

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'My ALL Diagnosis: Alan's Story'

Description:

Listen in as Alicia and Lizette speak with Alan Kraimer. Alan is an acute lymphoblastic leukemia (ALL) survivor who owns a small medical supply distribution company in Georgia. In 2014, what Alan and doctors believed to be strep throat soon proved to be otherwise. It was not until his third visit to Urgent Care that he was referred to a hematologist in which he received his leukemia diagnosis. Join Alan, Alicia and Lizette as Alan shares how he was diagnosed, questions he had for his healthcare team, the important role his wife played as his caregiver, and how he learned about an interesting new treatment for his dry eyes called autologous serum drops.

Transcript:

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

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

Alicia: Today we will be speaking with Alan Kraimer. Alan is an acute lymphoblastic leukemia survivor who also runs a small medical supply distribution company in Georgia. Thank you so much for taking time out of your day and joining us today, Alan.

Alan Kraimer: Well, thank you, ladies. I appreciate you having me.

Alicia: Of course. So, on today's episode we'll be talking about your story, your ALL diagnosis, also known as acute lymphoblastic leukemia. And for those listening, it's a type of cancer in which the bone marrow makes too many lymphocytes. So, Alan, for you, what was going on around the time of your diagnosis and how were you diagnosed?

Alan Kraimer: Well, actually, I had supposedly had a cold. They thought it might be a, a, a strep infection. So I'd gone to a walk-in; and the first walk-in I went to, they told me, they said, "Well, take this antibiotic for a few weeks, and it should go away." And a few weeks later nothing had happened, so I went to a different walk-in; and they said, "Well, you know, you could have "some swelling in my lungs" So, it's probably an infection. Take this antibiotic, and they had taken an x-ray, and they saw a little spot in my lung. So, I did that for another three weeks, didn't get any

better. So, I went to another walk-in, and on the third walk-in, they actually did a blood test; and that was how I finally got diagnosed with what was going on. And, and it, it started that way. You know, I'd been healthy up until that point. I really hadn't been to a doctor in a while, and my primary care had just retired, which is why I went to the walk-ins instead of to my doctor. And, right before I got diagnosed, I was out, you know, I do a lot of exercise; and I was out bicycling for 30 miles. I finished up, and I told my friends. I said, "I am completely exhausted." I said, "I've never been this tired." And the next day I got a call that I have leukemia.

Lizette: And so that was the third walk-in that called you and told you?

Alan Kraimer: Yeah. The third walk-in called me, and they said, "You need to come in. We need to discuss your blood test." And I said, "Well, can't you just tell me over the phone?" And they said, "No, you really need to come in." And, and I went in and as soon as I went in, the doctor said, "I've already set you up for an appointment with a hematologist at the hospital, so you need to go now."

Lizette: Okay.

Alan Kraimer: Kind of like a shock. You know.

Lizette: Right.

Alan Kraimer: I wasn't really sure what leukemia was.

Lizette: Right.

Alicia: And, unfortunately, we're hearing stories like that where it's taking a few visits to the doctor or, to an ER for them to actually diagnose them with what they have. Was there something that you felt was off that you, were pressing doctors about? Or was it just a matter of, "Oh, it didn't improve. Let me see what else they have to say."

Alan Kraimer: You know, I kind of felt like I had some lung infection. That's kind of what it felt like. I was, you know, coughing and had a low-grade fever. Nothing, you know, nothing to really concern me to the point where I thought I had something bad.

Lizette: Hmm. And when you were more fatigued?

Alan Kraimer: More fatigued was the big thing. You know, I'd also been doing this class called "Orange Theory" at the time.

Lizette: Oh.

Alan Kraimer: I was like three-fourths of the way through, and I had to get on my hands and knees, I was breathing so hard, and I'm like, "Wow, I don't know what's happening; but I'm so worn out."

Alicia: Right. And probably, when your lifestyle is like that, I mean there's probably a lot of times people will think, I'm tired because maybe this was just a brutal workout today.

Alan Kraimer: Right.

Alicia: So, to pin it to that is, I can imagine how you were thinking, you know, this probably isn't serious, something that I should check out.

So, what questions did you have at that time? Because, I mean, this is big news. This is new news. You know, were, what were you thinking? What were you asking doctors during that time?

Alan Kraimer: It was mostly my wife that was, she was more concerned about what was going on. I was just, I guess I was kind of in shock; and I was, you know, saying, "Well, you know, I'll do whatever you tell me to do." You know, I didn't really feel I, I know I didn't have a choice to do, you know, to ask questions or anything like that because I, you know, I didn't really know what to ask.

Lizette: And they wanted you in treatment right away?

Alan Kraimer: Yeah. After the blood test diagnosis, I went to the hospital, to the hematologist; and he goes, "well, I think you have chronic leukemia." He goes, "But I'll give you a call at 4:00." And then at 1:00 he called me, and he goes, "No, it's acute leukemia."

Lizette: Wow.

Alan Kraimer: He goes, "You need to come in now. We're going to check you into the hospital today. We'll start chemo tomorrow."

Lizette: Wow.

Alan Kraimer: So, didn't give you a lot of time to think about it.

Lizette: No, not at all. And, actually, most people are told, "Please go to this doctor. I have an appointment for you," just like the walk-in medical said, "I have an appointment with a hematologist." Not everybody even knows what a hematologist/oncologist is.

Alan Kraimer: No.

Lizette: Did you know

Alan Kraimer: You know what, I had been a chiropractor when I was,

Lizette: Oh.

Alan Kraimer: -before I started my medical company, so I have some medical, you know, knowledge; and, I knew what a hematologist was. I knew that they were blood doctors, and I knew that they were just going to evaluate my blood, see what was going on.

Lizette: And did they tell you to bring your wife with you on that visit?

Alan Kraimer: The doctor goes, "Go to the hospital, and go get your wife first and have her drive you over to the hospital, and, we'll check you in." And, you know, they, hadn't made a complete diagnosis, so I told my wife, I said, "Well, can you drive me to the hospital?" And she's like, "Why?" And I said, "Well, I don't know. The doctor's got to, you know, let me know." I just really didn't want to tell her.

Lizette: Wow.

Alicia: Right.

Alan Kraimer: She's not too good with the kind of medical diagnosis. She doesn't, she's, you know, a little nervous about cancer was her big thing.

Alicia: Right.

Lizette: I think we all are nervous about cancer.

Alicia: Yeah.

Lizette: You know, that C word is a very scary word.

Alan Kraimer: Yeah, you know. Well, it always used to be followed in my house like, by like, you know, "Well, let's hope you, God forbid, don't have cancer."

Lizette: Hmm.

Alicia: Yeah.

Lizette: I know.

Alan Kraimer: But after I got diagnosed, the “God forbid” part left, and it was just talk about cancer.

Alicia: Right. So, your wife was, you said, your caregiver and, of course, the person that filtered the information in and asked the questions and things like that. How important was it to have that support because we always talk about having support as a patient is so important, whether it be on a caregiver level or just a community of other survivors where you can ask questions and really tap into a new, like they say, a new normal because this is something that comes out of nowhere. You have no idea what questions to ask. So, I mean, how important was support and having that system around you?

Alan Kraimer: Well the caregiver is really crucial. You know, without that, it’s hard, you know. When you go through chemo and stuff like that, I didn’t even know what medications I was taking. You know, my wife would put ‘em out every day for me. She goes, “All right, take this, do this.” And I just, you know, did whatever she told me to do. You know, she was kind of more in charge of my daily care, especially than I was, probably even more than the doctor was.

You know, because she was on top of everything. And she, one of the mistakes she probably made was she was on the Internet looking up all the time what was going on. And there’s so many different things that you can find on the Internet that may not be applicable to your particular case.

Lizette: Right.

Alan Kraimer: So, too much Internet is bad.

Alicia: Absolutely.

Lizette: Well, acute lymphoblasts leukemia is very different in, in people. And when you start looking it up on the, on websites, you see, it is very different with children and adults.

Alan Kraimer: Sure.

Lizette: That’s one of the biggest things because everybody says, “Okay, ALL.” A lot of people are used to it in children but are not used to it when an adult is actually diagnosed

Alan Kraimer: Yeah, they were kind of, they told me, they said, “Wow, you’re a little old for this.” Like, well, all right.

Alicia: You’re probably thinking I wish that; I wish I’d aged out of this.

Alan Kraimer: Sorry about that. Yeah.

Alicia: Oh, man.

Alan Kraimer: But the caregiver is a crucial role, you know. That's, the person that you're really going to rely on for your information, helping you to survive and take care of you.

Lizette: Especially when you have an acute type of leukemia where they want you to start treatment right away. You don't have that time to really ask the doctors a lot of questions. But a lot of times we find that the caregivers are the ones that are calling us and asking us the questions, the ones that are talking to your healthcare providers, asking those questions because you go into your fighting mode. You know, you're just.

Alan Kraimer: Right.

Lizette: Like you said.

Alan Kraimer: Survival.

Lizette: Exactly, exactly.

Alicia: Yeah.

Alan Kraimer: That was my job was to, to live.

Lizette: Yup.

Alan Kraimer: You know, that was really my only job that I had was, you know, do whatever I need to do to survive.

Lizette: Now did you have your medical supply company at that time or?

Alan Kraimer: I did.

Lizette: Because you do have to go into inpatient.

Alan Kraimer: I had my company. Yeah, I was, you know, well, first, they kind of tell you that you're going to be in the hospital for a week. I'm like, "Oh, no, not a week. That's way too long. I've got my own company." They're like, "Well, you know, that's what's happening." So, I told my wife, I said, "I need to bring in my computer and my printer." I brought in my entire office because I work on, online and

over the phone. So, I brought in everything into the hospital room and had a whole office set up.

Lizette: Wow.

Alan Kraimer: And, yeah, I didn't miss a beat on my business.

Alicia: That's great.

Alan Kraimer: Yeah, you know, a lot of people are not that fortunate, which is, you know, that's a hardship for them because when you go somewhere, usually, one, it's not that close to you where you have to go to a facility. A lot of people have to get a hotel room, rent an apartment for six months, things like that, and they lose their job.

Alicia: Right.

Lizette: That's true.

Alan Kraimer: You know, which is a, that's a hard component for them.

Alicia: Right.

Alan Kraimer: But one of the things I got really involved in, which I did not know when I first got it, was the First Connection program. Which I had not heard about that. And that would have been beneficial because what they do is they take people that are like me, at the end of their treatment, almost done with their treatment, and they match up with somebody newly diagnosed. So, the newly diagnosed people go, "Well, look, this is where I am at this point. What can I expect? What am I going to go through?" You don't give them any medical diagnosis, but you give them mental support, which is crucial.

Lizette: Yeah, it's very different than, you know, calling here and asking us how's the process. We could tell you, but isn't it different hearing from somebody that has gone through it?

Alan Kraimer: Yeah, exactly. You know, it's always better to have somebody that's, that's lived in those shoes that can tell you what's going on. You know, there's things that I know that a lot of people wouldn't know that haven't gone through it.

Lizette: Yeah, it's those little things, too, that are so important that sometimes the doctors don't tell you. It's those little things that make you a little bit more comfortable, you know, during the process, that they don't tell you about. "Oh, bring a blanket here because it might get cold," and those little things, you know, very helpful.

Alan Kraimer: Right. Yeah, you do get cold; that was a big shocker because, you know, after I had my bone marrow transplant, it was in June, and, that summer I was freezing, you know, no matter what. It could be 90 degrees out; I'd still have a blanket on.

Lizette: Hmm.

Alicia: How was treatment for you? And, what resources did you find that were useful during that time?

Alan Kraimer: Well, the treatment, you know, you go through the few rounds of chemotherapy which, you know, some are worse than others. There's one that's a shorter period of time, but it's more intense. And what you do is they take you through the, you know, the week of chemo; and then they take you down to basically zero is what my doctor told me. He said, "We'll take you down to the bare minimum, where you're barely alive, and then we'll let you build up again, and then we'll do it again." And they keep doing usually about four rounds of chemo is, the, like the minimum, I think, that you can get for this type of cancer.

Lizette: Yeah.

Alicia: And how important was it to trust your healthcare team because I'm thinking hearing that as the treatment plan, you know, we're going to get you down to barely being alive, and then we'll do it all again.

Lizette: Yeah.

Alicia: I mean, you kind of, you have to trust what your doctor's saying and feel as if this team is listening to you and hearing you and, of course, has your best interest at heart. How was that relationship between you and that team?

Alan Kraimer: You know what, it's great. There were four doctors that were in my group, and, I had a primary care which, you know, was the, my doctor that was with me most of the time. But when he isn't there, there's three other guys that are covering also. And don't ever be afraid to ask anybody questions about anything. Any question that you have that concerns anything, just ask because that's what they're paid for.

Alicia: I think it's really great to hear from a patient and, and to hear it more and more that this is your diagnosis. This is your team. This is going to be the people intimately involved, in this period of your life. And any question that comes up should be asked without feeling intimidated or foolish or whatever the case may be because this is your life. And, like you said, that's what they get paid for, right?

Lizette: Right.

Alan Kraimer: You're right, you know. You, you know, they work for you, you don't work for them.

Alicia: Hmm.

Alan Kraimer: You know, they're there for your benefit; and you need to ask anything that you have, write down any questions that you have, have your caregiver write down questions, and ask every single question. Don't leave anything unturned.

Alicia: Absolutely. Were there other, places or people that you, reached out to that you thought really helped you during this time?

Alan Kraimer: The nurses are very helpful, you know. The nurses, the physical therapist, you have occupational therapists that come. And they all, you know, listen to what they tell you to do. You know, it's a lot of times with the physical therapist, he'd come in, and he goes, "All right, well you need to get up, and we're gonna walk around the hall." And you're just like so tired out and you just want to lay there in bed. And they're – you have to just really force yourself to do whatever they tell you to do and try to push yourself as much as you can.

Probably the best thing that I learned from a physical therapist was, he said, "Think of your body like a car." He said, "You have a gas tank." And he goes, "You're starting off with your gas tank, it's full." He goes, "While you're using it and walking around and doing whatever you have to do, keep a check on your gas tank." And he goes, "Once you get to a quarter of a tank," he goes, "that's when you stop, you refill, and then you can do some more."

Alicia: That's a great analogy.

Alan Kraimer: So.

Lizette: It is.

Alan Kraimer: Yeah, for me, that was very helpful. I still use that when I work out now. But, you know, listening to the doctors, listening to – take any source that you have and just really try to, you know, be proactive. The major thing that I can tell anybody is to keep a positive mental attitude. That's more important than almost anything that you can do.

Just, believe that you're gonna get better and never doubt that you're gonna get better.

Alicia: But I think it's so important for other patients to stress that because, like you said, they understand exactly how that person is feeling. It might not be the same diagnosis. It might not be the same treatment plan. But they can really speak to that experience. So, I think it's so important when other patients can say, you know, "It was really hard for me, too, but having a great attitude is so important."

Alan Kraimer: Yeah, you know, you're gonna have days where you feel like crap but, you know, that's just part of, you have to go in knowing that you're gonna feel that. And when it comes, then you're not surprised, when you feel bad. Like, all right, this is one of the days and one of the times where I'm gonna feel bad. It's gonna go away. I'm gonna get better. Focus on the end goal.

Alicia: Yep, I read this quote, this week. It was from this, this Instagram post. I believe the user name is @heyamberrae. And what she said was, "When you doubt your power, you give power to your doubt."

Alan Kraimer: I like that.

Alicia: Yeah, I think it encapsulates exactly what we're saying, where you just, they might, you might have off days, but that, fight and that grit has to be, has to be ever present.

Alan Kraimer: Yeah. You know what, you're your best advocate. So, when it comes down to you getting better, if you give up on yourself, it's gonna be much harder to get better. But if you know that you're going to get better and you know, you keep an attitude like, look, I'm not gonna let this get me down. I'm, you know, I'm gonna go through it, I'm gonna get better, then your chances are much better.

Lizette: And how long was the process for you, the treatment process?

Alan Kraimer: Well, I got diagnosed in March of 2014, and I'm going in two weeks for, hopefully, my final appointment. So, I'm still going through treatment.

Lizette: Wow!

Alicia: Yeah. Well, we hope that that final appointment is indeed the final appointment.

Alan Kraimer: Yes, me too. Five years is long enough. But you know what I've learned a lot from it. I learned, you know, it's given me a lot more mental strength I think than I had before I went in. You know, I can – now I really know that, you know, there's nothing that can stop me. If I have something I want to do, I can do it.

Alicia: Right. And how does that mentality, inspire or encourage you with your business?

Alan Kraimer: It definitely helps because, you know, now I said, "All right, look, I can, I can get these customers on, I can do whatever I need to do. It's gonna be a success; I'm gonna have a big business."

Lizette: You have a different look on life, you know. Life changes.

Alan Kraimer: Yeah. You know what, if things happen to people, and, you know, if you have resentment and you keep going, "Well, why me, why this, why that?" You know, it's – that doesn't get you anywhere, you know. You have to just say, "All right, look, I, I got this. I'm gonna get over it. I'm gonna do what I need to do to get better."

Alicia: Right. We did a video with these young adults; and there was one couple where the doctor said you will not be able to have children. And that was the statement, that was what they, what the doctor, you know, said was final. And they ended up having two children. And I think no one knows what the future holds, and nobody can speak to the future.

But, like you said, in this moment that we do have, your attitude and your approach and your mindset towards it means everything.

Alan Kraimer: Yes. And you know what, nobody knows what the future holds. So, you know, you have to not really create your own future, but kind of create your own future where, you know, you, you said, "This is what I want for my future. This is what's gonna happen." And if you believe in that versus going, "Well, you know, this isn't gonna be good," that's not gonna get you anywhere.

Alicia: Right. And going back to your wife, and speaking about the crucial role of a caregiver. at the LLS we have resources specifically for caregivers because we know how essential that role is in providing regular assistance and consistent care. And for anybody listening who would like to see the list of those resources and what we have available to caregivers, we encourage you to visit www.LLS.org/caregiver.

When your wife was going through this time of looking for information, and because she would also need support for herself as well, did she reach out to any organization or have any resource that helped her get through this as a caregiver?

Alan Kraimer: You know, the hospital that we went to every two weeks has a, they sponsor a lunch for all the caregivers so that all the caregivers can kind of get together and, you know, they have speakers. Like I've spoken at a couple of them because I wanted to let them know from a patient's viewpoint how important they are.

Lizette: Wow.

Alan Kraimer: But it's a great tool for them to all get together, and, you know, LLS.org is the place where you can find any information that you need about anything.

Alicia: And that's why we're here. I mean this is not something to just promote LLS but really stress the idea that we have these resources, these free resources, these up-to-date resources that people can use at a time like this. And like we said, whether you're a caregiver or whether you are a patient, whether you're an HCP, we provide those resources so people can say LLS is helping me alongside my journey.

Alan Kraimer: Yeah, and I think the doctors in the hospitals really have to get more involved in promoting LLS and promoting this, the resources that are available for patients because I didn't know about a lot of these resources until I was almost done.

Lizette: Wow. Yeah, and we want people to know about our support services, not just for patients, but also for caregivers.

Alan Kraimer: Yeah, you guys have great resources on, on everything, so people need to know to take advantage of that.

Alicia: Absolutely.

Lizette: Yeah, we want to help you throughout your whole journey, you know, once you're diagnosed and throughout.

Alicia: Yeah. There're varying definitions on the word survivor; but we believe survivor is the day of diagnosis because that is when it all begins. That's when the journey begins. So, I think it's something like-

Alan Kraimer: You start surviving.

Alicia: Right, right. And so, I'd like, to Lizette's point, we want to be there from the beginning so that we can provide as much as we can as an organization that is doing their best to try to eliminate blood cancer because that's the goal.

Lizette: Hmm.

Alan Kraimer: Exactly.

Alicia: We have a saying on our home page that says, "After diagnosis comes hope." If you were to finish that sentence, what would you say? So, after diagnosis comes, how would you finish that?

Alan Kraimer: Comes the next stage of your life. There's always stages in your life, and this was a stage that, you know, unfortunately, some people have to go through. But it's not, not necessarily, you know it's a bad thing, but it's not the worst thing that you can have because you can learn from this. You can, you know, like they say, take lemons and make lemonade. You can, learn from the experience of going through everything and be able to help other people and be able to help yourself.

Alicia: Well said.

Lizette: Alan, has there been short-term or long-term effects that you've experienced from your treatment?

Alan Kraimer: Well one of the things I, I have, because the chemo kind of destroys your tear ducts in your eyes, so I have one eye that's pretty consistently dry. So, I was using Restasis which is one of the common medications, but it really wasn't effective for me. So, they did a treatment I had never heard of. They took my blood and they spun it and they separated the serum out, and there's a pharmacy that makes that serum into eye drops. So, I got that done. The first time I put it in it was better.

Alicia: Wow.

Lizette: Yeah, this is the first time-we're hearing about this.

Alan Kraimer: It was pretty incredible.

Alicia: Yeah, yeah.

Alan Kraimer: Yeah, there's so many kinds of little, little fringe things that people don't know about. And especially the Restasis, an ophthalmologist told me, he goes, "That's really not that effective because your tear ducts are gone."

Alicia: Right.

Alan Kraimer: But the, I think it's called autologous tear drops.

Lizette: Oh, wow.

Alan Kraimer: And they just take your blood and they make it into a tear drop. If something's not working for you, like say a medication's not working for you, there's always another option that they can use to get you better. You know, there's different options for everything. So, if one is not working for you, and you're getting bad side effects, you need to tell the doctor, "I'm getting bad side effects from this. Is there anything else we can use?"

Lizette: Hmm, yeah, we've heard. We've heard about side effect before from a lot of individuals. So, it's good to know that there's different options out there for people.

Alan Kraimer: Yeah, I had, actually had a bad drug interaction with one of the medications that I took; and I ended up getting what's called cardiac effusion where the sac around your heart swells up, and my heart was barely beating. So, they had to cut a little hole in the pericardium, which is the, surrounding of the heart.

Alicia: Wow.

Alan Kraimer: So yeah, but that was all medication-induced. And after that, you know, we switched to a different medication.

Alicia: Right. And I think it's important for patients to hear you say that because for the less severe side effects, a lot of the times patients won't say anything because maybe the medication is working great, and so they don't want to kind of rock the boat you know, to be taken off of it. So, they bite their tongue when it comes to the ones that may not be as severe.

It's important for the patients to speak to their, healthcare team and have that communication, and that conversation so that they can see what other options might be possible because you never know unless you ask.

Alan Kraimer: Say everything on your mind.

Alicia: Hmm, Hmm

Alan Kraimer: Don't hold anything back.

Alicia: Right

Alan Kraimer: If you have any symptoms, anything that you're concerned about, any questions you have, get everything out. Don't hold anything in.

Lizette: Yeah, a lot of people don't feel comfortable speaking to their doctors or their treatment teams about quality of life issues, which a lot of times is these side effects from medication that are everyday issues that really aren't letting you live, you know, your fullest life.

And people think, like Alicia said, that the medication is working for me; but at the same time, the medication is actually also giving you side effects that aren't helping you on a daily basis and making it harder for you to live. And those quality of life issues are very important to bring up with your treatment team, and we do find that people just don't feel that they can.

Alan Kraimer: Well, just remember that the doctors are your employees. You're not their employees. They're there for you. You hired them to get you better, so if you have anything that you need to tell them, you tell them just like an employee.

Alicia: Right.

Lizette: That's so true. I don't think we think of it that way, and usually we don't think of, because we also talk about second opinions and how, you know, it's not a bad thing. Some people think that a second opinion, you're going to hurt your doctor's feelings. But we go when we're trying to buy a car. We go to as many car dealerships as we can, you know, to find the best possible car for you, yourself. So, we often try to tell people, and put it into context like you're doing, that, you know, this is your health. And you can get second opinions, and you can stay with your doctor if you like them. But also, blood cancers are not the most common of cancers, so you may need a second opinion at a larger center, because there's so many new treatments every day which is great to be able to say at this point for blood cancers.

And it's very important that your physician knows of these new treatments and more individualized medicine is coming out. So, you're, you know, personal ALL, the actual mutations that you have might not be the same as somebody else; and they can really look into what may be the best treatment for you. So, it's very important and like you said, to advocate for yourself, or have somebody there too that can provide that type of support, that advocacy for you.

Alan Kraimer: Yeah, when I was diagnosed, I also, I had a chromosome defect. So that was part of, you know, and, and before I got diagnosed, like about, I think about six or seven years ago, the fatality rate for the one that I had was like 90%.

Alicia: Oh, wow.

Alan Kraimer: And after they came out with this new treatment protocol in January, and I was diagnosed in March, it went down to like 20%.

Alicia: Wow.

Alan Kraimer: So, it was really dramatic. You know, you can, it just changes, you know, on a dime. You know, they come up with something and, boom, there's a new treatment for you.

Alicia: Right.

Alan Kraimer: There's always new treatments coming out. And that's what's good about LLS is they keep funding all the, all the things that people do and donations and

walks, Light the Night walks, all that kind of stuff is crucial to help, you know, research and development, finding new cures.

Alicia: Absolutely.

Alan Kraimer: Now the worst thing that I had, I did have one really bad symptom that, you know, I used to have really thick hair; and then my brother was my bone marrow donor, and he has thin hair. So now my hair's thinner.

Lizette: So now you blame your brother, right?

Alan Kraimer: Oh, yes, I've given him a lot of hard time about it. People need to never lose their sense of humor. You know, even though you're going through probably the worst thing you'll ever go through, don't lose your sense of humor. Don't ever give up hope. Don't ever give up anything. Don't change yourself.

Lizette: Hmm.

Alicia: That's so true.

Lizette: Yeah. Or some people actually get a sense of humor.

Alicia: That's true too.

Alan Kraimer: Hmm, true.

Lizette: We heard that from one of, the young adult cancer patients. He's like, "You know, I didn't have a sense of humor before my diagnosis, and now I do."

Alan Kraimer: I was in the hospital on April Fool's Day, so the doctor came in and, you know, I was really pretty sick, and I just had lost all my hair. I was asking him a couple questions, and I said, "Well, do you think that I would qualify for a hair club?" Would that cover my insurance? He was like, "Seriously." I said, he goes, "No." And I said, "I know, I know."

Alicia: Alan, is there anything that you think we haven't covered that you think would be important for our listeners to hear?

Alan Kraimer: You know what, there's, there's probably a million things that, you know, I could think of; but, you know, you never have enough time. That's why the, the First Connection program is important for people going through the treatment because you can talk to somebody that's been there; and you can ask them questions like, "Oh, gee, you know, I'm feeling really down about this. I'm feeling," whatever you're feeling, and they can say, "Well, you know, yeah, I understand that. I was like

that when I was going through treatment. I had this and this.” It’s nice to talk to somebody that’s already been through it so you can ask them anything that you really can’t ask your doctors because they don’t know.

Lizette: Right.

Alicia: Right. That is so true.

Alan Kraimer: I was just going to thank you ladies for having me on. I appreciate it and appreciate the work you’re doing to try to help people with blood cancers.

Alicia: Of course.

Lizette: It’s not the easiest thing to share your story, we have a lot of people on our podcasts that are so gracious enough to share their stories with us. And, you do it so eloquently.

Alicia: Yeah.

Lizette: But we know that you’ve been through such a tough time and we don’t want to make light of, of your journey or anything. But we do really appreciate you being able to share because it’s difficult because sometimes you have to relive that in your head to speak about it, and we really do appreciate you.

Alan Kraimer: Well, it’s my pleasure to be here. You know, if what I can say will help somebody else, to make it a little easier for them, that’s, you know, that’s why I wanted to do this.

Alicia: We always hear people say, like, like you said earlier, I wish I’d known about, you know, this resource or that resource at the time of diagnosis. But I mean the great thing is, is that you’re, like Lizette said, you’re graciously sharing your story; and, if someone is given the news of their diagnosis or is diagnosed with something, that they can find comfort and can, and find strength in hearing another person speak about it like you did today.

So, thank you so much for chatting with us and sharing your story.

Alan Kraimer: Well thank you, and, uh, you know, I hope people take advantage of all the resources that LLS has to offer because there really are resources for everything you need.

Alicia: Absolutely. And for those who would like more information about the support resources we mentioned on today’s episode, like our peer-to-peer, Patti Robinson Kaufmann First Connection program, you can visit www.LLS.org/support.



And for those who would like more information about leukemia, you can visit www.LLS.org/leukemia.

We'd also like to hear how you liked this episode, what you liked most about this episode. So please comment below. Thanks so much for listening.