

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'My MCL Diagnosis: Stan's Story'

Description:

Listen in as Alicia and Lizette speak with Stan Friedman. Stan is a trial lawyer and mantle cell lymphoma (MCL) survivor from Savannah, Georgia. After receiving abnormal lab work and noticing swollen lymph nodes that his doctor pointed out, Stan was referred to a hematologist/oncologist for a bone marrow biopsy. Join them as Stan describes how he was diagnosed, the initial questions he asked his healthcare team, side effects that were both common and uncommon, the importance of support from those around him, and how he is doing five years later

Transcript:

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

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

Alicia: Today we will be speaking with Stan Friedman. Stan is a trial lawyer and mantle cell lymphoma survivor in Savannah, Georgia. Thank you so much for joining us today, Stan.

Stan Friedman: My pleasure and, hopefully, something I will, say today will be of help to other folks who go through a similar treatment protocol and go through mantle cell lymphoma.

Lizette: I'm sure. Definitely. Not many people know that mantle cell lymphoma, is even a type of lymphoma. Have you ever heard of it before you were diagnosed?

Stan Friedman: Never and, of course, we do work being a lawyer and litigation, we know or encounter medical matters. But I had never heard of mantle cell lymphoma.

Alicia: And for those listening, mantle cell lymphoma, known as MCL, is one of several subtypes of B-cell non-Hodgkin lymphoma; and, usually, it begins with a lymph node enlargement. So how did it present for you, Stan? when and how were you diagnosed?

Stan Friedman: Well, I went for my annual physical in about mid-July of 2013; and I had my lab work first as is normal for most annual physicals. And shortly thereafter, a

couple of days later, I had the clinical exam or go see my primary care physician. And when I saw him, he said, "Stan, your lab work came back abnormal. Your platelets were very low." And during the physical exam of me, my lymph nodes in my neck turned out to be enlarged. And he said, "I think we have a problem." He said, "How do you feel?" And I said, "I feel absolutely normal" and did not notice the swollen lymph nodes.

So he sends me to a hematologist/oncologist who does a bone marrow biopsy in his office; and a few days later, I go back, and he tells me that I've got mantle cell lymphoma. So that's the story of how I got diagnosed. I had really no symptoms whatsoever that I was aware of. Of course, if I'd been more, I guess-

Alicia: Right.

Stan Friedman: If I could have, you know, realized that my lymph nodes were swollen, I might have, you know, made a note of it and called the doctor. But I certainly didn't.

Alicia: And then what's interesting is, you know, we were talking to another doctor who said a lot of times patients are skeptical because, like you said, you feel fine. There's nothing, out of the normal to, report on. So, when someone gives you such a huge diagnosis. You say to yourself, "Like how can that be? I'm fine. I feel fine."

So during this time, as you're getting this information, I mean like we said earlier, it's one of about 70 different subtypes of NHL. So, once you got this information, what did you do? Where did you go for more information about what the doctors were telling you?

Stan Friedman: Well, to some degree, you do some research on the Internet, of course. But my doctor was very available. Barry Luskey. He's an oncologist in Savannah, not only a great doctor but it turns to be a good friend.

He was wonderful about answering any and all questions I had. You know, the questions I had, first of all, I guess ranged from how bad a cancer is mantle cell; and what's the likelihood of survival? He said, "It's bad, but it's not, there are others that are worse." And he said, "Survival depends on a lot of factors. Mantle cell is a very aggressive cancer, but from the bone marrow, transplant, they were able to come up with, I think they called it, the Ki-67 value, which is a value ranging from 10 to probably 70 to determine how aggressive it is on the mantle cell scale.

Mine was a 10, as low as it could be; and I'm, to say the least, very thankful for that. So that was the first question. How bad was it? What are my chances of survival? And I guess from there, what is the treatment, and what happens if I declined to get chemotherapy? And, of course, he said, "You would be at Bonaventure Cemetery within a year." So that-

Lizette: Wow.

Stan Friedman: So that took that out of the equation pretty quick. You know, so he said, "You would need different treatments. You'll have to end up going to, in his opinion to a major medical center to get a stem cell transplant, but most of your treatment can be here in Savannah." And that, of course, that's why I ended up at Sloan Kettering. I think the choices were MD Anderson in Houston, Texas; Duke, in North Carolina; and then Emory here in Georgia. But I chose New York and Sloan Kettering.

And, of course, I asked him about the length of time of the treatment and how much treatment. You know, I had a lot of questions for him, the normal side effects of the treatment are what? And those were anywhere from, you know, losing your hair, which is certainly moderate when you look at everything else, to you're going to be fatigued probably. You're going to lose weight. You're going to lose your appetite. Ah, you may well be nauseated. I think those were the main things. Oh, mouth sores. That was another big issue.

But, thankfully, I was so lucky in that I had really none of those. I mean I had weight loss, yes, and I lost my hair. I lost 20 pounds during the treatment. I lost my appetite, but I gained it back very quickly. I weigh as much now as I ever did. I was fatigued to some degree, but I was able to work the whole time.

And when I was in, at Sloan Kettering for 22 days, receiving the last part of the treatment, which included a stem cell, I had to work with my laptop from the hospital. And then when I came home, I had to stay in New York for seven weeks, unfortunately, because my immune system was pretty much destroyed temporarily. And they didn't want me to travel while my immune system was so low.

And then, of course, I ask him, you know, what's the cost of all this? I was already under Medicare insurance. You know, what will Medicare cover? What will my Medicare supplement cover? And it was very minimal, truthfully, compared to what I thought it would be. So, again, it was much less unpleasant than I ever thought.

Lizette: Now you did have to travel for some of your treatment. And for mantle cell lymphoma, it's not one of these diagnoses, that are prevalent, we always like to tell people that it's always good to get a second opinion from a larger cancer center.

So the ones that you mentioned are larger institutions. They're designated cancer centers by the National Cancer Institute. And they are places that are affiliated with academic centers. So some hematologists/oncologists may not even see a person that's diagnosed with mantle cell lymphoma because it is more of a rare diagnosis. But in these larger centers, there are doctors that see people with this diagnosis. So your doctor that you did keep in Savannah, did work along with the doctor in New York, correct?

Stan Friedman: Yes. I mean he, he immediately, once he told me about the diagnosis and what the treatment I would need, he said you have this choice of centers because only a few centers in the country, at least in this part of the country, do stem cell transplants.

And he coordinated my treatment with them. I received most of my treatment here in Savannah, except for the last part of the chemotherapy regimen. I had three different chemotherapy regimens. The first one, R-CHOP, and I can't recall exactly what that involved. Received four treatments here in Savannah. Didn't have any side effects except hiccups.

Lizette: Hmm

Stan Friedman: That was really interesting. I had to receive; I think they had to give me some steroids to reduce the hiccups. That was an unexpected side effect.

And then I had what they call R-HiDAC, and that was actually given in the hospital for three days here in Savannah. And then later on I had to spend three days in New York getting the same treatment.

And then last, I got the last seven days of treatments in the hospital in New York. The problem with that is your immune system gets basically destroyed temporarily; so, you have to be basically in isolation.

So, I was in isolation in a room for seven days, and the only people I ever had contact with were the medical staff. It wasn't that bad. I had a laptop, I had a TV, and I could walk around the room for an hour or more a day to get exercise. So major medical centers are the only place you can get a stem cell transplant. You can't get

them in Savannah, Georgia. You could get them in Atlanta, at Emory, I'm sure. I chose not to.

Two additional side effects during treatment, were night sweats and the second was when you blew your nose, or I blew my nose, there would be a small amount of blood.

Lizette: Hmm.

Stan Friedman: The night sweats really became pretty heavy.

Alicia: Was it something that went away just as time went on?

Stan Friedman: Never got any prescriptions. I don't recall how long it lasted after the treatment, but I don't think it lasted very long at all. It was, you know, certainly, not comfortable and would wake you up when you're perspiring at night, but you probably lose sleep anyway thinking about what's next while you're going through the treatment. So it wasn't that big a problem, but I did, you know - I think many women who go through menopause know much more about night sweats than I ever will.

Alicia: Right. Right.

Lizette: A lot of people with lymphoma actually have night sweats as part of you know, a sign and symptom of the disease. So, they don't, they're not diagnosed yet, but they have these drenching night sweats like you're, like you're explaining. So, it's not just, you know, you're hot at night but it's actually you're sweating so you have to change out of your pajamas or change your sheets because it's that much. And a lot of times people do have that before they're diagnosed. And they go into their doctors and they tell them, you know, "I don't know what's happening." Or if you're a woman, sometimes you think you're going through menopause, but it is for lymphoma, one of the symptoms of the disease.

Stan Friedman: I might add one other long-term effect that I think is not common—

Alicia: Hmm.

Stan Friedman: -but I've developed a number of nonserious skin cancers since my treatment. And I've inquired with the doctors about that and they say that's really not that unusual. And I had been told even before I got diagnosed or had - I'm talking about 15 years ago - that the type of skin color or texture I had made me susceptible to skin cancer, so basal cells. You know, I go twice a year to get a full body exam. And I had a number of basal cells and a couple of squamous cells but, thankfully, no

melanomas. And what they now say is that because of the treatment and my proclivity to get skin cancers because of my skin type, I am substantially more likely to get skin cancer. So, again, I go every six months or when I see something that's unusual.

Lizette: I'm really glad you mentioned that, Stan, because a lot of people, unfortunately do get skin cancers as a secondary cancer, because of their treatment. So, it's very important for our listeners to know that their doctors should be tracking them for any type of skin cancer years out of treatment because that is something that could possibly happen due to treatment. So, I'm glad that you really brought that up. Thank you.

Stan Friedman: Well, again, unfortunately, it is a side effect and it makes me much more susceptible to it, but you just have to be alert. And oftentimes, especially if it's on my head, ears, nose, I'll go to a plastic surgeon. They can't make me anymore, you know, more attractive, but he can take the skin cancer off and minimize.

Alicia: They're taking care of the important things, Stan, the important things.

Stan Friedman: That's it. He can minimize the disfigurement from taking off the skin cancers. In fact, I had one on my nose, a squamous cell, he not only had to take it off, he had to do a skin graft as well. But, again, you can't tell it, and it's not a big deal.

Alicia: I know that you were in isolation; so, of course, you couldn't be in contact with people. But in regards to support, where was that coming from?

Stan Friedman: My wife, of course. My children. My staff here in the office, and my brother and his partner were amazingly supportive. They lived in New York. When I got out of the hospital, they actually gave their apartment in New York to me and my wife; and they came to Savannah to stay while I was in their apartment in New York. So, they were a tremendous help. I never expected them to move to Savannah temporarily, and it was in January, which is not a bad place to be, Savannah versus New York, I have to admit. But, again, they were wonderful. And friends were, were wonderful.

The Leukemia Lymphoma Society put me in touch with two people who were willing to discuss their treatment for mantle cell lymphoma and what to expect. It was wonderful to hear from them. One of them had had mantle cell lymphoma about 12 years earlier. His treatment was much different, the treatment had advanced a great

deal since then. The other person, a young woman, had had it a year before; and her treatment was very similar.

But discussing the issues with them and what I might be able to do to mitigate or lessen the side effects was very, very helpful; and that's one of the reasons that I'm doing this podcast with you is that if anyone wants to speak about it, tell them to pick up the phone or send me an email.

Lizette: No, but that's so nice that, you know, you, you feel like you're not alone in this-

Stan Friedman: That's for sure.

Lizette: -especially when you have mantle cell lymphoma which not a lot of people have heard of.

Stan Friedman: Well, again, they were so helpful; and they were wonderful. In fact, both of them lived in New York now. New York City. And one of them actually came by the hospital while I was in the hospital at Sloan Kettering, and she was very, very nice to say the least. And, I had contact with her about three or four weeks ago; and, thankfully, she's doing well. So regardless, they were very, very helpful.

Lizette: Some people, are fine starting treatment right away, and some people really want to find out about everything before they start. I was just wondering how that was for you, especially since, you know, you're a trial lawyer.

Stan Friedman: I flew up to New York, met with Dr. Paul Hamlin and also Dr. Matthew Matasar; and they are the specialists in mantle cell lymphoma, or at least were. I'm not sure they're still there or not because mine is over five years ago. And met with them and went through everything that they anticipated, and they anticipated I would go through.

And they always give you a worst-case scenario. There's no doubt about that. They don't want to minimize what potential effects will be. And so, I spoke with them, but from diagnosis to first treatment, it was six weeks; and the first four treatments were all here in Savannah.

Lizette: that was the R-CHOP that you got—

Stan Friedman: That is correct.

Lizette: -initially.

Stan Friedman: Yeah, the R-CHOP was first, and the worst thing I had from that was the hiccups. And I said, "If this is all that's going to happen, that'll be a pleasure."

Alicia: That's an interesting side effect.

Lizette: It is. I think I've heard about it before. I think one of—

Alicia: Yeah.

Lizette: -our programs somebody mentioned that they had that, and they were asking the doctor if that's something that's, you know, usual. And, and it wasn't usual, but it's something good to know.

Alicia: Right. the resource that you were referring to earlier is called our Patti Robinson Kaufman First Connection Program. And it's basically our peer- to peer program. And it's a free service. And what it is that, LLS believes that no one should got through a diagnosis alone, so we have so many support resources like LLS Community where people can create a profile and speak to other patients, caregivers, survivors, and just really get up-to-date information or just ask a question, on that social platform as well as First Connection where, like you said, you can connect with another person who's been through either the same treatment, the same diagnosis and provide that care and that comfort and that information, to each other. So, for anyone listening, I encourage you to go to www.LLS.org/support to see all of our support resources available to you.

And going back, Stan, to what you were saying earlier about side effects, you said that you had lost weight, you had lost your hair. How did you manage those side effects and others if there were others? How did you find yourself kind of getting through that?

Stan Friedman: Well, the hair loss, I didn't have a lot of hair to start with, so that was less of a problem, you know.

Alicia: Yeah.

Stan Friedman: By the way, the interesting part about weight loss, of course, you lose your appetite, I lost 20 pounds when I was in the hospital. By the time I - seven weeks later when I came back to Savannah, from start to finish, I was, I went up there the end of January, came back to Savannah in mid-March. It was - I'd already gained

back 10 pounds, so that was not a problem. But interesting, that I was unable to eat fresh foods. And when I say, “fresh foods,” like salads—

Lizette: Okay.

Alicia: -hmm.

Stan Friedman: -or fruit. You couldn’t eat salads or fruit for about four months because of your low immune system. I’m an exercise freak, was then and am now. I had to stay out of the gym and had to exercise at home because there are too, too much bacteria and germs in gyms. I couldn’t go to the movies. Same reason. And you couldn’t fly.

Alicia: -hmm.

Stan Friedman: Same reason because of so many germs in an airplane. So those were interesting things that I never expected until I was in the hospital and, of course, they said, “When you get out of here, you’re going to be restricted to some degree.” But nowadays, not only do I work full time still, I could eat anything and everything, and I still, I go to the gym every, basically every day. So those things were just temporary, but those were interesting.

The side effect that has stayed with me to some degree is that I will get a rash on my arms and legs every now and then, and it’ll just come out of nowhere and I’ll have to take some steroid treatment for that. When I say, “steroid treatment,” it’s a foam that I put on it and it goes away.

One of the people I spoke to who had gone through the same treatment I did, she developed neuropathy or numbness or loss of feeling in her foot. I have not experienced any of that at all thankfully, but that is a problem with her as she said, “I can’t wear high heels anymore.” So—

Lizette: Hmm.

Stan Friedman: -again, everyone is different.

Lizette: Right.

Stan Friedman: Some people get mouth sores, so you have to be very careful about oral hygiene during the treatment. And they will instruct you on that at, Sloan-Kettering or wherever you are.

Alicia: Right. We did an episode, on dental hygiene and that's something that people don't really talk about much or really know how important it is in regards to, their treatment and, and how well they can do.

Stan Friedman: I was going to add, the first thing I did even before the treatment, the first treatment, the first thing I did or was required to do was to get a port-a-cath placed in my chest so that I could get the chemotherapy through that rather than through the veins in my arm because chemotherapy is not going to be very nice for the veins in your arm. And the port-a-cath was nothing, truthfully. I mean it was a nonevent, but it was very helpful.

Alicia: -hmm.

Stan Friedman: and I kept it in in order to get platelet transfusions after the treatment and during the treatment but after the treatment for a couple of months because my platelets were still so low. They have never returned to normal. And I—

Lizette: Hmm

Stan Friedman: -presume it will always be low. But I've not had any bleeding problems at all.

Lizette: Yeah, cause when platelets are low, platelets are there to clot your blood. So, if you don't have enough platelets, you might have bleeding problems and also bruising. You can have a lot of bruising.

Stan Friedman: I did not have any bruising, but my platelets got down below 20 a number of times. I think normal is about 150 to 300. So, you can see my clotting factors were very, very low. And I got transfusions, which were, again, given to me through the port-a-cath. Nonevent. Just took up an hour of, hour and a half's time.

Alicia: So, I'm just interested in knowing was it a request not to do it intravenously from you and your family or was that just something that was determined based off of conversations that you had with your team?

Stan Friedman: The doctor gave me the option and the—

Alicia: Okay.

Stan Friedman: -pros and cons of it. And I said, "Let's go with the port-a-cath. If, if it's too much of a problem, we'll go to intravenously." And port-a-cath was not a problem whatsoever.

Alicia: That's great.

Stan Friedman: And I would highly recommend that because if you, you get chemotherapy intravenously, you may well, have problems with your, blood vessels in your arms.

Alicia: I mean that's why we do these podcasts really is that people can hear a story of a patient talk about their experience and also hear the questions that you asked and, hear how your journey was, to see if it's something that they can then bring up with their healthcare team. So, we really appreciate you sharing your story and allowing us to, to ask these questions and, hear about your journey. So, thank you so much for what you're doing today and what you'll be doing for those listening. We really appreciate that.

Is there anything that we didn't cover in detail that you would like to share?

Stan Friedman: Most people have heard of Stage IV cancers, okay. Mine had shown up in various parts of my body. I did not require any surgery. But, normally, when you have Stage IV cancer where it's metastasized to various parts of your body, that is a horrible diagnosis.

Well, my cancer responded to the chemotherapy treatment and the stem cell treatment. I have no signs of any cancer at this point and, again, it's been over five years, which is always an important marker when you go through cancer treatment.

Lizette: It's really important what you're saying, too, because even lymphomas, Stage IV means something totally different for blood cancers than they do for solid tor cancers. So, your Stage IV, really meant that you had disease above and below your diaphragm, so that it was throughout your body. And a lot of people do have it at Stage IV because if you have it in your bone marrow, which a lot of people do that is above and below your diaphragm. So it's a different type of staging with our blood cancers, so I'm glad that you brought that up because when you hear Stage IV, traditionally we all think, you know, that that means that it's towards the end and there's not many treatments available for you.

And with lymphoma, it doesn't mean that. Stage IV can also be treated. It's just really telling the physician, the treatment team, where in your body you have the

cancer. So that's really important to let people know that Stage IV is still treatable with blood cancers. Everybody's different, every blood cancer is different, but the staging for blood cancers is also different. So, thank you.

Stan Friedman: You're welcome. And, again, I appreciate you clarifying that for not only me but whoever's listening in.

Alicia: Absolutely. This is exactly the type of information and conversations we want to have so that patients are made more aware of their, diagnosis and feel comfortable, asking questions with their healthcare team and not thinking that, because I've never heard of this, I shouldn't talk about it. And the more that they know, the more stories they hear, the more that they could feel comfortable in having those conversations. So, thank you so much again.

Stan Friedman: My pleasure. Again, hopefully, it will be helpful to someone who is unfortunate enough to get diagnosed with any form of cancer but, in particular, mantle cell.

Alicia: Absolutely. And for those listening, who would like any free booklets about mantle cell lymphoma or NHL subtypes, please visit www.lls.org/booklets and also comment below, , this episode and let us know how, how you liked it and what you would like us to talk about in future episodes. Thank you, guys, for listening.

Stan Friedman: Well thank you for your work in this area. And I know what you're doing is very helpful to folks who go through, a diagnosis and treatment of this. So, thank you.

Lizette: Thank you.