloproliferative neoplasms, that's not the first thing that people are looking for. And like you said, there's not that knowledge about cancers that are a little bit more rare, so it's really important to find that person.

And I think I really want to highlight what you said. We're talking a lot nowadays about shared decision-making, which is the patient taking an active role in his or her or their treatment and actually having a conversation with their treatment team instead of having a one-way conversation where your healthcare team kind of tells you what your treatment is. It's having that back-and-forth discussion and the patient really taking an active role in and determining the treatment that is right.

David: Yeah, absolutely, and that's a great point. In previous physicians that I had seen, and I tried to get on interferon for probably, I don't know, a year and a half, maybe two years before I actually figured out that I'm going to have to fly somewhere to see an MPN specialist who can prescribe me that drug, make sure that I'm the proper candidate for the medication. I have been on hydroxyurea for a month, which my background and being in touch with fellow members of the community let me know that, hey, this is a chemotherapy agent. A little scary when you pick up the bottle and it says, "Make sure you're wearing gloves before you handle a capsule." That's a little worrisome, but I actually started on hydroxyurea after a flareup in the number of phlebotomies that I needed. Typically, during the course of the year, I might've had maybe six or eight phlebotomies a year.

What happened was during the second year with PV, all of a sudden, my counts just spiked, and I ended up needing a flurry of three phlebotomies in a course of about ten days. And I asked my doctor, "Why am I needing all these phlebotomies when things were kind of rolling along fairly well?" He's like, "I don't really have a clue. But you need to be on a myelosuppressive type therapy, essentially something to knock back your hematocrit."

And at that point they prescribed me hydroxyurea. In taking that medication, it made me just feel terrible. I just felt awful. I had no energy. I was fatigued, I was dizzy, and I was on that medication for about three weeks and went back to my doctor and took blood test on me every week when I started on that medication and my counts were all over the place. And after like the fourth visit, I just told my doctor, "Look, I can't handle this medication. Let's find a plan B."

And the plan B was Pegasys, but the problem was none of the local physicians actually knew about treating PV with Pegasys. So, I kind of went on a journey to find a physician that would prescribe me the medication that I wanted to use to treat my PV, and that's what resulted in having to see an MPN specialist who understood all the treatment options and knew everything that needed to be known about treating PV properly.

Edith: So, David, you were able to find support within the MPN community. Where did you find that support and how did it impact your life?

David: Yeah. So, I found private groups on Facebook that specifically dealt with PV and MPNs in general. And many of the groups were very welcoming and everyone kind of tried to help each other. It was a very collaborative environment. Every day I would read post and I learned who the patient leaders or advocates were. Many of them were helping me with questions, and they would share the latest research reports on PV as well as sharing their personal experiences. So just being in communication with some fellow patients, and many of those folks became friends, was very comforting to me. It helped me gain the knowledge that I needed to become my own advocate, and I was really very grateful for their help, and I encourage other patients to seek online support.

Elissa: You took your personal need for support and accurate information about your disease and started the website *PV Reporter*. Tell us about that website and what it does for the PV and MPN community.

David: I formed *PV Reporter* in 2013 because I found that the websites that were out there - some of them had good information here and there, but everything was internally focused. I didn't find that there were a lot of credible resources out there, and I wanted to create what I consider to be a resource hub for MPN patients. And I was, really wanted to create a one-stop-shop if you will that patients could come to and find out about a MPN specialist, what are the latest treatments, support groups, you know, all kinds of information that was not available at the time in one website.

And one of the hallmarks of the website at the beginning was MPN Search. And that search engine was based around some of the top MPN websites that were out there at the time that were credible sources. And so my strategy was to create a resource in *PV Reporter* that patients could simply type in PV treatment or MPN specialist and the search engine recognized those abbreviations and would pull back information from trusted resources. I created *PV Reporter* to be a one-stop-shop that would go out to those other resources.

Elissa: That's incredible. So, you were able to then help people find specialists, correct?

David: Yes. Now the specialist part was not in the first iteration of *PV Reporter*. That resource was actually added in 2018, and it became the number one most visited page on the website. I got emails from patients all over thanking me for providing that tool and asking me questions, and it became a standard in the industry. So, in social media if a patient is looking for an MPN specialist, fellow advocates would direct new patients to the MPN specialist page and that way they could see a specialist that was in their state or nearby that they could travel to.

Elissa: I'm sure that is just such an important and incredible resource for the patients to be able to find that information again in the one-stop-shop with all those other things, but as you found out, being able to find a specialist is just so incredibly important.

David: Yes. Yes, it is very, very important and that's why I made that one of the great focuses. Seeing an MPN specialist is really the first thing that's recommended to a patient. And having that resource on *PV Reporter* has led us to be one of the top visited websites in the industry today. So. I'm very proud of everything that we've accomplished with *PV Reporter*, and I'm very pleased with the assistance that I've got from members of the community who are willing to share their stories and doctors who share their research. What started off as a hobby and I never really expected that it was going to turn into my life's work, but it's something I'm very proud of.

Elissa: Now after starting the *PV Reporter*, you went on to found a nonprofit called MPN Cancer Connection. What is the mission of your nonprofit?

David: Yes, so MPN Cancer Connection is a nonprofit, whose mission is, first of all, to bring greater awareness of MPNs to the community, and it was also recognizing that MPNs are, in fact, a cancer. And because of that, there are numerous programs and support groups that are available to you as a cancer patient that would not otherwise be available. I'll give you an example that I learned early on.

During the early part of my journey, I was going through quite a bit of stress, and I wanted to get support. I needed a therapist, quite frankly, to talk to. And I didn't have the money to go out and pay for a therapist, and my insurance that wasn't something that they would cover. And I actually started doing some research, and I went to another cancer clinic – not the one I was going to – and I just told them on the phone, "Look, I'm a cancer patient, and I need somebody to talk to. What can you do for me?" And they said, "Oh we have a therapist that helps cancer patients and they know how to help you deal with your illness and think that it'll be very helpful for you." I remember mentioning to that person, I said, "To be honest with you, I'm not even seeing a doctor in your system." And they said, "Don't worry about it. We're here to help all cancer patients."

And from that point, I'm like, "Oh my gosh, there's so much out there that is available to cancer patients." By having our illness associated with cancer, it's actually a positive. It's not a negative.

Elissa: That's even more important because, you were initially told it was a blood disorder, and you need to be told that it is a blood cancer and that you are part the cancer community and have those additional resources available that would not be available had it just been a blood disorder.

David: Yeah, exactly. So, there were so many other programs that were available, whether it was counseling for nutrition. At the time, they were doing no cost massage therapy, which was awesome. I believe they turned that into a pay for program due to overwhelming demand, but other programs that were offered dealt with things like yoga, nutritional counseling, programs that would actually pay for assistance for airfare and hotel to fly out and see an MPN specialist. And at our local cancer center, there was even valet parking.

And I'll never forget how that came about, but when I came into the clinic one day after being a little late for my appointment, I had to park way down the street and walk a long ways and then try to remember where the heck did I park my car in this huge parking deck. And by the time I got to the front door of the cancer clinic, I was already winded and nervous. And I had seen a valet providing the service for fellow patients, and I walked up to the valet and I said, "I'm not in wheelchair, but I am a cancer patient. Can you provide this service to me?" And they said, "Absolutely, sir. Who are you seeing?" And I told them my doctor on the third floor, and they said, "Yes, don't ever worry about parking in the parking deck again. You come to us, and we'll take care of you." And I'm like, "Oh my God, this is fantastic!"

Elissa: That's great.

David: Yeah.

Edith: David, your story is truly inspirational. Thank you so much for sharing. So, on our patient podcast Home Page, we have a quote that says, "After diagnosis comes hope." Based on your cancer journey and advocacy experience, what word would you choose to complete that sentence, "After diagnosis comes?"

David: After diagnosis comes opportunity. And the way I look at that is an opportunity for knowledge, opportunity for treatment, opportunity to connect socially through a community that's supportive. So, it's really about becoming your own advocate, learning what the opportunities to connect socially are out there, and you kind of have to embrace the illness, as difficult as that sounds, and get out there and become your own advocate.

Elissa: Well, thank you so much David, for speaking with us today. I think that some of the things that you shared today about advocacy, finding a specialist, learning more about your own disease, and then the resources that you have come up with for all these patients are just so important, not only for PV and MPN patients, but just blood cancer patients in general. I think everybody can learn something today whether you're a patient or caregiver, so we really appreciate your time with us.

David: I'm so glad to have a chance to appear on your podcast. This is excellent. Anyone out there that's new be sure to check out the resources that I provide through *PV Reporter* and MPN Cancer Connection. And thank you so much for having me. I've enjoyed it.

Elissa: Thank you. And we will definitely have all those resources in the Show Notes for our listeners.

David: Okay, awesome. That's great. Appreciate it.

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. To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes. This is your opportunity to provide feedback and suggested topics that will help so many people. 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.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

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. You can find information specific to PV or MPNs at LLS.org/MPN. All of these links will be found in the Show Notes or at TheBloodline.org.

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.