

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Worrying is Not My Plan: Viviana's Story'

Description:

Join Alicia, Lizette and Edith as they speak with Viviana Onofre about her follicular lymphoma diagnosis that she received in November 2015. On this episode she describes minor signs that she noticed prior to being diagnosed, the importance of patients educating themselves about their diagnosis to help relieve anxiety, asking questions to better understand health insurance to avoid delays in treatment and how her diagnosis has helped her to shift perspective and embrace growth.

Transcript:

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

Edith: I'm Edith.

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

Alicia: Today we'll be speaking with Viviana Onofre. Viviana has worked in banking for 19 years. She currently resides in Texas with her family. And on this episode, we'll discuss her follicular lymphoma diagnosis that she received back in November 2015, the impact it had in her life, and her overall cancer journey. So, thank you so much for joining us and welcome Viviana.

Viviana: Thank you. Thank you for inviting me to speak.

Alicia: Of course. Now, Viviana, for our listeners who don't know what follicular lymphoma is, follicular lymphoma is the most common subtype of indolent NHL or non-Hodgkin lymphoma, indolent meaning slow growing. So, in indolent lymphoma, the first diagnosed, patients have fewer signs and symptoms than patients with aggressive lymphoma subtypes, aggressive meaning fast growing.

Viviana, what was the case for you? Were there any obvious signs and symptoms around your time of diagnosis?

Viviana: No. I had only felt a slight little lump in my neck after a massage, so I just, you know, thought that maybe it was related to that. You know, didn't mention

anything to my husband; and I, then crazy things happened in my life that I just forgot about it.

Alicia: Interesting. And was it painful at all?

Viviana: Yeah, I mean it was kind of silly because I've never seen when I get a massage to have like a lump; but, you know, maybe I thought they did it wrong. But, no, it wasn't painful at all, which maybe that might have been the first kind of thought that maybe it wasn't normal. But, no, no pain, so just kind of left it at the back of my mind.

Alicia: And so, with having no pain and no obvious signs or symptoms, how were you diagnosed?

Viviana: I had no symptoms and, actually earlier in the year, my regular doctor had told me that I was kind of the picture of health, right? So, I went to my Well Woman exam in September and, again, no symptoms other than that little lump that I totally forgot about. And it was during that exam that the, the doctor, the OB/GYN told me, "Hey, you're kind of up for another mammogram," because I had had one in the past; and I didn't think much about it. She didn't tell me that she had any concerns.

So, I had my mammogram, and then they called me afterwards and told me that they needed me to go in for an ultrasound because they had found a lump in my armpit. And so, I wasn't very good about doing the breast exam, self-exam, but I never would have thought to do the armpit. So, I didn't know about it. And, you know, I didn't worry much because I thought, you know, maybe it's a cyst or something.

And then after the ultrasound, when I was there, the technician told me that, yes, it was a swollen lymph node; and I had more swollen lymph nodes in my chest. And then that lump that I had found, she checked it, and she said that it was also a swollen lymph node; and, you know, she asked me had I lost weight or had night sweats? And I said, "No, nothing at all."

And then a little bit after the ultrasound, so in November they did a biopsy; and then when the results came, my OB/GYN called me and told me that it was follicular lymphoma and that I needed to go see a hematologist/oncologist. It was just totally out of the blue, unexpected. I don't even think my OB/GYN thought she was going to be telling me I had a lymphoma.

Alicia: That's interesting when you hear about these diagnoses happening from a specialist that you wouldn't necessarily think of as the primary person.

Viviana: Yeah, my doctor didn't say, "Hey, you have maybe higher white cells or something," right? The typical, bloodwork that you get doesn't show or doesn't, maybe they don't look for certain things that you would see when you do the bloodwork whenever you go, you know, whenever I go to my, my exams with my oncologist.

Alicia: Right. You're feeling fine the entire time and they're giving this information that you might have something else, but they're still doing testing; and they're telling you that there's more swollen lymph nodes, what's going on in your mind during this time? Or are you busy and thinking that whatever, if it's serious, they'll let you know but not thinking about it? Where were you mentally?

Viviana: So, it was like a process. So, first when they told me about the ultrasound and that there was a swollen lymph node, I checked my armpit and, sure enough, I felt it and I was like, "Oh." But my mom had had cysts before, so I was like, "Oh, okay, maybe something like that, right?"

It wasn't, I think it was at the time when I was having the ultrasound and the technician mentioned lymphoma that I just kind of felt like the floor just you know, I don't know, I was floored, right? And so, but again, I said just don't freak out. Try to not dwell too much into it.

I think that in between the ultrasound and the biopsy I was just, you know, kind of just praying that it wasn't anything serious. My first thought was, how much time, because at that time my youngest was seven years old. So, I guess that was for me the hardest part.

And then when I got the biopsy and I got the diagnosis, then it really, it hit me a little bit more, in the sense of, okay, what is the prognosis? Like how many years are we talking about, right, and kind of just comparing that to how old my child was, you know, my youngest. And my other two were still not that much older. And just kind of going through, okay, what if it's five years? Well, how, you know, kind of how much years are you going to have? If it's ten, you know, things like that that you suddenly realize that, well, five to ten years isn't, you know, not enough, right?

But I've always had an attitude of, you know, just dwelling too much on things is never good. What is already is, whether I worry about it or not. Maybe, if I would let myself get too much, it was just going to be too much.

After a period of “Oh my God” and hyperventilating and kind of thinking it’s not fair and, and angry, one day I said, “You know what, you just have to stop and, again, what it is, it already is.” No matter how much amount of worry you do, it ain’t going to make me better.

So, it was kind of like a, a journey. I guess that was, was, that would have been like the first survival, you know, because they call us survivors. And so, everybody is different, but the first survival that you have is from hearing the news and that process.

Lizette: Now when you heard you had lymphoma; did you know what lymphoma was?

Viviana: I knew what lymphoma was because, I guess, funny, I don’t know if it’s funny or kind of God works in mysterious way. I had become involved with LLS through the Light the Night Walk, and an individual had come to my work office to talk so that we would put a team together.

And so, he was diagnosed with follicular lymphoma, and it was in his 30s, similar to me because I was 37 when I was diagnosed. And so, so I knew what follicular lymphoma was in terms of the name. What particularly it was, no, because you never research it until you need it.

Lizette: Right, right.

Viviana: So, I had heard the name. I didn’t know the particulars.

Lizette: Wow, and you already knew somebody that had follicular lymphoma.

Viviana: Yes, yeah, yeah. And I guess that also kind of, at the beginning kind of helped maybe a little bit because I had the image or the example of somebody that had had a lymphoma diagnosis young; and he had been, I think when he went to talk to us he had been like, I don’t know, 10, 15 years in remission.

Lizette: Yeah, so at least knowing somebody and they’ve gone through treatment can give you that hope-

Viviana: Yes, yes it did.

Lizette: -and strength from the beginning.

Viviana: Yes, exactly.

Lizette: Yeah. Did the doctors let you know that there were so many different types of non-Hodgkin lymphoma? As Alicia said in the beginning, there's actually so many types and some are slow growing, some are aggressive, and the actual goal of treatment for slow-growing non-Hodgkin lymphomas versus aggressive non-Hodgkin lymphomas is very different. Did they go into all of that with you at the beginning?

Viviana: Well, I did some research. Not the doctor. The doctor did explain at the beginning what follicular lymphoma was and my particular type, meaning how far it has spread, right?

I had done some research, so I knew there were a ton of non-Hodgkin's lymphomas and kind of where each one was placed in the sense of indolent and what indolent meant. So, in doing that research, it also helped. Then many coworkers in my office also kind of gave me information.

So, when I went to the doctor, he focused on mine, and I had an idea of the differences.

Lizette: And did they tell you the goal of your treatment?

Did they utilize the word cure with you, or did they say that this is going to be something that at this point is not curable?

Viviana: Yes, so from the beginning, the doctor said that, you know, this wasn't going to go away, that unlike other cancers, there was not a cure, and that the idea was to put it, so to speak, to sleep.

Lizette: Yeah.

Viviana: And it could come back. And, but he also told me that it's slow growing; and he told me that I have seen patients who, years pass and they end up dying not by this type of cancer. They die by something else.

So, he gave me, he tried to alleviate my concern, knowing that I was younger and that I have children, like try not to worry too much, right?

And so he did explain that, and I ended up going to MD Anderson. The doctor, at the beginning, told me, "Let's," you know, he says, "Let's see what the scan shows because if you do have several lymph nodes in several areas," and he kind of explained what about, what are the reasons under which we would treat versus there's also what they

do with my type of cancer which is wait and see – meaning you don't do anything, and you just kind of monitor it.

So, he did tell me the circumstances under which treatment would be considered. And so then after the scan, it came back that I needed to be one of those that needed to be treated because I had lymph nodes, swollen lymph nodes in all parts of my body – upper, bottom, left, right – and that I think there was some, if I'm remembering correctly, there was a little bit of inflammation in some organs. So, again, there were enough things in the exam that made him think that we needed to have treatment.

They also did a bone marrow biopsy that came out with also having follicular lymphoma in it; and the doctor had told me, "We're going to do this, and most likely this is going to happen. It's going to be that you're going to show that there is cancer there too, right?"

So, again, all of that put together, the doctor said, "You know, you, we do need to treat you." And the goal was going to be, we'll give you treatment so we can put you in remission. We didn't talk about afterwards what would happen.

Lizette: Right. Now you mentioned that you went to a larger cancer center. What brought you to the larger cancer center?

Viviana: So, whenever I first heard, my OB/GYN gave me options. She had done some research and gave me names of things that were close to my home. But then she said, "But, I would strongly advise to consider MD Anderson because it's so, you know, here in, in Houston, it's a well-known cancer center focused on cancer," right?

Lizette: Um-hmm.

Viviana: And so, so she told me that, and then also, like I said, I knew people that had been, you know, knew or knew people that had had lymphomas, right? And so all of them said, "We suggest go to MD Anderson." I actually got names of doctors, and they were all in MD Anderson.

So, I just went to that one because I just heard that, "Hey, they're the specialists. They're focused on this." I did have other options because, for me, MD Anderson is about like an hour away.

Lizette: Okay.

Viviana: So, there were other options in where I live, but for me it was a decision. You know what, they're the specialists. They do a lot of research on it. So I think, you know, not only being the specialist, but they might be at the forefront of any new things that are coming out. And so that, that's why I went. I had decided going to a large center.

Lizette: Sure. Here at LLS, we try to encourage our patients, if you can, to go to one of these larger national cancer institutes, designated cancer centers because, like you said, there are specialists there; and our blood cancers aren't the most prevalent cancers out there. So, if you can get information from a specialist, that's something that we would deeply encourage. And I'm glad that you were able to.

It does make a difference with treatments since our blood cancers, like I said, are not the most common, so it does make a difference. And there's so many new treatments out there specifically for our blood cancers that I think it's really important to be able to get that second opinion or to get more information about the treatments available because things are changing with the blood cancers; and, you know, we're really excited about having more treatments out there for people.

So, I'm glad that you were able to go to a larger center, see a specialist. I'm glad that you had that support to really tell you it's really great to see a specialist.

And I'm happy that you knew about The Leukemia and Lymphoma Society from the beginning, right? There's some folks out there that don't know about us; and we really want to make sure that everybody knows about us, especially if they're just diagnosed because we want to give people so much support right at diagnosis all throughout the cancer journey.

So, did you utilize any of our resources? I know it's so difficult. You know, you try to research once you're diagnosed, like you said.

Viviana: So, whenever I was first diagnosed, so it's funny, but you kind of go into this blank, right? So, I knew about LLS. I knew about Light the Night Walk, but it never dawned on me when I was first told to just go to LLS. Most of the research that I got, it was either something that my husband looked up or that I, one of my, because when I was diagnosed, I was at a work lunch. The coworker, the very first person that knew about this was the coworker I was with. We got back to the office, and she immediately went online and researched.

LLS has this resource [*LLS's First Connection Program*] they put me in contact with, not the individual that had gone to my office but another one that had been diagnosed around the same time, same age.

So, we talked and, you know, they explained a little bit more. They asked me about my diagnosis, and they explained a little bit more. And they kind of talked to me about their journey from the beginning and then later.

And so that one, I'm going to say that was like a game-changer as well, you now, not just knowing somebody that wanted to talk to me, but actually talking to someone at the moment, explaining your differences, telling them, "Hey, look, you can expect this or that" and also telling you, "Look, traditionally, this is what we would, this is how they treat, but more things have, have happened," right?

And another thing that also helped is telling me his journey while being treated, kind of how he felt. So that helped tremendously. That alleviated a lot of my anxiety in the initial, you know, when I was initially diagnosed.

The one thing that I really liked was the LLS puts together a lot of education lunches or conferences and webinars. And so at the beginning, that was also very helpful because in terms of the conferences, mostly at the lunches you were able to talk with other survivors, and it really helps you put things into perspective. You hear their stories, what they're going through, how they're being treated, and it gives you a sense of perspective so that you could say, "Okay, how am I?" You know, kind of how are they, right? And also know about the many different options that there are.

And then, you know, in the conferences, because you have specialists over there, you can hear what is being done on your particular cancer and what they're looking at for future therapies. And so those resources really helped and talking about the many topics that one can have as a survivor. So those were the resources that I used with LLS and found very helpful.

Lizette: Great.

Edith: Viviana, what advice about your cancer journey would you share with other patients and caregivers listening today?

Viviana Onofre: Well, I think that, you know, the first thing is, you know, try to get educated and cause education or knowledge is key, but the most important one is that attitude is also very important. Try to stay positive. I understand that, you know, my journey, thankfully, I didn't have that many side effects with my treatment, so my

journey might be very different than others. But at the end of the day, you just need to try to stay positive.

We didn't get a choice in this diagnosis. No matter how you slice it or dice it, if it was, if you think it was maybe you did something in the past or just plain bad luck, you can't change it. That's out of your control.

So, but we do have a choice of what we want to do once we're diagnosed. Do we want to let this define who we are, or do we just want to say, "Okay, I acknowledge my negative feelings," right? "I accept them, I acknowledge them; I might be angry and then I might be scared, but I don't let them overwhelm me or get me too much," right. And I just accept them and accept that this is going to be part of my life and just keep moving.

If you talk to more people, you're able to see that sometimes no matter what you're hearing, there is always somebody who is going to have it harder. You need to take that and put things into perspective and not get carried away and, you know, share your story because other people will gain hope or will learn or, or get something from your story.

So, again, and this is an everyday process. I mean I got a very good response with my treatment but now it has, you know, I didn't last in remission too long, so I have again swollen lymph nodes. So it's an everyday process of trying to stay positive and try to focus on the things that you have control on, not on the ones that you don't and feel the pain, feel the anger, feel the unfairness but don't let it get too much that it doesn't let you keep going. So that would be my advice.

Edith: Very wise words. A patient never goes through this journey alone. How important is the role of the caregiver?

Viviana Onofre: I think it is very important, and, for me, personally kind of odd because I'm, since I have smaller kids and I've taken like this, this idea of I need to be strong, right. So I think the caregiver is important to give you the support and I would tell people, try not to get too much into "I need to be strong for everybody" that you're not able to let yourself be taken care of."

And every caregiver and survivor relationship is different. You know, for example, I'm not the type of person that whenever I was diagnosed, it was like, "Oh, okay, well, now everybody has to take care of me and I'm not going to look into insurance or into

all those things.” And, you know, with my husband, I’ve always been the one that deals with that, right, and so I continue doing it.

Thankfully, I wasn’t feeling sick that I couldn’t, so I was the one calling the insurance and all of that. But what I’m trying to say with this is that the relationship of a caregiver and a survivor is different for everybody but still you need to have that person where you can, you know, lean on.

I remember the first time that the doctor came back and said, “Hey,” just a couple of months ago that you’re, you know, you’re no longer in remission and, you have swollen lymph nodes again, it made a huge difference to have my husband there cause he always goes to the appointments with me and be able to just kind of, how to say it, not keep it together anymore and have somebody there to be, you know, just simply holding your hand and be there.

So, again, even if you’re the type of person that, you know, kind of has to keep it all together and be strong for your family so that they don’t feel it as much, it’s good to have that caregiver or partner to be able to let go sometimes of the whole, oh, I’m keeping it together kind of thing.

Lizette: Sure.

Alicia: Viviana, I mean it sounds like, again, you had such great, great support. Your side effects weren’t anything that prevented you from doing things that you were basically doing every day. What resources do you use that help you address things either psychosocially or, or other ways?

Viviana Onofre: With my experience and my treatment having almost no side effects, it made me realize, that I needed to share my story to kind of try to give hope. I’ve been involved with the LLS, not just the Light the Night Walk, and I’ve met other people that have been diagnosed. And so that is a resource I also, I think it’s also a resource because you can be there for each other, right.

So, trying to stay connected with other survivors through the whatever options you find, whether it be LLS or another organization, but to just trying to stay connected-

Alicia: Sure.

Viviana Onofre: -because you can find support groups because there is things as a survivor that- And if you kind of like are the type that feels, you know, I have to kind of be strong, right, there are things you might not share with your caregiver or even

your support group, like other friends that, you know, they haven't gone through this. So, there are things you just can't share or even if you think you share, they don't understand. So, having that connectivity with others that are going through this or have gone through it helps with those things that, you know, others won't understand, right?

And then the other resources is mostly it's LLS, you know, the webinars and I sign up for the advocacy group to just see what's going out there, what they're doing in terms of lobbying and, you know, the webinars and education. And I've even gotten some of the webinars that LLS has done with other organizations, like I think, think Triage Cancer was the most recent that I heard, which was very helpful because they were talking about things like, you know, insurance and Workers' Comp you know, the benefits you have as a survivor, right. Things I didn't even know.

So, I guess the advice, long story short, is just stay connected, get involved to whatever level you want but to get those resources of information. Like sign up from your newsletters or things like that so that you get that information because, again, information is power and it helps with not make you create this this negative outcome and kind of put things more into perspective. And definitely I continue to be involved with the Light The Night Walk, and so that has also been a really, for me personally, a really nice, visual way I see all of the support and that, you know, I'm not alone in this and kind of how everyone's journey has been different and kind of keep connected.

Alicia: Absolutely. And you mentioned something that I, I would love to shine light on, the more accurate information you have, the better this entire situation is because, like you said, you hear the word cancer and for your experience, the floor dropped from beneath you. And we've heard similar stories where you hear the word and everything, you start Googling. You start trying to figure it out for yourself what's going to be your treatment and, and it can be overwhelming. And so it's so important to understand that there is information out there, and I'm so happy to hear that you find our tele-webs useful for credible information.

I know earlier Lizette mentioned that we encourage people to visit large cancer centers, however, we know that many don't have that option; and so we encourage everyone to contact our LLS Information Specialists who help to assist a patient, a caregiver through a cancer journey answering questions about treatment, financial and social challenges, and to give accurate and up-to-date information. They're not doctors, but they are master's level oncology social workers, nurses, and health

educators. So, for those listening, we encourage you to give them a call Monday through Friday 9 AM to 9 PM ET at 1-800-955-4572.

So, thank you again, Viviana, for shining light on the importance of accurate information.

Viviana Onofre: Thank you. If I may add a little bit more on that, I would say that that even gives you more up-to-date information cause, originally, I remember Googling prognosis, right, and the results I would get were very dated, not very positive and so definitely LLS has helped get more updated information in my particular type.

Alicia: Absolutely, and we're so happy to hear that.

Viviana, is there anything that you feel we haven't shared with our patients and caregivers listening that you think would be important for them to know?

Viviana Onofre: I guess one, one word of advice whether as a survivor or caregiver, whenever you get diagnosed, and I know this is not going to be forefront, but, you know, some point, get into the details of your insurance. I'm a detailed person just because of where I work, right, but if you never read or you just sign up for insurance, you know, it's your work, right, and you just sign up, pick the plan, and kind of looked at the cost, and you never took the time to kind of look at the details, this is the moment where you need to look at the details.

So whether it's the survivor, if they have the mind for that, or the caregiver, because why I say that because it will take a lot of the angst that you can experience at the beginning with dealing with insurance, so that if you are prepared and know what you can expect, whenever you start dealing with them because it is hard at the beginning, you have knowledge.

Alicia: Right. I know that when we spoke before this podcast, you were trying to get into a new clinical trial, right, and, and due to insurance issues, you couldn't get into the specific one that I think you and your doctor were looking at. Is that correct?

Viviana Onofre: Yeah. It took some time for me to be treated because I was diagnosed in November and started getting treated, I think, in May the following year. They originally wanted me to get into a clinical trial that they were putting together, right, and, you know, you kind of sit back, I thought, well, I mean if they're dealing with this, they're going to be the ones to check whether it's covered or not. And all

the time that I was having conversations with them, they were like, "Oh, the insurance covers it. The insurance covers it."

Well, long story short, we're ready to get, you know, this clinical trial is getting opened because it, it had been, when I was first diagnosed it had, it was starting, right. They had to do all the administrative stuff. So, anyway, long story short, by the time they are getting ready to start enrolling people, then they checked and, oh no, my insurance doesn't cover it.

And so that just created a very negative experience in the sense that they're telling you because the reason they wanted to put me there was because one of the medicines that I had was considered like a newer or it wasn't like FDA approved kind of therapy for my type and it was a very expensive medicine and so sometimes they had problems with insurance covering it. But if you went the clinical trial route, you would get the medicine for free and then you won't have to worry about that.

Well, again, long story short, my insurance didn't approve it and all this time they were telling me, "Oh, this is going to be so great for you and this is, you know, this is going to, we have such good outcomes." So, when you hear that it cannot be covered, right, and that there's the potential that the insurance won't cover the medicine that is \$17,000 a month-

Alicia: Oh, wow!

Viviana Onofre: -you're like, "Oh my God!"

Alicia: Right.

Viviana Onofre: I mean I remember crying and being so, so disturbed when they told me insurance didn't cover it. And just say, "Why didn't anybody check beforehand because then now what's going to happen?" I felt like, like, oh my God, this could be life changing.

Thankfully, that didn't happen. My insurance did cover the very expensive medicine, and so I was able to get treated with two of the three medicines that were on the trial and had a good response. But if you, had I had taken it upon myself or my husband to look at the details of our insurance, we could've known beforehand all of this and maybe not make a change but know beforehand so it wasn't a surprise and it wasn't a feeling of, oh my God, does that mean that now I'm going to get the traditional chemo and lose my hair and get super sick, you know, kind of that difference?

So that's kind of why I give that advice. And understand as well, I mean a lot of the people that listen are already survivors and know all of this, but if there are anybody that is new, it's not going to be easy at the beginning. You would think that an insurance company hears cancer, diagnosis and everything is smooth, or doing a scan and, everything goes smoothly. It does not. It's difficult. So, don't stress too much. That is normal and not just to you, right. But, yeah, that's kind of my advice, additional advice.

Alicia: That's great advice.

Lizette: It is. Very well said. Thank you. And I know that it's a newer offering here, but at The Leukemia & Lymphoma Society we do have nurse navigators that do help and assist patients and caregivers to find and to see if a clinical trial is appropriate and to help with all of these issues that you did bring up. So our Clinical Trial Support Center definitely is here to help patients and caregivers look into clinical trials as an option and to help with all of those things and, and to have all of those questions to ask your doctor, like you said, you know, to be prepared to know more about the trials and the treatment options.

Alicia: Absolutely. Now, Viviana, we're going to play a little game. So, on our website, we have a statement that says, "After diagnosis, comes hope." If you were to fill in that last word based off of your experience and everything that you've gone through, how would you finish that sentence, "After diagnosis comes"?

Viviana Onofre: Oh, okay, I'm going to take a little while to think about this.

I think I would add growth. After diagnosis comes growth. And just to kind of explain a little bit is from all of this, believe me, I wish I didn't, I wouldn't have gone through it, but I've grown as a person. If you can't control it, don't dwell on it; and if you can, do something about it, that helped. That point of view kind of helped. But this experience made me grow even more from that. It, made it even clear that there are things outside of my control that you just have to accept them and move on and then also let me see how blessed I am. And so that's, that's why I choose growth.

Alicia: I think that's awesome and so true, and there's no better way to end this episode. So, thank you so much for joining us today, Viviana, and for sharing your story.

Viviana Onofre: Thank you very much for having me and giving me the opportunity to share my story.



Lizette: Very well said. Thank you for inspiring us and inspiring others.