LEUKEMIA & LYMPHOMA SOCIETY®

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Statistics Don't Color My Outcome: A CAR T-cell Therapy Success'

Description:

Join us as we speak to Laurie Adami, a follicular lymphoma (non-Hodgkin lymphoma) survivor. In this episode, Laurie shares her long journey through multiple cancer treatments, which eventually led to CAR T-cell therapy and complete remission.

Hear one patient's story of hope, as new treatments continued to come out, keeping her stable until the one that finally worked was approved for her disease. Her story of resilience and determination to stay alive for her young son is the inspiration that so many blood cancer patients need.

Transcript:

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

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

Elissa: Today we will be speaking to Laurie Adami who was diagnosed in 2006 with Stage IV follicular lymphoma, which is a type of non-Hodgkin lymphoma. She spent 12 years in continuous treatment, which included seven different lines of therapy, three of which were clinical trials. Failing to reach complete remission in prior therapies, she participated in a successful CAR T-cell therapy trial and finally reached remission where she remains today.

Laurie spends considerable time assisting cancer patients navigating the challenges a cancer diagnosis brings. She is a Patti Robinson Kauffman First Connection® volunteer, an LLS public policy volunteer advocate, and an active volunteer fundraiser for LLS, currently raising money for LLS-funded immunotherapy research grants.

Welcome, Laurie.

Laurie Adami: Thank you, Elissa. Nice to be here today.

Elissa: So, Laurie, let's start with your diagnosis of follicular lymphoma, which is a type of non-Hodgkin lymphoma. Could you tell our listeners what that is?

Laurie: Sure. So follicular non-Hodgkin lymphoma is the second most common type of non-Hodgkin lymphoma after diffuse large B-cell. And it tends to act more indolent. They call it an indolent or slow-growing lymphoma, and so, many patients are actually able to just watch the disease, in some cases for years, without requiring treatment because it acts in a much more slow-growing way than the more aggressive types.

The thing about follicular that is different than in more aggressive types is that follicular is an incurable type of non-Hodgkin lymphoma. And non-Hodgkin lymphoma impacts the lymphatic system of an individual, so you end up with malignant cells in your lymph system. And so non-Hodgkin lymphoma is a blood cancer and much more commonly diagnosed than say Hodgkin lymphoma, which is a different form of lymphoma but that's a much more rare type. I believe there's about 25,000 Americans diagnosed each year with follicular.

Elissa: Now what were the signs and symptoms leading up to your diagnosis? How did you end up getting diagnosed with this?

Laurie: I had a very difficult time getting diagnosed. I was 46 years old. Well, actually, a few years prior to 2006, I was 43 and I started to feel unwell. I was an older mom. I had my son at the age of 40 and a very active career person, traveling, running a company. When I was 43 years old, I started to have some nonspecific symptoms. I started to develop frequent sinus infections, which became a chronic sinusitis. I developed a very dry eye. So, I'd been a long-term contact lens wearer and suddenly after 30 years of wearing contacts, my eye was so dry I couldn't wear the contacts.

Elissa: Oh!

Laurie: I had a node in my neck that was enlarged, and I also had felt something in my abdomen that I was being told was very likely a hernia from when my son was born. And probably most importantly, I had incredible fatigue. I was so tired. I remember my mother-in-law coming over to babysit my son, and I would just go sit on a bench and just rest. I was so exhausted. I had all these weird symptoms, and I'd actually done a Google and I know everybody you're not supposed to Google, WebMD® or whatever. Well, I did.

Elissa: It's a little dangerous.

Laurie: And I got Sjogren's syndrome came back, and non-Hodgkin lymphoma came back. I go to the doctors, and they'd look at me like I was a hypochondriac. "You don't have lymphoma. You're traveling all over the world, you have a little boy, you're running a company. I'm exhausted just listening to you." So, it took me two years for somebody to actually listen to my symptoms and order me to get the CT scan at which point we discovered I had lymphoma.

Elissa: Wow!

Laurie: It took me quite some time, which at the time was very frustrating because you can imagine not feeling well you want to know what's wrong so you can fix it.

Lizette: Right.

Laurie: But in hindsight, if I'd been diagnosed two years earlier than I was, I would've had that first treatment and it would've failed me and then there wouldn't have been anything else. So I was, in a way, very fortunate it took the doctors a couple years, and it took me finding a new doctor for them to listen to me and get me diagnosed.

Elissa: That's so frustrating to not be listened to. We hear that quite a lot. It happened to me when I was an AML patient. It happens to a lot of cancer patients in general that you just know something's wrong.

Laurie: Right.

Elissa: And you might have these small symptoms that could be attributed to something else, right. It could've been Sjogren's syndrome, and it could've have been just general tiredness after having a baby. I'm glad you were able to finally get diagnosed and get started on treatment.

Laurie: It's interesting, my husband had accompanied me to an ear, nose, and throat doctor. Supposed to be one of the best in Los Angeles. He had come with me when we were trying to nail down why I kept getting these sinus infections.

I said to the doctor, "What about lymphoma?" "Oh well, why would you think you have lymphoma?" "Well because I have an enlarged node, I have a very dry eye, so clearly stuff is going on in various glands in my head. And I have this thing I'm feeling in my abdomen and I'm so exhausted." And he said, "Well how did you come up with lymphoma as a possible diagnosis?" I said, "Well I went on Google, and I put all my symptoms in."

He just totally blew me off and said, "You don't have lymphoma. You have allergies." Now mind you I'd been tested for allergies, and I didn't have allergies. I said to him, "Well I've already been tested" "Well their tests must be faulty. We'll retest you. And if I just treat you for your allergies, you're going to be fine."

At this point, I had gotten to a new diagnostician who said, "We don't guess about hernias. That's why we have CT machines." So, they sent me to get a CT scan. Come to find out I had Stage IV non-Hodgkin lymphoma.

Elissa: This is exactly why we really encourage patients to self-advocate because it is so important. You could've been one that might not have been comfortable with it and just gone home and not known and just dealt with the sinus infections and the fatigue and not continued pushing until you found an answer. So, I'm so glad that you did. You knew something was wrong and you kept pushing until you finally got a diagnosis.

Laurie: Correct.

Lizette: Yeah. And I know that I do want to hear more about your treatments, but along the line of what Elissa is saying, it is so important to self-advocate. What made you so comfortable at the very beginning to start advocating for yourself because I know that we have a lot of patients that don't feel comfortable right from the beginning and really have to listen to our podcast, reach out to us, and really learn and get more information before they feel comfortable enough to speak out.

Laurie: Right. In response to that question, really there were two issues and two things that happened. The first was that my little boy was only in kindergarten when I was diagnosed, and I just couldn't bear the thought of him losing his mom. I just kept thinking about my husband having to tell my son, August, "Mommy passed away." I was going to do everything in my power to stay alive for my son. My husband said, "What about me?" I said, "You'll get another wife, but my son can't get another mom or dad," So that was the first thing.

And then at the beginning, I was so shocked. I think we all are when we get a cancer diagnosis. We never think it's going to be us, and we have no idea how to navigate. And there are barriers everywhere for a new cancer patient. There's barriers with work, we have to go out and have doctor appointments. Well, is our boss going to let that happen. Is our boss going to give us a bad time? You have barriers with your insurance company. "Oh no, we're not going to approve this. You can't get a second opinion." You have barriers to getting medication. So, there's all these barriers placed right upfront even when I was trying to get second opinions.

I remembered that a gentleman had worked with me years prior who I'd recently heard had been diagnosed with a very rare type of sarcoma. I got his contact information, and I reached out to him because I knew he'd been alive for a couple of years, and I wanted to find out what he did.

And so he told me all about clinical trials, how to find experts, how to find nonprofits that worked with patients with my kind of disease. How to reach out and find a patient who was a survivor because if I could talk to a patient on the road ahead of me, that would give me a lot of hope.

And it's great. We all talk to the doctors, but, honestly, the doctors come in and out, they diagnose, and they prescribe. They don't really witness what the patient goes through.

We also deal with nurses. Now the nurses understand it a bit better because they're actually in the infusion rooms with us administering the chemo, seeing the side effects, trying to help the patients deal with the side effects, but they too usually have not lived through a cancer diagnosis. So, the most helpful people for the patient is another patient on the road. And this gentleman, Dave, was so helpful with me just helping me to navigate. He actually called me and I was so depressed, I was so overwhelmed. One doctor told me I had a 50% chance that I would be alive in two years. I got very upset. He said, "Well what's wrong? Two years is a really long time." And I said to the doctor, I said, "Not if you're 46-years old and you have a kid in kindergarten. Two years is nothing!" So, I never went back to see that doctor because I wasn't going to let his statistics color my outcome.

So, I learned from someone else, another patient, and that's why I do as much as I can to talk to other patients who were recently diagnosed or recently relapsed because getting that patient perspective can change your life and can change your hope and can give you new hope. When the doctors might paint a negative outcome. Those were the two things, my son's major motiving factor for him to have a mom and then this gentleman who helped me and taught me how to do this.

Lizette: That is very motivational.

Laurie: The other thing is the patient has the most to lose. The doctors are going to tell you what you're going to do and then the doctors go home. But we have the most

skin in the game, so we need to get the most informed as we can about our disease and about our options. If we can't do it and we can't advocate for ourselves, which not everybody is able to do, then get somebody to help you. Get a child, get a close relative, get a close friend, get a partnership with someone else who can help you navigate the road.

And I am a firm believer that if I hadn't done this and I hadn't been as engaged in my own care as I was that I wouldn't be here today. I have no doubt. I wouldn't be alive. I think it's just critically important and that's what I tell other patients. Now not every patient, as I say, can do that. So oftentimes when I talk to a patient, I may talk to a son or a daughter or a wife or a husband who's helping that patient to navigate.

Lizette: Right. And now you're doing the same thing. You're doing well right now and you are a volunteer for us in the Patti Robinson Kauffman First Connection® Program, which also gives back to others.

Laurie: Right. And it's interesting. I've been doing this for over ten years. I had been connected with a First Connection volunteer close to the beginning of my journey and she was very helpful. And so, I asked her, "How do I sign up for this program?"

Recently, I've been very busy with The First Connection® Program because CAR T is a relatively new therapy and so there aren't a lot of us CAR T First Connection volunteers. So, I've been getting a lot of CAR T patients and, as CAR T rolls out for use in diagnoses beyond leukemia and lymphoma, for example, it's been approved now for multiple myeloma, I'm talking to a lot of multiple myeloma patients who are considering getting CAR T.

As CAR T moves beyond blood cancers, it's being trialed for just about every type of disease that you can imagine. In fact, there was just a news story a couple weeks ago about early-stage trials for an autoimmune disease called lupus and very successful early-stage trials with CAR T in lupus. It has applications well beyond the blood cancer

space into solid tumors. There are trials now ongoing for glioblastoma, which is the devastating brain cancer. There's trials for ovarian.

I am on Facebook groups that are diagnostic groups. I'm on a follicular non-Hodgkin group, a CAR T patient group, a non-Hodgkin group. And those Facebook private groups have thousands of participants that are patients, and so I'm getting connected with patients all the time through there.

Lizette: Let's talk about your journey. You had other treatments before CAR T-cell therapy, correct?

Laurie: Correct. As I mentioned initially, many people diagnosed with follicular and non-Hodgkin are able to do what's called watch and wait. But because I was so sick in the beginning, I was Stage IV, that dry eye that I had was a tumor in my tear duct that was blocking my lacrimal gland. Your lacrimal gland is your tear duct. And that was why my eye was so painful. I had to order a patch because when it was open, it was so incredibly painful. I had very extensive and symptomatic disease. I had a tumor the size of a grapefruit in my abdomen. That was the supposed hernia they thought I had was probably my primary tumor, which was as large as a large grapefruit.

So, I started right away with the only approved treatment at the time which was called R-CHOP. And that's a combination of a monoclonal antibody, Rituxan®, with a number of alkylating agents, traditional chemotherapy. I was diagnosed on Good Friday of 2006, which wasn't such a good Friday for me, and I started treatment. You know, I had the full excisional biopsy, verified the diagnosis, and began my six-cycle journey.

Tt was really interesting, and it was really encouraging because by three treatments I had a scan after my third cycle. Every three weeks I had chemo. I was to get a total of six cycles. So, after three I was scanned, and the doctor called me up that night astonished that my cancer was gone already after three cycles, which was an incredibly wonderful response, so I was very encouraged. We did the remaining three

because it was approved as six cycles and scanned at the end. My last treatment was on 9/11/2006, I was scanned, and I was told I was in complete remission.

S, I merrily went back to regular life. I had gone out on disability for the treatment, and I went back to work and began to work. I was doing maintenance Rituxan to try to extend my remission. Unfortunately, three months later when I had my first follow-up scan, I already had tumors back in my lungs, so I had relapsed.

At that point, I was told I needed to do an autologous stem cell transplant, which is where they use the patient's own stem cells. That was considered the second-line therapy at that time. Being my own patient advocate, I started to research stem cell, and I discovered I'd probably be in the hospital for a month, which is a problem having a little kid and a husband who had his own business. It was going to be very difficult to do that, but more importantly, at the time I said, "Well if I've got pretty good assurance this is going to work, I'm going to do the stem cell." But unfortunately, when I researched, I discovered that 50% of follicular non-Hodgkin patients relapsed in less than a year after auto stem cell. I would've had another brutal chemotherapy and then I had a 50% chance that it would put me in complete remission. So, I began to explore other options.

I went to three or four different locations in Los Angeles, and I found a clinical trial of an HDAC inhibitor, which was an oral therapy that had been approved for T-cell non-Hodgkin, which was being trialed for B-cell indolent. I started that in combination with Rituxan. I watched and waited with it for quite some time until I started the therapy. And we just watched the tumors come back right where they'd been.

So, at the end of 2008, I started this therapy with this HDAC inhibitor called vorinostat. And that didn't do a whole lot except it stabilized my disease. So, it capped off the growth in the disease. It bought me time. Unfortunately, in less than a year, the cancer had outsmarted it and started to grow again, so my second line had failed. By then bendamustine and Rituxan had been improved as a new treatment option, so we

switched to that. I, again, went to get consults at different lymphoma specialists, and I did a whole year of bendamustine. And we reduced the disease quite a lot, but we didn't eliminate it.

I then consulted with some specialists up at University of Washington, Fred Hutchinson and in Los Angeles about a newly approved radioimmunotherapy called Bexxar®. That was my fourth line. Again, I was trying to get a complete remission. Bexxar is a one-time infusion. It's actually not on the market anymore, but a similar treatment called Zevalin® is still available on the market.

I had met several people through The First Connection Program who had successfully had Bexxar, so was very optimistic that this was going to work, this was going to put me in a complete remission. It worked in a whole different way than the three previous treatments I'd had. At the end of 2010, so now I'm, four years into my journey getting my fourth therapy, Bexxar.

Four months later, I was sitting reading the paper on a Sunday and with my hand on my neck and I felt tumors.

Elissa: Oh no.

Laurie: So, the Bexxar had already failed. I went to see my oncologist the next day. He said, "The only thing you can do is an allotransplant." An allotransplant is where you get a donor's stem cells. They give you chemotherapy. You're hospitalized. You, hopefully, have a sibling match because then you get a better match. Unfortunately, my siblings were not matches, so I was going to have to go into the unrelated donor bank where I did have matches, but when you have an unrelated donor match, the match might not be as good as if you had a sibling match. Also, you can end up with what's called graft-versus-host disease (GVHD) where you're now donated immune system begins to reject your organs and you can have troubles with your kidneys, with your liver, with your skin. Graft-versus-host disease can really impact the patient's quality of life.

So here I am, just failed my fourth therapy, just barely five years into this cancer journey, and I went to three different places in Los Angeles, and they were all telling me, "You've got to do an allotransplant. That's the only thing you have left."

I was really depressed. I had dropped my son at school. I went home. I put my pajamas on. I went back to bed. And I had sent out an email that oh my gosh my cancer's back again. I'm going to have to do this allogeneic stem cell transplant. I was very concerned because there's a risk of mortality even when you're in the hospital and then there's a risk that it didn't get rid of my lymphoma. There's the risk that I could have GVHD. So, all these risks were really impacting me in my state of mind.

A close friend called, and she said, "What are you doing?" I said, "I'm in bed, I'm so depressed." She said, "Laurie, get out of bed. Turn on your computer. I'm coming over. We're going to find you a clinical trial." We emailed eight researchers all around the world looking for clinical trials as an alternative to a stem cell transplant.

In these emails I explained my diagnosis, I explained my long treatment history. An hour later my phone rang, and the caller ID said UCLA. It was a doctor from UCLA. He said, "This is Sven De Vos at UCLA. I read your email. I have a clinical trial that I think will work very well for you. It's a new approach. It's what's called a small molecule drug. It's a PI3 kinase inhibitor. It's a pill, but I need to see you today because I only have one slot left in the trial."

Elissa: Wow!

Laurie: It's a "Phase I trial. You would fill the 20th slot, but I need to see you today or one of my associates is going to give away the slot." And I said, "Well why do you think this is going to work? Look at my treatment history." He said, "Because I have patients in this trial who treatment histories look just like yours and they're responding very well to this therapy."

I went in. He did my bilateral bone marrow biopsies that day. The next day I started the pill. I was doing it in combination with Rituxan and my tumors immediately started to shrink like visibly. I could feel them. I can see them. When I first met the oncologist, I had a tumor in my face that was so large, it was blocking my ear.

Elissa: Oh, my goodness!

Laurie: So, he said to me from across the room, "I can't see your right ear. All right, we're going to get you on this drug. Let's see how we do." Immediately the tumor started to shrink. That was my second clinical trial, and I was on that drug for five and a half years. So, it bought me a lot of time. It wasn't without its side effects. Rarely is it the case the drugs have no side effects, but the most important thing for me was it kept my cancer either stable or slightly reduced so that I could buy time.

The drug was called Zydelig®. I was on it from 2011 till the end of 2016. In 2012, I attended a Leukemia & Lymphoma Society event in Beverly Hills near where I lived, where for the first time, I heard about CAR T. I happened to be seeing my oncologist after I attended the LLS event, and I said, "Dr. De Vos, what's going on? Why are you holding out on me? I heard about this CAR T last night. Why am I not getting that right away because it sounds so much better than what I'm doing?" He said, "Because it's not ready for follicular yet. It's being trialed for CLL, for ALL, for diffuse large B-cell, but because follicular was considered a less aggressive disease, it wasn't being tried yet."

He said, "We just have to keep you riding on the horse you're on. You got to stay on this drug. Let's ride it as long as we can. Let's buy time."

So, at the end of 2016, unfortunately, my cancer finally outsmarted Zydelig® and I started to get new tumors. And he's like, "Okay, this horse is done. Let's put it out to pasture." By then CAR T still wasn't available in trial, this is early 2017, but there was a new monoclonal antibody called Gazyva®, obinutuzumab, which had just been approved for relapsed follicular. This was a third-generation anti-CD20 monoclonal

antibody, kind of a third generation Rituxan. So, he said, "Let's do a course of that. It's a nine-month course. You'll come in once a month. Let's see if we can get you to stabilize. Let's see if we can buy some more time."

I started Gazyva and it worked. It started to reduce my tumors. The good thing about me is I could always feel my tumors. I didn't need scans to know that I was relapsing or that it was working. The tumors began to shrink and, unfortunately, that treatment ended September of 2017; and as soon as I stopped, the tumors started to grow again.

At that point, it was a race against time, and I just was getting sicker and sicker. We were looking at other things as a bridge to CAR T, but we just were in a race against the clock.

And in the spring of 2018, my oncologist from UCLA called me. He said, "I've got great news. The ZUMA-5 study is opening at UCLA. We're going to have five patients. You're going to be patient number one. Come on in, let's get your paperwork going. You'll sign up for the trial. There's a whole series of steps we have to go through." That was my history of treatment. And all six of those treatments never resulted in a complete remission for me. At best, I had stable disease, slightly shrunk disease.

Elissa: What you've said here is an important point for our patients and caregivers listening is that sometimes, even if a treatment isn't working, if it is keeping you stable, there is so much research continuing to come in and it's going on in the background and preparing to be ready. If you can stay stable, then you never know when that next treatment is going to come out that is actually going to work, which is just really exciting. We have seen it just with so many treatments for all these different blood cancers that nothing has worked. Nothing has worked to get people into complete remission. And all of a sudden that one thing comes out that works for you. And-

Laurie: That's right.

Elissa: -it may not work for everybody, but if it can work for a few, if it can work for somebody, then they could just keep going. They can keep building on it. Keep coming out with new medications. And so that's just really great.

Laurie: Right. What's really interesting is, Elissa, I was in the clinic and I was talking to a nurse about CAR T. This is about a year after I had my CAR T. And a woman in a treatment chair next to me overheard and she said, "Do you mind if I ask you about this CAR T?" And she has pancreatic cancer. And I was explaining to her how I navigated through time. This woman was so motivated by my story.

She has been now on two different trials for pancreatic and is buying time until something else comes along. And she said, "I never thought about it that way." You think you have to have the homerun, well you don't. Being in the game, being alive, moving. If you're not underground, you're winning. You just don't know when you're going to get that solution that's going to finally do it. And like you say, medical research, they're making leaps and bounds in progress.

Elissa: Yes.

Laurie: And that wasn't the case in 2006. When I started, it was really slow going, in terms of what was coming out. And that was also why I started to do fundraising because I thought selfishly, if I can fundraise and raise money for a research project, then maybe I can benefit from the research that's happening.

And in this case of CAR T, The Leukemia & Lymphoma Society was very early to the game funding researchers at University of Pennsylvania and UCLA. Very early in the game when people thought this idea of CAR T was crazy, like Frankenstein science. Well Leukemia & Lymphoma Society said, "You know what, we're going to fund these researchers." LLS has put something like $70 million into CAR T research. And I know those numbers have probably gone up since that last statistic update I got. That's why I do what I do with LLS and for other patients because you just never know.

Elissa: Yeah.

Laurie: The therapies coming out today, are, by definition, more targeted, better understood than these old brute force chemotherapies that I also had to get over the years just to stay alive.

Elissa: Now let's talk a little bit more about CAR T-cell therapy. For our listeners who don't know, could you explain what that is?

Laurie: So unlike the first six therapies I had, which are off the shelf, every patient gets the same treatment, CAR T therapy uses the patient's own immune system. The patient's T cells are extracted in an apheresis clinic where you just go in and you have a line connected. T cells are part of your immune system along with B cells, NK cells; they're white blood cells.

The patient's T cells, about a million of them, are removed from the patient. They are couriered into the lab where they are reverse engineered, modified and had a target placed on those T cells and grown in the lab for three weeks. They are then returned to the patient with this target placed on the cells that is only going to recognize your cancerous cells. And on the patient's birthday, which is considered day zero, you go in and you get your cells infused directly into your bloodstream.

It's a 16-minute infusion where you get these cells infused back into you and these cells, they're still your own cells; they're still your white cells, but they've been modified to be much smarter so that they only recognize the cancerous cells in your body. They then are like heat-seeking missiles that go through your body to target and destroy only the cancerous B cells. In my case, because I had a B cell cancer, my T cells were trained to recognize.

So, this is very different from a chemotherapy where a chemotherapy drug is going to kill every dividing cell in the body regardless of what kind of cell it is. So, it could be a hair follicle, for example, and that's why your hair falls out with chemotherapy. With

CAR T-cell, it's very smart and targeted and only recognizes the malignant cells in the patient.

Lizette: So many CAR T patients say that it is challenging while waiting for the T cells to actually be manufactured. How was that lag time for you?

Laurie: The lag time between when your T-cells are harvested and when you get them back, for me it was really challenging because my disease was growing quite rapidly. You know, at every point of my seven treatments before I did them, I had biopsies to confirm that my follicular had not transformed into more aggressive. But in spite of the fact, it was still follicular, my disease was growing by leaps and bounds.

My doctor decided to do what they call a bridging therapy for me. I had one dose of chemotherapy during that time period to try to shrink things. Unfortunately, it didn't do a whole lot. And so that three-week period for me was really challenging. I had tumors that were in my abdominal area that had begun to interfere with my right kidney. My oncologist, in that waiting period, had said, there was a possibility they were going to have to put a stent in me so that my right kidney would continue to function.

I also had to have sinus surgery because, unbelievably, when my cancer started to grow back, it started to impact my sinuses again. My oncologist said, "You cannot go in and get CAR T with an active infection."

Elissa: Ugh.

Laurie: So, I had to go see my ENT. I said, "I've got to get this sinus thing fixed." He called his assistant in, he said, "Call my patients today and postpone my surgeries for tomorrow because I need to operate on Laurie tomorrow."

Elissa: Wow!

Laurie: Here's a guy who stepped in and did it. I was terrified, but at the same time I had so much hope because I had heard some preliminary results about follicular in the Phase I study that was done at National Institute of Health (NIH) with the CAR T approach. They'd only had 14 follicular patients, but 75% of them were in complete remission. And my doctor had told me this. So, I still had so much hope.

Elissa: Yeah.

Laurie: I just got to make it. But it was hard. My son had just graduated from high school. I had a house full of family who'd come out. I was having a graduation party for him, so I had 50 people showing up and I was sick as a dog. And scared to death about was this going to work, was I going to make it, to get my cells back? So, it can be a bit anxiety provoking, but at the same time, the doctors were managing me. They were watching everything really closely.

The other thing I was worried about, what if they mess up and there's something that goes wrong? So, I kept saying to my oncologist, "Have you heard? Have you heard?" And then as soon as he got the word my cells were done, everything was fine, that was also a relief.

I recently had the opportunity to go into the facility where they made my cells in El Segundo, and I got to speak to the employees. There were about 30 employees that worked there four years ago when my cells were made, and I got to thank them in person. And they rarely meet a patient. And they're my heroes-

Elissa: Yeah.

Laurie: -because they babysat my cells for 18 days and it worked.

Elissa: That's wonderful. One of the difficulties with CAR T-cell therapy is that some patients can't wait four, five, six weeks for their cells to be remanufactured, but then that opens the possibility for, in some cases, there's what's called off-the-shelf CAR T-

cell therapy where they are using donor cells that are genetically manufactured to go in and fight.

I'm so excited that the CAR T-cell therapy has worked for you. You have remained in remission four years later. Let's talk a little bit about your work with LLS and what you've been doing. We mentioned First Connection® earlier but you've also been doing public policy, advocacy and raising money for immunotherapy grants. Could you tell us about both of those?

Laurie: Sure. I reached out to Dr. Lou DeGennaro, the CEO of LLS, and I said, "I really want to become involved with this advocacy at the legislative level because we have all these new improved treatments, but if patients can't access them because they have crummy insurance plans, or they can't get access to trials where they live, or they're Medicare patients who can't afford drugs in oral form. And if they're a pill, they're covered through your Medicare Part D plan, which had no out-of-pocket cap. So, there are all these issues I was aware of. He said, "Yeah, I'll hook you up with our public policy people in Washington."

For the last three years, since 2019, I have been doing advocacy work both in Washington as well as in California. That's been really rewarding. And that's reaching out to my representative in the House of Representatives. That's reaching out to the senators. Once a year we do advocacy meetings with those folks. We've been, unfortunately, virtually since 2019 because of COVID hitting in 2020, but, hopefully, in the spring, we're going to get back out and walk the Hill, which is great. We've made progress. So, Medicare Part D, we just had a cap placed so that patients have no more than $2,000 out of pocket for prescriptions. These oral cancer therapies can cost $100,000 to $200,000 a year.

Elissa: Yeah.

Laurie: And if you have no cap, you walk away from the pharmacy counter and can't afford these better therapies. So we've dealt with that. That's been very rewarding.

As far as the fundraising is concerned, I started with a friends and family team at the Light the Night events. And I was still working at the time, and a bunch of my employees joined my team, and we did fundraising. I set my goals always at $50,000 because at that point, if I could raise $50,000, I could figure out where the grant was going to go to fund a researcher.

And so, I would raise $50,000 each year in that. I did Light the Night for probably six years. In 2014, I was nominated as a Woman of the Year candidate. I raised $160,000 for LLS. Half went to a researcher at Stanford, half went to Mayo Clinic.

Then three years later they had started the Student of the Year fundraiser and they nominated my son.

Laurie: So at that point, my son was a junior in high school.

Elissa: That's so great.

Laurie: He did the first Student of the Year, and raised over $100,000, so he made two grants to researchers that were working on follicular and the indolent non-Hodgkin's.

Elissa: Wow!

Laurie: So that was how I did the fundraising. And then before I went in for my CAR T, one of my oncologists at UCLA who's been an active LLS funded researcher, said to me when I was going in, he had been trying to get me to go to Kilimanjaro with Climb 2 Cure. This was at the end of 2017.

Elissa: Yes.

Laurie: And I said, "I can't go to Kilimanjaro. I am so sick. I can barely move and get out of bed." He said, "All right, you're going to get CAR T next year, and it's going to be successful, and we're going to go to Everest Base Camp with Climb 2 Cure, LLS Team In Training."

Elissa: That is a good goal.

Laurie: That was my goal. So, when I survived, I found out one month after CAR T that I'd had a complete response. At my first post CAR T scan I was already in complete remission. And remember, when I went in, I was really sick. My oncologist estimated I had eight pounds of disease.

So, a month later it's gone. All right, I'm going to Everest Base Camp and I'm going to raise $250,000. And we were supposed to go March of 2020. And I had my tickets with two of my oncologists from UCLA, my trial coordinator from UCLA, three other patients, and then I was taking a documentary filmmaker. And we were all set to fly into Kilimanjaro. I had all my gear all ready to go and the world shut down because of COVID.

Elissa: Oh no!

Laurie: So.

Elissa: Oh, I hope that is still a goal.

Laurie: That is still a goal.

Elissa: I mean if you're about to run a marathon, I think that you could climb a mountain too.

Laurie: Yeah. So, I set myself goals in 2021. So, 2021 I did the Los Angeles Marathon. 2022 I'm doing the Washington, D.C. Marine Corps full Marathon, and then the hope is fall of 2023, we will go and do Mount Everest Base Camp.

Elissa: That's perfect.

Laurie: That's the plan, because I have a pre-existing condition, my oncologist has to sign off that it's safe for me to go. it's still a risk with COVID. We just have to be

mindful because yes, I want to do this goal, but I don't want to kill myself in the process.

Elissa: Yeah, you don't want to put your life at risk for this. I'd like to point out very quickly for our listeners that don't know we said that you are raising money for immunotherapy grants. If you raise over $50,000, you can choose where that money is going to go.

Laurie: Correct. There is still so much work to be done to identify new targets, making CAR T have fewer side effects. Why would I not pay it forward and try to help the people on the road behind me just like people on the road ahead of me helped me? And I was very fortunate. I've already raised over $100,000. So-

Elissa: Wow!

Laurie: - it's going to the immunotherapy research that's ongoing. When I did CAR T four years ago, you had to do it in a hospital setting. Now it's being done outpatient. And a huge benefit of that is that it brings down the costs dramatically because a hospital stay can be a large component of the cost for the patient.

Now insurance is paying for CAR T and Medicare is paying for CAR T because the reality is, while CAR T may be expensive relative to other things, if you think about my treatment journey, I was in treatment for 12 years. I was on the PI3 kinase inhibitor for over five years. The cost of that was $180,000 a year!

Elissa: Yeah.

Laurie: Times five. Now I was under trial, so I didn't have to pay for it, but all these therapies are expensive. If I could have gotten CAR T as my second or third line, think about all the money that would save. Now CAR T is being done outpatient because they have such a handle now on side effect management that they can medicate any side effects away. The progress has been phenomenal.

I was one of five patients at UCLA that was in the ZUMA-5 trial. There were 80 initially across the US. Then because it worked so well, they enrolled another 80 patients. But the results of the ZUMA-5 study are like no other treatment for follicular non-Hodgkin. There was a 95% response rate in the ZUMA-5 study where patients' tumors responded to the CAR T and over 80% got complete remission. That's astonishing.

Elissa: Amazing.

Laurie: So, patients need to know about CAR T. They need to ask their doctors about it. If their doctors don't know about it, they need to reach out to LLS. LLS has an 800 number where you can talk to a clinical trial nurse who can connect you with these newer therapies. Oftentimes, trials the patient doesn't pay because the pharmaceutical and the researchers need patients to enroll. It's a changing world for the patients.

Lizette: Wow! Well thank you so much for literally walking, running, and climbing mountains for patients with blood cancers. Thank you so much.

Elissa: Our last question for the day, Laurie. On our patient podcast Home Page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, how would you complete that sentence, "After diagnosis comes."

Laurie: Life.

Elissa: Yeah. What does that mean to you?

Laurie: I got my life back. I'm 62 now. I was diagnosed at 46, and I'd been feeling really unwell for at least three years. I look back to where I started this; my life is unlike anything it was before. My attitude, my gratitude, how I feel. I feel better now than I felt 20 years ago. I could never do a marathon 20 years ago. It's all about life and actually being alive and appreciating the fact that I'm alive.

It's about helping other patients to stay alive and to be able to experience what I have been blessed to experience just in the last 4 years. If I can be a positive influence for someone else, that's the most rewarding thing for me.

Elissa: Well, thank you so very much, Laurie, for sharing your story about all the treatments that you went through and then finally getting into complete remission with CAR T-cell therapy. We are so happy for you and so thankful for all that you have done for LLS, for other patients over the years between your First Connection® Program volunteering, your public policy advocacy, and then, of course, raising all of that money to fund research which is what saves so many people and will continue to save so many people.

I'm glad that you are doing so well, and I hope that you have provided so much hope to patients and caregivers with this episode. So, thank you, again, for joining us.

Laurie: You're welcome and thanks for the opportunity. And I always say yes to a request from LLS because if it weren't for LLS I wouldn't be here, and I really believe that.

Thank you so much Elissa and Lizette. It was really nice to visit with you today.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that could be found in the Show Notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people. We would also like to know about you and how we can serve you better. The survey is completely anonymous and no identifying information will be taken.

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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 find information about follicular lymphoma at LLS.org/Lymphoma and CAR T-cell therapy at LLS.org/CARTTherapy. All of these links will be found in the Show Notes or at TheBloodline.org

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