

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Cancer Doesn't Define My Life: A Non-Hodgkin Lymphoma Story'

Description:

Don't miss this story of a patient who refuses to let cancer define his life.

Join us as we speak to Bruce Rieder, who was diagnosed in 2019 with mantle cell lymphoma (MCL), a type of non-Hodgkin lymphoma. In this episode, Bruce shares about his diagnosis and subsequent search for a clinical trial. He connected with the LLS Clinical Trial Support Center, sought out a second opinion and ended up with a specialist in a nearby cancer center. He received a stem cell transplant in February 2020, right before the world shut down due to COVID.

Now, two years after his transplant, Bruce stays active in the LLS Community and has received support from the Patti Robinson Kauffman First Connection® program.

Transcript:

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

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

Elissa: Today, we will be speaking to Bruce Rieder, who was diagnosed in 2019 with mantle cell lymphoma, a type of non-Hodgkin lymphoma. Following several rounds of chemotherapy and immunotherapy, he had an autologous transplant in February of 2020 and has been in remission ever since. Bruce was able to connect with LLS immediately upon his diagnosis, receiving assistance from the Clinical Trial Support Center and, also, enrolling in First Connection where he was matched with a fellow mantle cell lymphoma survivor. He has continued to remain engaged with the lymphoma community and staying current on research for his disease.

Welcome Bruce.

Bruce Rieder: Thank you. Glad to be here.

Elissa: So, Bruce, let's get started with your diagnosis of mantle cell lymphoma, which is an aggressive type of non-Hodgkin lymphoma. Could you tell our listeners what that is?

Bruce: So, mantle cell is identified by a particular gene mutation, and, on a microscopic slide, the biopsy cell is identified by kind of a ridge along the mantle or the periphery of the cell. And that's what technically differentiates it. It kind of starts off slowly but, without treatment, is a fatal prognosis of less than two years. And it is one of the lymphomas that always recurs. Even after treatments which are available, there's lots of them, right now it always recurs. As a result, there's a tremendous amount of research being done about it. There's a lot of clinical trials about it. It's an interesting area of study, so there's a lot of hope there.

Elissa: It is also one of the B-cell lymphomas, correct?

Bruce: Yes. So, that's sort of the technical piece of it or at least as much as I know, and it has just been amazing to me about how much science has advanced knowledge of it over the last 10 years or so.

Jesse: What were the signs and symptoms leading up to your diagnosis? How did you end up getting diagnosed?

Bruce: So, I was diagnosed actually by a biopsy. I had no symptoms. I was on vacation in July 2019. I had what I thought felt like a kidney stone, which I had before. Got home, went to my doctor. They said, "Oh yeah, let's do a scan of that. Oh, sure enough there's a kidney stone. Let's take care of that." And at the very bottom last sentence of the CAT scan report was, "Oh, by the way, there seemed to be a lot of lymph nodes in the abdomen, maybe you should check this out."

So that was July. We cleared the kidney stone. I was referred to an oncologist. The oncologist said, "Oh this doesn't look too bad." Took bloodwork, looked fine. "Let's do

another CAT scan with contrast. Let's do a little more investigation." And that came back a little more worrisome at which point I was then sent to get a biopsy, and they took cells from under my arm. And August 23, 2019, that biopsy came back as identified mantle cell lymphoma.

So, that's when I found out. I mean it was sort of a kind of rolling process. But I knew the moment I saw that first scan of my kidney stones that something was not right there, and this was going to be something. And it was.

Elissa: I think we hear that a lot from cancer patients that sometimes they just know, even if it is not confirmed yet, if it is just some initial scan or something else or a feeling.

So, Bruce, now after your diagnosis, you connected with LLS, which we'll talk a little bit about more later, but one way you connected with us was through the Clinical Trial Support Center. Could you tell us about that experience and what kind of assistance they provided?

Bruce: Well, that was super. So once I had a name for the lymphoma, mantle cell, then just this whole firehose of information opened up just by clicking on that and looking around, and I quickly found LLS seemed to have most of the information about it. So almost immediately I connected with them. I mean I quickly saw clinical trials is where kind of the action is. And they got back to me within a couple of days with a very comprehensive list of all the different institutions across the nation that were doing research on my specific mantle cell lymphoma. Even though there was not one that I exactly fit into, it was extremely helpful to me to figure out, okay, who's doing the work around this specific cancer. Where are the knowledgeable people? Even though there was not a specific trial for me, that piece of information was extremely helpful to me in determining where should I go to get a second opinion.

Elissa: What did you end up doing for the second opinion?

Bruce: I ended up going to Memorial Sloan Kettering in New York City. By happenstance, my sister-in-law is a cancer survivor. She lives in Manhattan. She'd been there. She said, "Go there." The clinical trials told me, "Oh they've got a whole team that's working on this. Seems to be the place to go." And I want to say at first that was really intimidating. I was like, "Oh Memorial Sloan Kettering, my gosh, that's like this major place. This is going to be a big deal!"

Elissa: Yes.

Bruce: I called them on the telephone. I got a wonderful person. Within 24 hours, she was back at me with an appointment in their New York office for the following week. You know, "Send me your slides. Send me your information." And therein lies a lot of the stuff you learn is they're anxious to see anybody at Memorial Sloan Kettering. They're a research facility. They need to see as many people as they can to get a big picture. So, it was extremely easy for me to get in there and it didn't cost me a dime. My insurance covered it. The whole expense was just driving up there and sleeping on my sister-in-law's couch overnight.

Elissa: Yes. We always encourage those second opinions.

Bruce: Exactly.

Elissa: It's good for your comfort level. It's good to know what's out there, what research is out there, clinical trials, so that's great. And where did you end up then?

Bruce: For treatment?

Elissa: Yes.

Bruce: So, once I got the second opinion, came back to my local oncologist. Memorial Sloan helped us with the treatment schedule it was a different treatment than my local oncologist was going to do. And my local oncologist was delighted to have that contact of most recent research. He was a great team leader. Memorial

Sloan was perfectly happy with that treatment being done here for chemotherapy and immunotherapy, and they recommended then, if that was successful, to go onto a stem cell transplant. I had immunotherapy, chemotherapy here in Arlington over a period of about four months.

Jesse: Bruce, after you got the second opinion and ended up back in Virginia, with your original oncologist, could you tell us a little more about your treatment?

Bruce: The initial treatments, in Arlington was chemotherapy with R-DHAP, R-CHOP. These are all acronyms for a series of drugs. It was a session of chemotherapy once every four weeks over a period of four months, four sessions. I was really nervous about it. The first session I asked to be made inpatient, and actually did it in the hospital. Again, it was all covered. It worked out fine. Some of the drugs are pretty scary, but I tolerated everything fine.

And then after the succeeding three treatments were done; I would go in to get the initial infusions. Then there's one that goes overnight and that they would send me home with a machine and do the treatment at home, the last piece, the overnight piece, and then I would just bring the stuff back to them. Worked pretty well.

Elissa: That's nice to be able to bring something home with you rather than having to stay for each of your treatments in the hospital.

Bruce: Exactly.

Elissa: Yeah. Oh, that's great.

Bruce: It got me out of that environment because if I was to sit there the whole time, it was like an 8- or 12-hour treatment, so it was a long time.

Jesse: And then you went on to transplant, is that correct?

Bruce: That's correct. So, that being the recommendation going in, I was the lucky one. Lucky and unlucky. Lucky in that by the time of my second treatment

immunotherapy, the doctor was delighted at the results. And by the fourth, I was in remission by the fourth treatment of the immunotherapy/chemotherapy.

I will say I had a bump along that road. I had a reaction to one of the drugs, fortunately, not one of the main drugs that resulted in an ulcer, which put me-

Elissa: Uh-oh!

Bruce: -in the hospital for a while. Everybody's body is different. Everybody reacts differently. And we found in the literature that some people do have a reaction to this particular drug. By that time, the doctor had seen I was doing pretty well; he just took that drug out of the regimen, and we continued on, and it was still successful.

So, those things happen, and you have a team for that reason, right, that you can call.

Jesse: Absolutely.

Elissa: Now I want to clarify your autologous transplant a little bit for our listeners who may not know because there's two types of transplants. We often hear about allogeneic, which is using donor cells, but you had the autologous using your own cells, correct?

Bruce: Right, that's correct. I did research again, where should I go to have that done, and in my local area, the University of Virginia in Charlottesville seemed like a good option for me, not only because they were doing a lot of research but also because I was an alum.

I called Memorial Sloan Kettering in New York and asked my doctor there, "Do you want me to come there to do the stem cell?" And he was, "No, no, no, you have perfectly fine institutions right in your area, you don't need to come here," which, we'll get to later, turned out to be a really great decision.

Elissa: Yes.

Bruce: So, I ended up in Charlottesville for the autologous stem cell transplant, and that is using my own stem cells to reinvigorate my immune system after my immune system has been destroyed. And that's the goal of what they call the conditioning is to deactivate your immune system and then restart it with your own stem cells.

Elissa: Very interesting. Now let's talk a little bit more about that transplant and when it was-

Bruce: Yeah.

Elissa: -since it happened at a very crazy time in our world. You had the transplant in February of 2020 and then were released that following month, right around the time the country was starting to be locked down from COVID.

Bruce: Right.

Elissa: What was that all like?

Bruce: Oh my gosh! I mean in hindsight it was terrifying.

Elissa: Yes.

Jesse: Yes.

Bruce: And that's all just a testament to the great job they did at the hospital. They really just didn't communicate to me the kind of underlying concern that they must have all been having. I was admitted to the hospital on the 17th of February. Went through one week of the conditioning, which addresses the immune system, and then had my stem cells reintroduced into my body on the 24th of February.

The way that works is they give you the stem cells back, you have a few days of feeling kind of okay, and then you fall off a cliff basically as your immune system is shut down. There's kind of a waiting game until the new stem cells take hold of your immune system and start regrowing. So, they test for that every day.

I was released on March the 9th.

Elissa: Wow!

Bruce: The university had already closed down. Students did not come back from break. One day during my time in the stem cell unit, all the PPE disappeared. All the masks, all the gowns, all the gloves, everything just disappeared overnight. I suspect they were just redeploying it throughout the rest of the hospital, but—

usually in the stem cell unit, there's a whole rack outside of each door that's as big as the door with all the PPE (personal protective equipment) because everyone coming into my room had to have it on. I had to have it on when I left.

Elissa: Yes.

Bruce: And it all just disappeared. It was kind of freaky.

Elissa: That's probably one of the most immunocompromised floors on the hospital. I mean-

Bruce: Yes.

Elissa: -to have all that PPE taken away that must have just been very strange.

Jesse: Yeah.

Bruce: Well, they had it there. It was behind the desk. You had to go to the main desk and ask for it and that's how you got it.

Elissa: Wow!

Bruce: So, it was strange, it was just a lot of strange things happening. When you have a stem cell transplant, one of the things that happens is that you immediately become susceptible to infections and about 70% of stem cell patients get an infection while they're in the hospital. And I had three infections. I had two intestinal

infections, one of which was *C.diff*, which I probably don't have to describe. It's very unpleasant. And then the third infection I had was a rare lung infection, a fungal infection, which was fascinating. Everyone was fascinated for a number of reasons.

Elissa: I don't know if you ever want that.

Bruce: Exactly. Exactly. But one of the reasons was because it looked exactly like COVID.

Jesse: Oh!

Elissa: Oh!

Bruce: It had every appearance of COVID, but it was not. It was a fungal infection that comes from contact with dirt or soil, which I'm a gardener, so it was not unusual. They said-

Jesse: Oh!

Bruce: -"This is not unusual for a gardener because this is the kind of fungus that enters your lungs, and your immune system just automatically clears it all the time. You must have entered the hospital with some trace of it that it hadn't finished clearing and it just exploded." And it took six months to clear that infection. And they told me, "You-

Elissa: Wow!

Bruce: -cannot go to a hospital, you cannot go anywhere and get tests because they're going to immediately diagnose you as having COVID because it looks exactly like COVID on an x-ray."

Elissa: It's weird looking back at that. Right in the beginning what we didn't know about COVID and how we just didn't know what to do as far as mask wearing, PPE,

how it spread. And to come out of the hospital with being so susceptible to infection just must have been terrifying.

Bruce: Well, so a couple of things there. It would've been more terrifying had I had this done in New York City-

Elissa: Yes.

Bruce: -and left the hospital and having to stay there for 10 weeks. So that's that process with the stem cell transplant, they do about 3 weeks in the hospital and then you need to return to the hospital each day anywhere from 6 to 10 weeks for-

Jesse: Oh wow!

Bruce: -checkups. So, they get you out of the hospital proper, but you stay in a hotel or something nearby. So, I was in Charlottesville until May the 4th. I was much happier to be in Charlottesville than I would have been in New York City. It worked out great for me because I didn't have to explain to anyone that they needed to wear a mask, that I was compromised because everybody was wearing masks. It was suddenly much easier to have people understand that sensitivity.

When I first went for the orientation in January and they told me, "Well, you're going to have to wear a mask for probably about a year when you go out." And my mind was going, "Well that's never going to happen." I can't even imagine that happening, that people will do this.

Elissa: Here we are two and a half years later.

Bruce: I didn't have to say anything basically. There was a good and bad to that. My main stem cell doctor, about a week before I came into the hospital told me, "I'm going to a conference in Florida, but I'll be back about the time you check in." And I didn't see him for about two weeks. I'm sure they quarantined him because-

Elissa: Yeah.

Bruce: -he was traveling during COVID right at the very beginning. So, there was just all kinds of stuff like that going on that in hindsight I could say, "Oh, that's why they did that." They did a great job of getting me through it. And entering the world, I was very fortunate I had a place that I could isolate. Arlington, Virginia, was a hot spot at that time and, fortunately, I had a place that I could isolate that was much less of a hot spot out in the country, and I stayed there for a year.

Jesse: I wanted to say as a fellow Virginian, I'm so happy to hear of the care that you received in Charlottesville. That's very reassuring for cancer patients. But you have stayed in remission for over two years since your transplant, which is amazing. But during that entire time, as we've said, we've remained in this pandemic. What has life been like over these past two years living in a pandemic while immunocompromised?

Bruce: Extra care. There's still things I won't do. Anything in a big crowd. I pretty much won't do theaters. I'm just a little bit more careful, I think, than other people. In addition, for those that have my particular cancer, the maintenance treatment is Rituxan®, and Rituxan is a drug, that I learned through LLS, that counteracts the vaccine. So, I had four rounds of vaccine with no discernible development of antibodies. So that was another year even the vaccine didn't help until LLS let me know that Evusheld™ a monoclonal treatment, had been approved in December, and I got my first dose in January, and, boom, suddenly I had antibodies for the first time.

Jesse: Great news.

Bruce: Great news. A big load off my mind. I'm still careful. I mean there's still things I won't do. Dr. Saltzman at LLS has given very good advice. He says, "Even though you're immune and may have some antibodies, you still behave as if you're not. You're in a very sensitive place." And, fortunately, I've not been exposed.

Elissa: Yes. And Dr. Saltzman also has a B-cell malignancy, so he's right there with you and completely understands what it's like to not get a response from the vaccine. We spoke with him on the podcast last year and he completely understands as well.

It's been a scary time for blood cancer patients. I'm an AML survivor myself, so it's hard to go through this knowing that you may or may not respond to the vaccine. You don't know how your body would do with COVID no matter how far out you are from-

Bruce: Right.

Elissa: -treatment. So, it's been a scary time.

Jesse: Absolutely.

Bruce: Absolutely. I haven't totally retreated. I mean I have been able to take some trips. I've been on a plane twice, masked, glasses and the whole thing. And it worked out fine. I understand that's a risk. Again, those are all individual decisions that different people might do different things.

Elissa: Yeah. It's good to try to still live your life. You don't want to be sheltered in forever, and so it's nice to find things that you can try to at least do safely and still have a good life. We'll talk about what living with cancer is like, but for right now I mentioned earlier that you got connected with LLS very soon after your diagnosis. So besides working with the Clinical Trial Support Center, what other ways have you been engaged with LLS and the blood cancer community?

Bruce: Well about the same time that I contacted about clinical trials, I also contacted the peer-to-peer connection.

Elissa: Yes, the Patti Robinson Kaufmann First Connection Program®.

Bruce: And I immediately hooked up with my friend Bob in Ohio. We talked on the phone very frequently and right from the very beginning. Bob had my same mantle cell lymphoma at that time, 11 years prior, so he was a long-term survivor. He had

the same treatment. He had a stem cell transplant. And it was just a wonderful validation, one-on-one, friendly, am I doing the right things here, am I worried about the right things? He would say things like, "Well that's down the road. Don't worry about that right now. That'll come later." And just that pacing of getting through all of this was just invaluable to me. I hooked up with some local support groups, but that was my first contact and remained my most important one. So that was great.

Since I've been in remission I've been on a number of seminars. There have been several online programs specific to mantle cell lymphoma and the research being done. Like I said before, there's a tremendous amount of research being done, because you know they've not been as successful at keeping recurrences from coming back. So, there's a tremendous amount of research and it's very encouraging.

Elissa: And you've also gotten involved in our LLS Community, right?

Bruce: Yes, yes, yes, the online community, the weekly questions, the discussions, and that's where I found this great website that somebody posted and said, "Go to this website and they'll tell you where they have Evusheld." It was-

Elissa: Oh!

Bruce: -wonderful. It was like, "Oh here's what they ship to Arlington. Here's how many they have left." You may or may not know, it was kind of in short supply especially at the beginning and there was sort of a food fight to get it.

Elissa: Right?

Bruce: Yeah, exactly.

Elissa: You almost had to be in the know.

Bruce: That was really handy to be able to call my oncologist and say, "Hey, I understand there's some doses in Arlington Hospital, can you get me an appointment?"



Elissa: That's great. Now LLS Community is almost a little social network, right? And there's questions posted, but patients, survivors, and caregivers can also post questions and share things. Has that been helpful for you overall?

Bruce: Yes, it has been. Both validating of my own experience and informative for me. There's just so much information, and you've got a giant to-do list. You don't know what to do first. And I just think those contacts are helpful for people.

Elissa: Yeah.

Jesse: Absolutely.

Elissa: Support can definitely be invaluable. And we'll make sure at the end of the episode and on the Show Notes to post links to check out LLS Community so other people can hop on there. And if there's any mantle cell lymphoma patients listening, they can come say hi to you.

Bruce: Yeah. And as I say, the programs that LLS has had has just been great. And, in fact, during the last six months or so, LLS has updated the mantle cell pamphlet which increased the years of prognosis of successful treatment. So that was encouraging, and that the information is kept current because I learned that when I first started. It was like I was getting all this different information online until I figured out that it was all dated. It was like, if I was looking at something from 10 years ago, it was not accurate. You really had to concentrate on the most current because the landscape had changed so radically in that period of time, and LLS has the most current information.

Elissa: Yeah. And really just over the last few years blood cancer treatments have changed dramatically. With the number of approvals, the number of clinical trials going on right now that are turning out to be successful. So, it's very good to get accurate information.

Bruce: Yup. Yup.



Jesse: Earlier this year, our team did a podcast on mantle cell lymphoma with Dr. Lampson. And in the episode, he shared that one of the most important goals of treatment is quality of life. He wants to see the patients living their lives without the burden of cancer weighing them down. So, before we end today, Bruce, tell us about your life with cancer. What do you enjoy doing in remission and ultimately, what's important to you?

Bruce: So, I had already retired before I was diagnosed.

Elissa: What were you doing?

Bruce: In my career? I worked in real estate development and for the Department of Housing and Urban Development for a few years at the end of my career in public housing. It was a very fulfilling career, but I was ready to retire.

Elissa: Yes.

Bruce: And so, we did. My husband and I both retired at the same time. We like to travel to the national parks. I did a lot of work in my church. We travel a lot. A good bit to the national parks. My two flights that I've taken were to California to go to Yosemite where we like-

Elissa: Oh!

Bruce: -to go every year. If we go out there-

Jesse: Oh wow!

Bruce: -we do hiking vacations and very socially distanced vacations.

Elissa: National parks are good for that.

Jesse: Yes.

Bruce: Exactly. So that's worked out very well. So, there's a lot I can do. I can go out with friends. A lot of times we'll just have friends over to our house or we'll go over to their house and get takeout. So that kind of thing rather than go out to a crowded restaurant. My quality of life has returned to what it was three years ago, before-

Elissa: That's good.

Bruce: -this diagnosis. I'm pretty much doing most of the things that I could do then. I'm an active alumnus of the University of Virginia, which, by the way, since the time I was there, has now become a national clinical cancer center.

Jesse: Yes, they have.

Bruce: In the country.

Elissa: Wonderful.

Bruce: So, it was a great place to be. And this last year was my 45th college reunion, and I was able to be on the co-chair committee and be active in that.

Jesse: That is great.

Bruce: That was cool.

Elissa: Very nice. Bruce, our last question for you today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you finish that sentence, "After diagnosis comes?"

Bruce: So, immediately after diagnosis came clearing the decks and assessing my life-

Jesse: I like that.



Bruce: -and understanding that my life, my everyday was not always going to be defined by this cancer but today was not that day, but I could look forward to that day.

I have that day that cancer does not define every day of my life. It's there. I do the things. I do the things I need to do to continue my treatment, to keep up with it, but I'm living my life. And so, after treatment comes living your life. And that's been true for me.

Elissa: I love that. That's a great thing to think that cancer doesn't define you. It may be part of your story always, but it doesn't define who you are. You can definitely try to find ways to continue to live your life. Even if it's maybe not the same as before, find those small joys in life, find those small victories.

Well thank you so much, Bruce, for talking with us today. We really appreciate you telling us your story, and I'm so glad that you have been able to get involved with LLS and, also find so much support here. So, again, we appreciate you sharing with us today.

Jesse: Yes, thank you.

Bruce: Thank you. 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. 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 could be found in the Show Notes or at TheBloodline.org. 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.



In addition to the survey, we are excited to introduce our brand-new Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. Join for free today at TheBloodline.org/SubscriberLounge.

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 your 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 also find information about mantle cell lymphoma or other lymphomas at LLS.org/Lymphoma. 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.