

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Non-Hodgkin Lymphoma: Cancer & Pregnancy'

Description:

Join us as we highlight how pivots in therapy and self-advocacy were used to treat a young woman's diagnosis of non-Hodgkin lymphoma.

In this episode, Caitlyn Householder, diagnosed with diffuse large B-cell lymphoma in 2019, shares her incredible journey after finding out that she was pregnant the day she was admitted to the hospital to treat her lymphoma. An ever-evolving plan was then set into motion to not only save Caitlyn's life but allow for her pregnancy to continue.

Transcript:

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

Jesse: I'm Jesse.

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

Elissa: Today, we will be speaking to Caitlyn Householder, a non-Hodgkin lymphoma survivor. Caitlyn was diagnosed with diffuse large B cell lymphoma (DLBCL) in 2019 at the age of 26. On the day she was supposed to start chemotherapy, the routine pretreatment test showed that she was pregnant with her first child. After years of infertility, she and her team of doctors worked together to develop a treatment plan that would allow her to continue with the pregnancy.

She started immunotherapy during the second trimester, delivering the baby at 36 weeks and then started chemotherapy and radiation two months later. She achieved remission in January of 2021 and now has a healthy baby boy.

Welcome, Caitlyn.

Caitlyn Householder: Thank you.

Elissa: So, let's start with your diagnosis of diffuse large B cell lymphoma, which is a type of non-Hodgkin lymphoma. What were your signs and symptoms leading up to diagnosis?

Caitlyn: I had originally started working out to try and lose weight because we were going to start fertility treatments. And it felt like a pulled muscle in my leg for the longest time and then it just increased to the point where it kind of felt like my bone was going to explode. There was a lot of pressure.

Elissa: Oh!

Caitlyn: It would be worse at night than it would be during the day, and it didn't increase with any activity. It was really odd. And it took months of fighting with somebody to do any test more than an x-ray. But it increased to the point where I was asking my husband to cut my leg off because it was so painful.

Elissa: Oh my goodness!

Caitlyn: So that was the brunt of my symptoms. Looking back, I had night sweats, things like that that you don't really put two and two together until after.

Elissa: Wow! So how did you end up getting diagnosed then?

Caitlyn: I had went in to get an x-ray and they said the x-ray was fine. I tried calling my regular orthopedic doctor.

I went to him, and he said that he didn't feel anything out of place. If it continued, we'll try and get some testing in a couple months and see what goes from there.

I wasn't really happy with those answers, so I looked into going to a different orthopedic doctor in the area, and he requested an MRI, but he just brushed me off and was basically hinting that my pain was from me being overweight.

So, I went and got the MRI. The results came back. It showed that there was abnormal bone marrow signal, and nobody would tell me what that could possibly mean, but I was instantly referred to Pittsburgh, Pennsylvania, for an orthopedic oncologist office.

Jesse: Caitlyn, after you were told about your diagnosis, what was the initial treatment plan that was discussed with you?

Caitlyn: They really weren't sure because after the second biopsy when they went in and took bone out, my leg was so far decayed and there was necrosis of the muscle. They really didn't know exactly what type of cancer I had other than it was some form of lymphoma. So, they tried two more needle biopsies. They sent it to another hospital for a second opinion, just to see if their pathologist could figure out anything. And they were tossing up ideas, but they were hoping to do immunotherapy. There's a more advanced treatment, which is chemo, radiation but it's outpatient. And then if you have an advanced, it's inpatient five days.

They were tossing between, is mine so bad because it had taken so long to get diagnosed or is it an aggressive cancer? When the pathologist from the other hospital weighed in on it, they decided that they were going to do originally three rounds of R-CHOP outpatient. However, my insurance kept fighting them, and it took almost a month to even get any type of answer on whether treatment was going to be approved or not since they didn't have those concrete answers.

So we originally decided on the outpatient three rounds of R-CHOP. My insurance still had not come back that they were going to approve it and my doctor didn't want me to get denied and have to pay out of pocket for all of that.

Elissa: Right.

Caitlyn: His workaround was to actually bring me inpatient but still give me that same treatment because if he-

Elissa: Oh!

Caitlyn: -had admitted me, he said it would automatically be approved because it was just like getting medication that you would've needed. So, I was admitted into the oncology floor and was still going to get that same three rounds of R-CHOP, but the first one was going to be inpatient.

Lizette: Yeah. Now let's discuss that day that you were supposed to go in for your first treatment, as we mentioned in the introduction, that it was found in your pretreatment test that you were pregnant. Now can you tell us about that and what happened afterwards?

Caitlyn: Yeah. The ride down to the hospital is about an hour, so there was a lot of time of, are we doing this the right way? We were going to try fertility treatments that year. Going into this appointment to cure my cancer was going to inevitably affect my ability to have a child in the future. So, it was an emotional ride crying that I was basically having to cease all wishes of having my own child. I do raise my stepdaughter, but I still wanted to be able to experience that for myself. So that was a really hard hour of having all of these thoughts run through my head.

We finally got there, and I was admitted. They came in, got the bloodwork, and they were like, "Are you pregnant?" And I was laughing. I was like, "No, I'm on birth control. Never going to happen." Half an hour later the MyChart message popped up that your test results are available. So, we were sitting there, and I just happened to look at them and the pregnancy test lit up red with an exclamation point next to it. And I was, like, "Well what's this? I've never had a positive pregnancy test." And no sooner did it show up on my phone, the nurse was walking in and was like, "We have a major problem."

So, they came in and were, like, "Are you on birth control? When was your last cycle?" all of these questions. I told them, "I started the birth control in the middle of the cycle. Could it be a surge from that?" They weren't sure because, obviously, they're

an oncology floor, they're not an OB/GYN, so they had to look into all of these things. And I had a upper respiratory infection that was on really strong antibiotics at the time, and they were like, "You have to stop taking them. We're stopping all pain medicine. We have to just let you sit here until morning when we can get you an ultrasound and make sure what's going on."

We proceeded in the morning, and I later found out that they were livestreaming the images as they were coming into my file in this conference room.

Elissa: Wow!

Caitlyn: My oncologist and a couple others were in this conference room trying to wait and see if that's what was going on so that they could be there and get a game plan. They were talking to other doctors, and it was this big thing. But they were all surprised because on the oncology floor normally you're dealing with seniors that-

Lizette: Yes.

Caitlyn: -are not of childbearing age. So, this was like a big production, kind of like a *Grey's Anatomy* thing.

So, it was definitely a huge surprise when I got that.

Elissa: Wow! Talk about a scramble, I'm sure, for your entire medical team trying to figure out what to do. I would assume that while it does happen, it is still pretty rare for a pregnancy to actually come up positive on the day the treatment is supposed to start. On one hand, the doctors need to save your life and on the other, everyone involved wants to try to find a way for a healthy pregnancy to continue. So, what was the treatment plan that they came up with to do both of these?

Caitlyn: It changed multiple times throughout the day. Once they confirmed that I was pregnant, they couldn't confirm that it was going to be a viable pregnancy because I was anywhere between three and five weeks pregnant. It was past the

heartbeat stage, but it wasn't to where the yolk sac had formed. So, they weren't sure if it was going to turn into a viable pregnancy or it was safe to terminate, and they kind of were going back and forth.

There was maternal fetal medicine, my oncology team, and other oncologists throughout the area. They had consulted some other major hospital on the East Coast. They had the high-risk OB/GYNs. And they were all going back and forth. Some were saying that I needed to terminate, others were saying, "There's been success in doing immunotherapy or chemo in the second and third trimesters."

There was actually one case where somebody was pregnant and they didn't know and started getting Rituxan® infusions, which is the immunotherapy, in the first trimester and the baby was perfectly healthy whenever they were born. They kind of were going back and forth on what was safest for me.

They came to the conclusion that because my cancer had already been nine months since the symptoms had started, that waiting a couple more weeks until we see if it was a viable pregnancy to start treatment was safe. It wasn't like I should die within a couple weeks because it had stayed stable, it was just on my leg, it wasn't all throughout my body.

We went ahead and with my oncology team and maternal fetal medicine, they decided to start 100 milligrams of prednisone. If anybody knows anything about prednisone, that is a very touchy steroid. And-

Elissa: Yes.

Caitlyn: -100 milligrams was basically like I was at the highest of high and then it came crashing down on the third day because I did three days of that just to get my pain under control. But it was having such an effect on the pain and inflammation, and I started taking prednisone daily. I believe it was 50 milligrams for quite a long time and then I tapered down to 25 (mg) for most of my pregnancy. So that was the

quick fix. And then during the second trimester, at 15 weeks, I started the immunotherapy.

Jesse: What were those first few weeks like for you before treatment started? I would assume there would be a lot of anxiety with both the pregnancy and lymphoma not being treated yet.

Caitlyn: There was definitely a lot of anxiety. I felt that it was too good to be true that I didn't really have any symptoms other than a garlic sensitivity. I couldn't stand the smell of garlic anymore.

Elissa: Oh!

Caitlyn: And I couldn't eat eggs. Eggs just turned my stomach. It was terrible and I was like, "Well maybe I'm going to get lucky there's no morning sickness."

Jesse: Yeah.

Caitlyn: Later on they attributed it to probably being on steroids, that that's why I didn't have a lot of symptoms that other people do.

And I took these little increments of time, so instead of doing, day by day, it was a couple weeks at a time. If I can just make it to then, I set another goal.

So, it was a lot of anxiety. Not only did I have cancer, my stepmother and mother-in-law had cancer at the same time too, so there was just so-

Jesse: Oh!

Caitlyn: -much to,

Elissa: Oh my goodness!

Caitlyn: -focus on that we were just taking everything day by day.

Jesse: Yeah.

Lizette: Before we go on to you starting treatment with Rituxan, we always speak about shared decision-making.

You had a lot of input into what was going on with your treatment and with your pregnancy. Can you share about that?

Caitlyn: Yeah. The treatment team and the OBs (obstetricians) were really good with letting me take the rein because it took so long to get somebody to listen to me that I felt like I was always put on this back burner for months with all of these doctors, even though I had said that there was something wrong. So, whenever we did get the confirmation that something was wrong, I was being listened to.

My oncologist team that I worked through with my treatment wasn't the first oncologist team that I had been in contact with. I actually was with a different group in the area and this was a well-known doctor. There was no bedside manners. I was kind of talked down too. Just didn't get the respect and I feel like it was because I was a female. I've had some doctors, do that before, where they just don't take you seriously because you don't know what you're talking about.

So, I had reached back out to my original oncologist who contacted me as soon as he found out that I was diagnosed and really anxious and ready to go. He had this plan and he wanted to help me because it was such a rare form of lymphoma.

He was great through the whole thing. Still having the pain four years later, he's still always listening. I can just message him and he'll respond right away even if I have a question about what we should be looking in for my son because my son was with me whenever I had cancer. And it's kind of scary when you see certain things happen with him that well could it be that going on?

There was just so much openness with the whole team, including my OB, that I ended up finding during the time because my original just regular OB didn't want to deal with

my case. They said I was too complicated for them. They had never dealt with anything like that. They didn't feel comfortable. So, getting with the practice that was in there the day that I found out, everybody was on board, which was great.

Lizette: Yeah. That's great to hear. I know that all of us can say that it's good to know that you kept advocating for yourself. You knew something was wrong and you kept going to try to find out what that was. I'm glad that you did find some teams that were very good with communication as well as really including you as part of the treatment team, which you are.

Now I know that your first treatment after the prednisone was Rituxan, right?

Caitlyn: Yeah. It was the start of the Rituxan treatments.

Lizette: How long were you on the Rituxan and how did the treatments go for you?

Caitlyn: So that's kind of where everything snowballed.

Lizette: Oh!

Caitlyn: I started Rituxan and within 24 hours, my swelling went down significantly in my leg. I felt great. I was originally going to do four treatments. They were weekly and the infusions took between like eight and ten hours. So, I was in the hospital most of the day. It was very exhausting, especially being pregnant. It was a lot.

But I got through those first four and they saw how much they had helped me and that I wasn't really having any side effects. The baby had stayed stable. It wasn't affecting his heart rate. He was growing. They didn't see any issue with doing another four treatments. So, the plan was eight.

However, COVID became a thing and after my sixth treatment, they stopped because they shut down the chemo floor at the hospital to turn it into a COVID ICU.

Elissa: Oh!

Jesse: Oh geez!

Caitlyn: So, I wasn't able to get all of the treatments because of the COVID starting. The day that I went in for my sixth treatment, they actually had their first COVID come in the same time that I was there. So, it snowballed from there. We wish we would've been able to finish out because it had done so much for my cancer. However, it just wasn't able to continue because of that.

Elissa: So, what happened then between COVID starting and the birth?

Caitlyn: Not a lot. It was just the normal follow-ups. I was getting monthly ultrasounds. My chemo was on hold. It was just bloodwork to see how I was handling everything and where I was at with that. It was just on hold because they weren't doing it unless it was, I wouldn't say highly needed, but if you were Stage IV, that was basically the only chemo that they were doing at that time on anybody at that hospital because they just didn't have the staff.

Jesse: Wow!

Caitlyn: So that all got put on hold, but they were still monitoring me. Most of my appointments turned into virtual appointments because they weren't even seeing patients in-house.

Jesse: Yeah.

Elissa: Oh.

Caitlyn: It was definitely a weird time to, not only have cancer, but then add in the pregnancy, and it was this whirlwind of what is life going to be in a couple months whenever I deliver. So, yeah, it was definitely an experience.

Elissa: Wow! When it came time to give birth, did the cancer or the treatment that you had been on create any complications?

Caitlyn: The only effect I had was I had developed gestational diabetes because of the steroids, but it wasn't to the point where it was uncontrollable. There was a possibility that it could cause a low birth weight for my son, however, that was not the case.

Elissa: Which is good for 36 weeks. That's still a month early.

Caitlyn: Thirty-six weeks, he was just shy of seven pounds.

Elissa: Ah!

Jesse: Oh wow!

Lizette: Wow!

Elissa: Wow!

Caitlyn: Yeah. Yeah, he was-

Elissa: Could you imagine if you would've went to 40?

Caitlyn: No. He was like-

Elissa: On my goodness, no!

Jesse: No, goodness.

Caitlyn: -I couldn't have a natural delivery because he was too big. So, it would've been a definite scheduled C-section if I would've went to full term, not let's see if this works and then ended up having the C-section.

Elissa: Was that the plan for you to try to get the baby out early just to be able to start treatment as soon as possible?

Caitlyn: Yeah. That's why they scheduled me to be induced at 36 weeks. He would've been in the safe period. Yes, it's premature, but they knew he was coming



early, so they did the steroid shots for the lungs. I had been having preterm labor symptoms probably around 25 weeks, so they kept a close eye on that. I was having a lot of back labor, but I wasn't really dilating even though I was having contractions between every four and ten minutes leading up to the 36 weeks. It was debated between 34 and 36 weeks, and we settled at 36.

They said there would be a possibility that he would be born immunocompromised, but they wouldn't know because they had to wait to do the bloodwork after he was born, which, obviously, was kind of scary with COVID being new. That was before anybody really knew what was going on. That was only two and a half months after the first case in the US. So, being told that you're going to have an immunocompromised baby, that brought up a lot of concern. But we knew that, for the most part, he would be healthy. There was nothing that they could see on ultrasounds that his heart or his lungs wouldn't be developed.

They took me in, and I started to be induced. We thought it would be an easy induction because I had been having labor contractions for weeks. That was not the case. It took me 40 hours to dilate to even 6 centimeters. Finally, I got to 10 and that was at hour 50. I had tried pushing for 2 hours and they're like, "He's stuck. You're not going to be able to do it. We're going to have to do a C-section."

So, he was born via C-section around 52 hours after the whole thing started. I went the whole time without eating, without getting a shower. That was the longest almost five days of my life.

Elissa: Wow!

Caitlyn: It was a long time. I don't remember much of that week.

Elissa: Block it out.

Caitlyn: Yeah.

But my son was born immunocompromised. He was born without B cells, which we knew was going to be a potential side effect-

Elissa: Yeah.

Caitlyn: -of getting the Rituxan so close to birth. They kept an eye on it. He wasn't able to get his rotavirus vaccine because his immune system hadn't recovered since then and they said if he got it, it would be not detrimental to him, but he wouldn't build any antibodies to it so it wouldn't work. There was no point-

Elissa: Right.

Caitlyn: -in giving him a vaccine that was just not even going to work. So, his immune system B cells recovered around nine, ten months. He started building them by himself, and he was able to get his live vaccines after that, but there was a good, I would say probably six months between the time that the IgG that he got from me wore off to the time he started building his own immune system.

Jesse: Wow! We mentioned a couple months after the birth of your son, you started on chemotherapy and radiation. How long were you on those treatments and were there any side effects?

Caitlyn: I went in about a month after I gave birth, a couple weeks after that I got my port placed. The original plan was for me to try and breastfeed for a month. They were going to let me do that because he didn't have an immune system and that would just help if I was able to, but I got my port placed and started on R-CHOP. It wasn't terrible. It wasn't pleasant, especially raising a newborn, but I had some severe hair loss. They said that I probably wouldn't see any until the second treatment and by my next treatment, I was completely bald. I had lost it all within the first. That was one major side effect.

The other one was just a lot of fatigue. I was just rundown a lot and I felt like I couldn't do much as a new mother. And then the chemo fog was really bad. I actually

am still suffering from that and going with a neurologist. But that neuropathy, my arms kind of went numb. They came back for the most part, but my fingertips still kind of feel like you were out in the cold for too long.

Lizette: Yes.

Caitlyn: A common side effect of R-CHOP is the brain fog and neuropathy. So, those were my main side effects. I was thankful that I didn't really have any of the nausea issues, but we also were proactive with the Zofran® and other nausea medications.

Lizette: Sure. And thankfully after that, you were able to achieve remission in January of 2021. What's your current treatment or survivorship plan with your treatment team?

Caitlyn: Yeah. So, after the three rounds of chemo, they did 25 rounds of radiation and we achieved remission in January of 2021. And we've been on a watch and wait period. They declared me in remission, but this past year they started seeing that there was some uptake and we didn't really know what was going on. They did another bone biopsy, which they went in, removed another chunk of bone and two masses out of my leg in November 2022 and it came back as inconclusive. It is dead bone and tissue-

Elissa: Oh.

Caitlyn: -but it wasn't showing any cancer cells. They don't know if what is showing up is basically what's going to be my baseline or if it's on the verge of starting again. So I'm not on a regularly scheduled PET scan plan. My oncologist is like, "I'm going to let you lead. You tell us when you need one. When you feel that your pain's getting bad again, we'll do another one, we'll see where we're at." He doesn't want to expose me to too much radiation because I have already had the 25 treatments along with multiple PET scans, CT scans, x-rays over the past couple of years. It's really up in the

air and that's only developed over the past couple of months that we don't know what's going on because the pain in my leg has gotten severe again in some instances.

Elissa: Okay.

Caitlyn: And it's one of those deja vu moments, like, "Well is this pain just in my head or is it truly coming back?" So, we're just on a watch and wait and I am in charge of what I need. If he feels I need bloodwork, he'll send it. If I feel I need some type of imaging, him or my orthopedic oncologist is more than willing to do whatever I need.

Lizette: And you were able to know when your body needed that medical attention before and a lot of times doctors that treat lymphoma will say that a patient may be able to tell if and when there's a recurrence just with how they're feeling before they have any tests.

Caitlyn: Yeah. That's why they're letting me lead it because they feel that I knew at the beginning. They suggested that my weight, because I had gained a lot with the chemotherapy and the high dose of steroids that I was on for about a year. They thought that maybe the weight had some form of causing the pain in my leg, especially with how much it had been damaged by the cancer.

So, I went and got gastric bypass last year to try and help lose weight. Because of being insulin resistant through my polycystic ovarian syndrome, PCOS, which a lot of women are starting to realize they have, it was really hard for me to lose weight. I had lost 140 pounds and when the pain was still there, they took it seriously and that's what led to the biopsy in November because they were, like, "You did lose a significant amount of weight and you're still having the pain." They're really good about letting me make a lot of the decisions.

Elissa: That's great. Before we finish up today, we want to hear a little bit more about your life now. Have you been able to return to normal activities and then how is your baby boy who is not so much a baby anymore?

Caitlyn: I was pretty good as far as activity went, but this second biopsy that was the major one really put me down. I'm still recovering from it. They don't know if I will ever be able to walk normally again.

Elissa: Wow!

Caitlyn: It, it's a lot. Especially with my son being three, I thought I'd be able to go and run and play with him. I feel guilty some days in that aspect that I'm not able to be as active with him as I'd like, but I'm hoping to get the strength back in my leg from this second biopsy. I still have the issues with the brain fog, and they said that that probably will never go away at this point. I have an MRI on my brain tomorrow just to make sure that they're not missing anything. And with my son, he actually is going to be three in a couple of weeks.

Elissa: Wow!

Caitlyn: And he is definitely not little by any means. He's about 40 pounds and he's almost up to his sister who's 11. He's almost at her shoulders. And-

Elissa: My goodness.

Caitlyn: -he's a handful. He definitely gets his way, but he's a normal toddler and that's one thing I'm grateful for is that this really hasn't affected him at all. You wouldn't think to look at him that he would've been through everything. That he should have been deformed in some way with being exposed to fentanyl and radiation in days past conception when I had my first biopsy and they didn't know I was pregnant because it was too early at that time, to being exposed to those high doses of antibiotics, to the immunotherapy, to, and all of these things that something could've went haywire and somehow miraculously it didn't.



Elissa: Wow! That's so good to hear that he is doing so well. And we hope for you that this biopsy will just be a setback and you can get your strength back and be able to run and play with him. So, we are hopeful.

Now, our final question today. On our patient podcast Home Page, we have a quote that says, "After diagnosis comes hope." So based on your cancer experience during pregnancy, how would you complete that sentence, "After diagnosis comes?"

Caitlyn: I would say faith. It's led me down a path of finding my faith, realizing that maybe we're all given a different journey in life to go down because I didn't have faith that things were going to be okay. I didn't think that both of us would come out on the other side.

As I had mentioned, my mother-in-law had cancer and my stepmother. Unfortunately, only two out of the three of us are here today. My mother-in-law did not make it to see the birth of my son. So, that was really hard. I had to have faith in that we made it through for some reason.

Elissa: Yeah. Well, thank you so much, Caitlyn, for joining us today and sharing all about this incredible story. I hope that others listening who may find themselves pregnant after a cancer diagnosis will be hopeful and that you will provide some inspiration to them. But thank you so, so very much and we are so happy to hear that your little boy, or not so little boy, is doing so well. So, thank you again.

Caitlyn: Thank you and thanks for taking the time. I wish that there was more stories out there like this, so I'm glad that you're able to share it.

Elissa: Thank you. 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.

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