THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Bring It On: From Lymphoma to Advocacy'

Description:

Join us as we speak with Jan White, a survivor and thriver of Stage IV Non-Hodgkin Lymphoma. In this episode, Jan shares her story of how she went from facing immediate paralysis and death to using her experience to advocate for patients. She became a legislative advocate for LLS, started a website to share her experience, and has participated in numerous national conferences in support of cancer patients and healthcare access.

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 Jan White, a proud survivor and thriver of Stage IV non-Hodgkin's lymphoma. After completing treatment in 2016, she felt a strong calling to support cancer patients and their families. She became a legislative advocate for LLS, started a website to share her experience, and has participated in numerous national conferences in support of cancer patients and healthcare access.

Welcome, Jan.

Jan White: Hi, Elissa. How are you?

Elissa: Good, good. So let's start with your diagnosis of Stage IV non-Hodgkin lymphoma. How did you get diagnosed, and what signs and symptoms were you having?

Jan: We actually chased pain for about two months. It started off when I came down with the flu, and I was really, really sick. And I don't normally go to the doctors, but I went to the doctors. And he's like, "Okay, not only do you have the flu, you actually have some pneumonia going on here. What's bothering you more than anything else?" And I said, "I have this knife in my back, and he ran his fingers down my back, and he's like, "Okay, you're coughing so hard from the pneumonia, I think you've cracked a couple of ribs." At the time I was studying for my fourth-degree black belt, and he's like, "You have the musculature to crack ribs, so that's going to take six to eight weeks. Let's just get you over the flu and pneumonia." So got over the flu and pneumonia, but the pain stayed, and it kept getting worse and worse and worse. And we went back a couple of times, and we checked my shoulder, and we checked some other things, and nobody could figure out what was going on. And then one night I coughed, and it was lightning bolts down my legs; and suddenly my legs weren't working right. That gets everybody moving in a hurry.

My GP (General Practitioner) was on vacation; so, I got to the on-call GP, who was so amazing that he became my GP. And he checked me out. He's like, "I don't know what this is. Maybe you herniated a bunch of discs in your back." So, he sent me for an MRI, and that afternoon I get a phone call. "We're not sure what we're seeing. You need an MRI with contrast. You're scheduled for 8:00 tomorrow morning." And I had the second MRI, and I thought at the time, oh, they just got a bad image or whatever. I wasn't really worried about it.

And that night I get a phone call from the on-call GP who really doesn't know me, that says, "There are multiple tumors. One has invaded your spine. We think they're benign. You need a neurosurgeon right now." Okay, don't like the word "tumors." Do like the word "benign."

So, okay, I was scheduled for the next morning at the neurosurgeons. Got there. He's like, "Okay, big nasty invasive. Scheduled this huge surgery. You know, take out ribs, take out lamina, put me back together with an erector set. They'll biopsy me on the table." Okay.

So, they did all these detail studies, and God bless one radiologist who raised a 3% chance of lymphoma. And to the surgeon's credit, he said, "Okay, that didn't occur to me. I have to run this down because I could make it worse." They did a biopsy real fast, like the next day. And sure enough, I'm sitting in the surgeon's office for the last pre-op appointment, and it comes back non-Hodgkin's lymphoma. And I'm like, "Wait a minute, we were checking the box. What happened here? What do I do now? You know, I don't have an oncologist in my hip pocket." So, he's like, "I can't operate. Go home. Don't go anywhere tomorrow. Someone will call you."

So 9:00 the next morning I get a phone call from Dr. Shah's office that says, "Be in this office in one hour. Pack a bag. You are not going home. You are being admitted directly to the hospital from the office. We have to begin chemo today. We have to try to save your spinal cord and your life."

So, by 10, I was in his office. He was amazing. He spent 90 minutes with us the first day. What doctors spends 90 minutes with you ever? By noon I was in the hospital. They cycled me through heart study, lung study, bloodwork, PICC line shoved in my arm; and by late afternoon, I was on chemo. Welcome to cancer.

Elissa: What was that like? I mean that's happening so fast.

Jan: In hindsight, it was a good news/bad news deal. There was no time for fear or panic or dread or any of that. Mike and I held each other for a couple of minutes, went upstairs, threw clothes in a bag, and left. Mike and I run a business doing business meetings and special events together, a client said to us, "You went to show mode," and she was completely right. Work the problem. But I can also now say I know what it is to be in shock. It really didn't wear off for a couple of days where I looked around and went, "Oh God, what just happened here?"

But in a way, it was also interesting in that, you know, in the cancer center, you can't help but overhear conversations. So, one time we're in the elevator and there's another couple in the elevator, and I'm in full-on treatment at that point. I'm bald, no eyebrows, the whole thing. And the couple is talking about they have this appointment, and then they have this appointment, and then they're meeting with the team, and then they're mapping the game plan. And then they're going to start treatment. The couple gets off the elevator, and Mike looks at me and says, "Is that what's supposed to happen?" And I'm like, "Yeah, I think so."

Lizette: Wow. And lymphoma is such a complicated diagnosis. They say lymphoma, and then people don't know that there's Hodgkin lymphoma and non-Hodgkin lymphoma. And then when they say non-Hodgkin lymphoma to you, do they explain that there's so many types of non-Hodgkin lymphoma?

Jan: I was incredibly fortunate. Dr. Shah was amazing. He literally started off that day with this is a lymphoma. This is Hodgkin's versus non-Hodgkin's. This is non-Hodgkin's. This is your subtype as best we understand it. When they actually started treatment, they didn't have my full subsets back yet. But as he said, we couldn't wait. We're just throwing everything, and we'll adjust.

And then, you know, I also was non-Hodgkin's with central nervous system, with CNS, which adds a whole other layer of complexity. But he was really amazing in mapping it all out as Mike and I were madly scribbling notes. And I distinctly remember at one point he's talking and he's talking. And I said, "Wait, you didn't say what stage I am." And he looked me square in the eye and said, "You're Stage IV. Do you know what that means?" And I said, "Yes, I know what that means." He's like, "Okay, do you want me to stop talking?" I'm like, "No, keep talking. I need to know what we're doing here."

But he was really good about really defining it for us. This was Medical School 101 really fast. I am large diffuse B-cell with CNS.

Lizette: And when Dr. Shah went over that you're Stage IV, did he explain that that means that it was throughout your body; and that for lymphoma patients, it might mean something a little bit different than for other types of cancer patients?

Jan: Yes, he did explain, and he was very candid with us about the severity of what was happening. Though it was interesting. I've heard patients say, "You know, the doctor should tell you everything the first day." And I have learned, no, maybe they shouldn't because we knew it was very serious. We knew it was everywhere pretty much at that point. We knew we needed all of the big guns right now.

But I was actually complaining to him about a year after completing treatment about what I perceived to be my lack of speed of recovery. And he looked at me square in the eye and said, "I will now tell you what I did not tell you the first day. Your file got dropped on my desk at 8:30 in the morning. By 8:45 the partners met about you, and by 9:00 we were on the phone to you because we had to get you in here because the assessment was you were 7 to 10 days from being completely paralyzed and 3 weeks from dying. That of his career, I was his full-blown emergency, a dubious distinction at best. So, it was very, very close.

Elissa: Now what was causing you to potentially be paralyzed? Was it the lymph nodes pushing against your spinal cord?

Jan: Actually, it was really interesting. I was completely extra nodal, so one of the biggest of the tumors had invaded my spinal column and was compressing the cord.

Elissa: Invaded it.

Jan: Yeah, in hindsight, it was again a double-edge sword. The spinal tumor made treatment, recovery, all of it infinitely more complicated; but that was the one that gave symptoms. So, lord knows how far I would have gone without that. I remember saying to him, "I'm a martial artist. I studied for more than 15 years. I'd like to think I'm pretty in-tune with my body. How the devil did I get to Stage IV?" And he explained that this particular form was incredibly aggressive, and it chose places where there's not a lot of pain receptors, so we didn't know about it till it was really far gone.

Lizette: Wow.

Elissa: So, you had three weeks to live. What else could have come up? So, had the spinal cord issue not been there, I wonder what else could have been that would have caught it within that three weeks?

Jan: You know, there were subtle symptoms, as he said at the time. He's like, "If you think back, there would be really subtle things that you would have just dismissed," which I did when I thought back about it. I remember telling my Sensei about maybe two months before I was diagnosed, "My kicks feel floppy." And he's like, "Well, Jan, you're 52." And I'm like, "Yeah, okay." And I just dismissed it. Two years before or a year before I had been diagnosed with high blood pressure. Well, in my family, you know, the gift at 50 is high blood pressure. So, I dismissed it. All those things resolved after chemo, so there was just these really subtle clues that you dismiss.

Elissa: I think a lot of the patients listening can say just that, that they had symptoms come up. They attributed them to different things, and all of a sudden, boom, you've got cancer. And all these symptoms were because of the cancer.

Jan: Right, exactly. That's why everybody candidly, they're like, "Oh, how did the docs not catch it sooner?" I'm like, "You know, no bruising, no fevers, no sweats, no fatigue" – though I had some fatigue that I contributed that I wasn't sleeping because I was in so much pain. You know, did I have weight loss? Yeah, but not until the last two weeks before I was diagnosed when I suddenly started dropping 15 pounds in two weeks. So, it's very subtle.

Lizette: Wow.

Elissa: Thank goodness for the spinal cord issue. To get that found. Oh my goodness.

Lizette: And it's so hard because we do hear a lot of patients that say that they weren't diagnosed sooner and why.

Jan: Right.

Lizette: And it's difficult to diagnose. It's not the first thing that they're looking for. It’s not the most common cause of any of these issues that you're bringing up.

Jan: Like I said, when they did the first MRIs, they were looking for herniated discs in my back. Cancer was not on the radar, even when the neurosurgeon looked at me. And he's great. Don't get me wrong. He's fabulous. But I didn't have classic symptoms, so no one was looking there.

Lizette: Wow. I bet they did tell you though that since you were in good shape otherwise, knowing your background, that really did assist you through treatment.

Jan: I mean physically and mentally, my martial arts I would say probably is in the top five reasons that I'm alive. I was reasonably physically fit. I had the training for the focus and the concentration and the, okay, I have another good way to put it. I could literally take a punch. So okay, bring it on.

Elissa: Just like, "This is no problem. I'll get through this." I've been through worse.

Jan: There was never really even a discussion between Mike and I. It was just understood. "Bring it on. We're doing this, and this is going to work." That was it. There was no "what if." It was bring it on.

Elissa: Yeah, I think a lot of patients kind of go into that. You know, you get diagnosed like, "Okay, we're just going to do this. We're going to do whatever my doctor says, and, you know, let's go." And then they can deal with all the emotional ramifications once they're done.

Jan: Much later. That comes later. My family, of course, you know, a lot of them are screaming, "Second opinion." I'm like, "Guys, we have to start. I can always change gears, but we have to start." I need to go.

We were fortunate. I still cannot say enough about my care team and that I was in a place that could throw everything at me right away. I absolutely understand the lightning speed at which all of this happened is amazing, and I know that. We did get second opinions later, once, you know, once we had our subsets back. But until then, it really didn't make sense because what are you going to say? We don't even have all the data.

Lizette: And it's really important for everybody to know that you can get a second opinion anytime during your journey. It doesn't have to be right when you're diagnosed.

Jan: Right. And even now, as I go through, there's second opinions in active treatment, which is critical. You always want that second pair of eyes, that second set of thoughts.

But during survivorship as well. You know, I'll get an answer from one doc. "Hmm, that doesn't sound quite right," and I'll check with somebody else. All right, I'm not trying to opinion shop. I just want all of the perspectives because doctors are trained in a particular prism of their lens of treatment. And you want those different prisms to complete the picture. So, second opinions are, for me, an always thing, not just a first thing.

Lizette: Sure. And how long did your treatment take? You did say that they kind of threw everything at you.

Jan: Right. So, the first chemo I did is R-EPOCH, which don't ask me the acronym, but it's immunotherapy plus chemotherapy. It is very aggressive, and I didn't understand. I thought, oh, this is just the chemo you do. I didn't understand that this was the far edge of chemo because R-EPOCH is 96 continuous hours of chemo every three weeks. Hook me up Monday morning, disconnect me Friday afternoon. And I would go home actually with a 500-milliliter bag and a pump each day that would infuse all night and then go back the next day.

During each of those rounds, because of the spinal tumor, that first week, I did my whole first round in-patient for reactions on all sorts of things. And during that first week they also implanted what's known as an Ommaya, and that's a head port that's permanent. So, I had a chest port and a head port. The chest port's out, yeah. So during each of those 96 hours, I would also get injections of methotrexate and cytarabine into the Ommaya in my head to get the chemo to my spine.

Elissa: Wow. You don't hear that very often.

Jan: Yeah, that's pretty unusual. Even when I go for MRIs, everybody's like, "You have a what?" I'm like, "Yeah, it's okay, I've had MRIs. Don't freak." So, it's a little different.

So, we did that for six months, every three weeks. And then when that was done, we did a high-dose, high-risk, in-patient chemo that was a 4-hour infusion; but the toxicity level was so high, I was actually in-patient for six days to be monitored around the clock till enough of it had leached out of my system as to no longer be potentially lethal.

And so, when I recovered from that, then I did almost a month of radiation and remission. Yeah, let's stay there. Let's stay there. I like that word a lot.

Elissa: Yes, remission is a great word.

Jan: So, it was a long year. And I think we need to normalize mental health as a country but specifically within the cancer space. Yes, every single appointment I go, and they say, "Please rate your anxiety, please rate your depression." And I was stunned at how reticent I was to be honest that I was struggling. It was actually not until a couple of months into the adventure where my aunt, who's the big sister, best friend, mom I never had all rolled up into one, called me and said, "Are you talking to someone?" I said, "No, I'm fine." And she shot right back at me. She's like, "You are not fine! How could you possibly be fine? You're staring down stage IV cancer. Go talk to someone, please!"

And she was right. I think especially as women, we're taught you just handle it. You don't ask for help. You don't admit you want help; you might need help. There's too much stigma attached, unfortunately, to mental health. Nobody blinks an eye when you say you're going to physical therapy. They say, "Oh good!" But when you say you're going to a therapist, sometimes you get the eyebrows, and we need to normalize it.

Elissa: Yeah. It's so easy to go through your treatment and just kind of blast right through, be strong, and just do what you have to do. And then once the treatment ends and that coordinated care ends, and all of those things that you were doing on a daily basis go away, you're left to finally have that space to deal with all of the emotions that you dealt with for months or years that you never dealt with ever. I think that all cancer patients should be given that referral to go talk to somebody. Maybe during induction, they'll introduce you to the social worker. And you're like, "I'm fine. I'm just going to do this." "I'll be okay."

And then you're like, "Wow!" months later, "I really need help." "Something's wrong."

Jan: And that's exactly what happened. You only have so much bandwidth. And especially in our situation, every single ounce of bandwidth had to go to the physical because that kind of chemo, 96 hours I mean my hair was gone in ten days, my eyebrows were gone shortly thereafter, all of it. But we need to do that. I think we really need to normalize it. I didn't really begin dealing with anything till probably a year out of treatment because you can only do so much.

Elissa: Absolutely agree. We really do need to normalize mental health treatment during and after cancer. That actually brings me to my next question, because you did talk about it there. You started a website called, "Jan Says Onward!", where you talk about a variety of topics. What was the motivation behind that?

Jan: Really coming out of treatment, I wanted to honor my doctors, my nurses, my techs, my physical therapists. There were strangers who offered a kind word. My family and my friends. And I wanted to make a difference. And I heard about advocacy, so I signed up with LLS. And "onward", I don't even remember when or where it came from, but very, very early in the adventure. And we don't call it the cancer journey. We call it the adventure, and late effects are souvenirs because that's just what we do. Because I'm not going to use the medical jargon. I want my jargon.

So, during the worst moments, painful moments, incredibly frightening moments, frustrating moments, the mantra became onward. Mike and I would just look at each other and say, "Onward." And I can't tell you how many times I've said that in the last however many years. But the more I advocated, the more I realized I want to make a difference. For better or worse, the story is traumatic. It gets people's attention, so okay, let's go. Let's make a difference. And in talking with some speaking folks, I woke up one day, probably last spring, with jansaysonward.com in my head. And I'm like, "That's it."

Elissa: I love it.

Jan: So, On June 7th of 2020, which is National Cancer Survivors' Day, I launched *Jan Says Onward*! That's where it came from, and I'm speaking to national groups, to associations about what cancer really means and what cancer patients and their families from my perspective really need.

Elissa: Yeah, it's interesting hearing you talk about the traumatic moments and needing to feel that you're moving onward. It's kind of looking at hindsight where you just went through it. And it was just what it was. But then it was traumatic.

It wasn't rainbows and roses at all. And you do need some kind of forward motion, something to keep you going; and I love the mantra. Just go.

Jan: Just go, onward. You know, even in the last year of COVID, onward. When, you know, cancer and COVID really don't mix, so onward.

Elissa: Definitely. Now you have a lot of short blog posts on your website on various topics. There was one in particular that I loved, and I think that many patients who are listening could really identify with. It was called, "One More-Ologist." Better survivorship strategies. You strongly suggested needing a survivorship oncologist. So, tell us more about that, what your thinking was behind it.

Jan: Okay, so yeah, this is actually one closest to my heart. So, what my experience has been, is that because my care was split between two different hospitals, I probably had before cancer, we call it pre-C now, I probably had, you know, your standard GP, gynecologist, dentist. I had an orthopedist because my knees and karate, yeah, so not a lot of need for coordinated care there.

When I was in active treatment, care split between hospitals, physical therapists, GP, the care was very coordinated. You know, doctors talked to each other about treatment strategies, about challenges, about whatever.

Suddenly in survivorship, my experience is that not only is care much more fragmented now, I have infinitely more doctors now as a result of the souvenirs from the adventure than I ever imagined I would have. I have two primary oncologists, I have a radiation oncologist, I have a pain specialist, I have a cardiologist, I have a rheumatologist, what are my other ologists? Way too many other ologists! And no one talks to each other. I have no field general directing the nuance of care that's required in survivorship, so I have experienced multiple times where I'll start dealing with a challenge. A great one is I started having some new neuro symptoms, so I talked to the neurosurgeon because that seemed like the place to start, and he recommended some tests and a course of treatment and some drugs and some procedures. Well, my oncologist freaked out and I already was a halfway through! So, I have spent time, money, energy, angst, pain; no, you don't want me doing this? Wait a minute!

So, when I thought about it, it's like why is there not a subclinical specialty that would exist in every oncology practice that when you get in remission, yay, you are transitioned to a survivorship oncologist who will oversee the myriad of care in dealing through survivorship?

I actually have a friend who works in the health insurance industry, and I called them up and said, "Does this exist? You know, is there an insurance code for this?" because sort of my attitude was if there's an insurance code, it's it exists and if there's not an insurance code, it doesn't exist. And there was no insurance code. And then I called a friend of mine who's a surgeon and said, "Does this exist?" because she specializes in breast cancer patients, and she's like, "No, and there's a huge need." So, I really think having a field general to direct the care within the practice. And then God forbid you relapse, you go back to your same primary doctor within that practice for more active treatment.

You know, my friend whose insurance said, "Well insurance isn't going to want to pay for another doctor." I'm like, "You're not understanding me. I think ultimately this would result in less doctor's visits, less tests, less drugs, less procedures if there was someone directing the whole care versus the prism."

Elissa: Yeah, that's a really good idea because you really do go from coordinated care where everybody is on the same page, everybody is talking to all of a sudden dealing with all of these completely separate issues that are related to the same thing though they are completely separate. And when they don't talk to each other, you can get the same tests for different things. How are you moving forward if they're not coordinating with each other and talking to each other? I love this idea of a survivorship oncologist or coordinator or somebody at each cancer clinic that is taking this over to lead people through survivorship.

Jan: You know, we say it all the time here, me the one bringing everybody to medical détente, but me without the medical degree. It doesn't work!

Elissa: Yes, definitely.

Lizette: I agree with you. I think that in the long run, the idea is really to be proactive, right?

Jan: Right.

Lizette: You are in the long run going to have less appointments, possibly less-ologists. It's a great idea.

Jan: When you think about it, you want survivorship to be the longest part of the gig. You want active treatment to be the short chapter in the book. So why are we coordinated for the short chapter but not for the long book?

The other thing I would really like folks to think about is when you look at the "marketing," quote/unquote, of cancer, all you see pretty much is the big smiles and the pretty scarves and the wonderful look what I can do stories.

That's not exactly how it works, at least not for me. As hard as my chemo was, as hard as that year was, in its own way, survivorship is harder. You know, you're facing the myriad of doctors now. You're facing the continually evolving ramifications of the souvenirs. I know the docs refer to it as late effects and side effects. I refer to it as a souvenir because you should always have souvenirs from an adventure, right? I have chronic pain, chronic neuropathy. We've had to rebuild a lot of different parts of our lives to meet my needs. That is frustrating in the extreme, but it's real. And I would like to see a lot more education to the public about what survivorship really means.

Elissa: Yeah. Because it always looks like those super inspirational stories and everybody's happy at the end. And that's just not necessarily the case. People are left with posttraumatic stress and having to deal with all of these potential issues that have come up as a result of your treatment. And it should be out there more that things didn't end when your treatment ended—when you went into remission.

Jan: There's a really great meme out that I use sometimes. It's like, "Just because my hair's grown back doesn't mean everything's okay now." And that really sums it up. And I thought that's what would happen too. I thought you do your treatments no matter how rigorous, you take a couple of months off to put yourself back together, and then you continue on with life as you knew it before. Yeah, not so much.

Elissa: But I think that the more that cancer patients and survivors can share their experiences through treatment and after treatment. Share what they're going through, and I'm sure everybody thinks that, oh yeah, it's really hard once you're going through it. And then they're like, "Oh you're in remission, great!" And then that's the end. Stop checking in on you. I'm a blood cancer survivor myself so I get it that they just stop checking in with you. "Oh, you're better now, right?"

Jan: Right.

Elissa: I'm like, "Not really. Not really. You know, I'm not really better now." And all of these things that come after that remission, after that NED date if there is one-after the main treatment ends and people aren't as vocal about it or just their friends and family just kind of forget that you're still in it, you're still going through something.

Jan: And, and don't misunderstand me. I am incredibly grateful to everyone and to every drug and to every little bit of it. It was just a bit a surprise about what survivorship really means.

Elissa: I agree.

Lizette: That's true. It makes a lot of sense. Really does. And also, on your website you share videos of you participating, not only in cancer conferences, but also press conferences-

Jan: Yes.

Lizette: -for national public policy. How'd you get into sharing your story on the national stage?

Jan: Actually, I have LLS to thank for that because I went from 0 to 100 miles per hour with you all.

Lizette: We saw that inside of you, we did.

Jan: You did. The final impetus for me to get into advocacy was as I was coming out of treatment is when they were debating Trumpcare in the US House of Representatives, and a Representative out of Alabama gave a radio interview during that debate. And in the interview, he essentially said, "Good people don't have pre-existing conditions." And I looked at my husband and said, "Oh, no, no, no-

Elissa: Wow!

Jan: -no, no! They just woke up the wrong person." So, I registered with LLS. About two weeks later I got a phone call that said one of my US senators, who I knew from our events work, was going to hold a patient roundtable. He wanted to hear from actual patients about what the changes to ACA (Affordable Care Act) or eliminating or replacing ACA could do. Would I please come and tell my story?

So as an event producer, I have sat through way too many bad speakers in my life, and I vowed I would not be that. Sorry, it's true. So, I crafted a three-minute, this is my story. And 20 of us told our stories. And that afternoon, much to my shock, I got a phone call from US Senator Carper's office in DC, "You made an impression on the senator." Okay, great. "He would like to present your story on the US Senate floor as part of the healthcare debate. Do you agree?" "What? Excuse me!"

Elissa: Wow!

Jan: "Back up."

Elissa: Wow, that's amazing.

Jan: So, I was in shock. My answer, first answer was, "I'm incredibly flattered." My second answer was, "I need to talk to my husband and my son. This is much more public than we had ever talked about." The last part is, "I respect Senator Carper very much, but I write the script. My story, my rules."

So, Mike and Ethan said yes. They said yes to me approving the script, so ironically two days later my son and husband watched C-SPAN live as the senator presented our story on the US Senate floor complete with pictures, and I was in a client meeting. So, they saw it live.

Elissa: Wow!

Jan: I got home and said, "Please tell me it wasn't horrible." But that started me being known in my federal delegation here with my state representatives here. I've continued to go to the Hill to go to Legislative Hall here. For better or worse, this story is dramatic, so it gets people's attention, and I've been relatively successful in presenting legislation that we feel is important to the cancer patients and their families and getting them to say, "Yes, I'll sign on as a co-sponsor." To me nothing will ever make the adventure worth it outside of seeing my husband and my son. But that advocacy, making the change, trying to make it better gives it purpose, gives it meaning.

Elissa: Now for our listeners who don't know, LLS utilizes volunteer advocates like Jan to speak to their legislators on a state and national level. They share their powerful stories as patients and caregivers to influence legislation that will help protect patients and increase access to quality and affordable care, which we all want. So, what was the training like to become an LLS advocate?

Jan: There's a whole series of videos you go through where it talks about your roles, you talk about doing all of that and what's appropriate. We're completely nonpartisan. We come to talk about issues. I worked very closely with my executive director, with my state liaisons. I have all the statistics, the language, the talking points. They also always make me really comfortable in that, Jan, if you don't know, don't guess. Just say you'll get back to them, which is really great information.

Really important, "Don't guess. Just say we'll get back."

Elissa: You don't want to say something wrong there.

Jan: No, ever, ever, ever! That was really great to understand the roles. There are calls we can get on. I always have my state contacts or my regional contacts where I can call and say, "I heard about this," or "I'm worried about this." Or "Did you know about this?" or "What do I do with this?" So that's always really great.

Edith: Do you have any advice for anybody wanting to talk to their local legislator?

Jan: Certainly, you don't need to be an official "advocate," quote/unquote, to go talk to your legislators. You can always email, call your legislators, but when you do, I would recommend that you have all your source information with you about why you're calling, what you're concerned about. Check your sources. Make sure you have at least two corroborating sources. We want to be presenting very accurate information to them, so that you have all of that.

The other thing to remember is, I love all our legislators, but sometimes, a lot of the time the real work gets done with the aides. There are literally hundreds of bills that come across representatives' and the senatorial desks at all levels. It's the aides who sift through and say, "Sign on to this, do this, do this," unless something is very near and dear the representative's heart. So, if your actually get a meeting with the aide or you talk with the aide, don't dismiss it. It can actually be very, very powerful to do that.

Elissa: That's definitely something that I think a lot of people don't think about is how much the aides actually do in getting this to the senators and representatives.

Jan: The vast majority of my contact is with the aides, and it's very, very important and just as important as talking with the actual legislator face to face.

Elissa: Now that you've been an LLS advocate for a little bit, what would you personally like to see with future legislation?

Jan: I would like to see the ACA stop coming under fire. I would like to see that concern going away. I would like to see paid family and medical leave, and I would like the cancer funding restored to pre-COVID levels, as well as a bump to get the research restarted because that's actually more expensive than continuing.

Elissa: Yeah, that's really important to get the research continuing. We're already a little bit behind.

For our listeners who might be interested in getting involved with LLS advocacy and public policy, like Jan has done, stay tuned to the end of our episode for more details and be sure to take a look at the Show Notes for links.

Edith: On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based your cancer journey and advocacy experience, what word would you choose to complete that sentence, "After diagnosis comes?"

Jan: Comes life is the first word that came to my brain.

Elissa: What does that mean to you?

Jan: All I could focus on at that point was life, and I want my life. I look into the eyes of my husband and my son that day. I want my life.

Elissa: Thank you so much, Jan, for joining us today. You have such a powerful story and with your diagnosis and all of the incredible work that you have done afterwards to help current and future patients. And we really look forward to seeing more of you on the national stage as we all work to make sure that patients have access to that quality and affordable care.

Jan: 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 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 also find information to get involved with LLS advocacy by becoming an advocate or simply sharing your story at LLS.org/Advocacy. You can also text the word "SPEAK" to 69866 to join our Mobile Action Network. All of these links will be found in the Show Notes.

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.