

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'My AML Diagnosis: Elissa's Story

Description:

Join in as Shona sits down with Elissa Baldwin onsite at CancerCon 2019. CancerCon is an annual conference held every year by Stupid Cancer, an organization that provides support to young adult cancer survivors. Elissa is a young adult acute myeloid leukemia (AML) survivor. After a bone marrow biopsy two weeks earlier, she went on a solo trip to Europe and was diagnosed by email while staying in a hostel in Lisbon, Portugal. She was able to book an emergency flight back home to Portland, OR to begin chemotherapy within a week. On this episode, Elissa shares how and when she was diagnosed, the emotional and physical challenges she experienced and how her diagnosis served as inspiration for a career change. She emphasizes the importance of therapy during a cancer diagnosis and continues to serve as a source of encouragement for other young adult survivors.

Transcript:

Shona: Welcome to The Bloodline with LLS. I'm Shona. Thank you so much for joining us today. Today, recording on-site at CancerCon, in Denver, CO. Here with me today is Elissa Baldwin, a young adult acute myeloid leukemia survivor. Elissa will share how cancer, not only impacted her life, but helped her to redefine her calling, leading her to work for the Portland Light the Night team. Elissa, thank you so much for joining me today.

Elissa: Thank you for having me.

Shona: So, for those of you who don't know, CancerCon is an event held every year by Stupid Cancer, which is an organization that provides support and resources to young adult cancer survivors and young adult cancer patients. LLS has staff that attend every year, as we have—as probably over 40%, would you say, of the CancerCon attendees are blood cancer patients and survivors. So, we provide on-site resources and counseling and, support to the patients who attend the conference. So, I wanted to ask you, Elissa, why do you think that CancerCon is so important for young adult survivors?

Elissa: Oh my gosh! CancerCon is—this is my second year attending and it has been so tremendous for my personal growth, in my cancer journey and, I love my friends and family. They're so amazing, but there are so many parts of that they just don't

understand. They just don't understand, as much as they try to, and they be empathetic; and it's so nice to come here and be around so many other cancer survivors and I don't have to explain it. I just bring it up and they understand.

Shona: They just know.

Elissa: And, like, that's it. And it's so nice and it's almost an indescribable feeling to be here and I hope that every young adult cancer survivor would be able to do it because they really do address all these different issues that we are going through; and it helps to connect with people on all these different things that they're going through as well. And, you know, again, other people in my life just don't understand and they, you know—as much as they try to, it just doesn't happen. And so, CancerCon just means so much.

Shona: Right. Those who are going through the experience and can really understand what you're going through. And it's also a completely judgement-free zone, which is one of the reasons why I love coming here as well—seeing how everyone interacts—kind of relaxed and letting themselves be who they really are around people who understand what exactly it is they're going through.

So, I wanted to talk to you a little bit about your diagnosis of AML. What was going on during the time that you were diagnosed?

Elissa: Oh gosh! I guess it can all start back in October of 2015. I had lost a bunch of weight the previous year and started—I started gaining weight, even though I was eating really healthy, exercising every day, and then I also started having night sweats. And I couldn't explain it to anybody, but I just knew something was wrong. I just knew it in my gut that something was wrong. And so, by January, I started to continue to gain weight pretty rapidly and have, ah, have bloating that had become painful; and so, I finally made an appointment with a gastroenterologist, because, I've had irritable bowel syndrome for over a decade. And so, I just thought I was having just a ridiculously long flare-up. I am like, "I don't know what's going on, but I know something's wrong." And so, I finally got in—that takes forever—so I finally got in at the end of March and she did—she gave me a bunch of over-the-counter stuff to do and then said, "hey, why don't you come check in with me in 4 months. Let me know how you are doing?" And, right as I was walking out the door, she said, "you know what, let's just do a blood test. We'll check for thyroid disorder or celiac disease. Maybe something else is causing the weight gain." because that was a big concern because, I'm a healthcare professional. I know that I should not be gaining weight like this; and I shouldn't be gaining weight rapidly when I'm eating this well and I was training for a triathlon at the time; and, this doesn't--this isn't right. And she—I got a call a few days later saying that my test results came back and everything was normal except for my white blood cells were low. So, I didn't know why my white blood cells

were low and that got testing going with my primary doctor; one test every week, because they should replenish themselves. And then, they still weren't going back up so I got sent to a hematologist. He did a very extensive blood test and then he said, "you know, you're—let's get on the calendar a bone marrow biopsy just in case this test doesn't tell us what we need to know."

And, I was headed off to Europe in two weeks for a solo trip and so, I said, "can we just do it when I come back?" And so, we put it on the calendar, tentatively, and I got a call one-week later—I was at a conference—and saying that we need to schedule the bone marrow biopsy quickly. So I was, like, "well, that's a concern". They just moved up my tentative biopsy by four weeks...

Shona: Wow!

Elissa: ...and, so I went back home and got—I went in and—of course, they don't tell you anything over the phone...

Shona: Right.

Elissa: ...so I walked into the doctor's office and he said, "you either have leukemia or, an auto immune disorder called Sjogren's. And he was describing the symptoms for Sjogren's and I'm like, "none of that fits." So, I pretty much knew, at that point without actually confirming it, that I have leukemia. And I still tried to go to Europe in 5 days, and ah, so, yeah, so I said, "you know, I can keep in touch with you over e-mail. If anything comes up, I can always get on Skype and call you." And, , while I was in Europe, , I started having some swelling and, also, seemingly, got an infection as well from a bug bite; and so I called him and was e-mailing him—pretty concerned about it, but he you know, and he, of course, he was concerned. He did not like me being there. He was not a fan, but I was going to go regardless. And then, I was in Lisbon, Portugal—I was about one week into my trip, and I woke up and I was flying to Norway that night, and I decided to put my bags in the hostel and then head out on the town. So, right when I was walking out the door, I realized, oh my gosh, I haven't checked my e-mail yet—you know, when you are traveling and you are without service, you go Wifi.

Shona: Right, right.

Elissa: So you take advantage of it. And so, I looked at my e-mail and there's an e-mail that says, "lab results" from my doctor and it was pretty simple. It said, "you have acute myeloid leukemia and you need to come home." And, ah—oh man—it was—when I found out, it was 2:30 in the morning back home. So, and again, I was traveling by myself.

Shona: You were alone. You were traveling in Europe alone.

Elisa: Yeah; yeah. And so, I didn't have anybody to talk to. I forwarded the e-mail to my parents. I hated that they had to wake up to that...

Shona: Right.

Elisa: ...but they knew—they knew that it was a possibility. They knew about all the testing coming up to it and, then I, you know, I texted a few friends and—and then I just sat in the hostel and cried for, I think, probably about an hour. And, ah, and then, you know, I was like, "I have to get out of here so I am just going to continue to go out and look around Lisbon". And I did that until I knew that my parents would be awake and then I found an indoor food hall that I knew had WiFi.

Shona: Hmm; hmm.

Elisa: So, I went and Skyped to my parents. and I actually got there and there was an e-mail from my Dad saying, "we're awake. You can Skype whenever you're ready." And, ah, so I Skyped them. I don't even remember that call. It's a--I think I...

Shona: It's a blur.

Elisa: ...completely blocked it out at this point. I remember doing it and I remember seeing them; and then my Dad told me later that—I guess he brought up chemo—and I just totally lost it. Completely lost it. So, my Mom's a travel agent, so she started working on getting me a flight back. I still flew to Norway that night. And so, I got diagnosed on Wednesday and I flew back Saturday, and started treatment on Tuesday. My doctor is an AML researcher. He's on the Beat AML team, which is pretty cool. And so, he only comes in clinic one day a week. So, they're like, "if you're stable enough to wait 'til Tuesday, we want you to start on Tuesday." And so, I went in and got admitted and I was in for 32 days for my induction.

Shona: Wow!

Elisa: And then, went home and had 4 more rounds of, treatment. There was 3 double days and—because they let me do outpatient 'cause I only live 30 minutes from the hospital, which was awesome, but it was a lot. So, there was 3 double days with 2 rest days in between, and so chemo every 12 hours, and my family would come up. My parents would come up every time--they live 3 1/2 hours away--for chemo week, and we would do stuff on the off day, you know, like a wine tasting. They never told me I couldn't drink so, you know, I went wine tasting on the days that I didn't have chemo and you know, tried to do other stuff—tried to have as much fun as I could on

those days `cause, when they went home, I was lonely and I had to stay at home, and I was neutropenic, and I—I couldn't do anything...

Shona: ...couldn't do anything.

Elissa: ...and it sucked.

Shona: Right.

Elissa: So, actually, I grew to like chemo weeks, as hard as they were and as tiring as they were, because I got to do something. And my levels were usually good enough to be out in the public, at that time.

Shona: And your family was there.

Elissa: And my family was with me.

Shona: Which is so important—to have that support when you are going through something like chemotherapy.

Elissa: Yes; definitely.

Shona: What was going through your mind during all of this? What were your emotions, like how were you feeling?

Elissa: Oh my gosh! I mean, there's nothing that can really prepare you for a cancer diagnosis.

Shona: Right.

Elissa: Nothing! I had—I mean, again, like I knew—I knew that I had leukemia. I knew—I knew in my gut that I had it. And, you know, I tried to prepare myself, over the next week, for this coming. And I honestly, I didn't expect to actually get results during my trip because we had talked about, you know, potentially getting them after my trip, but obviously, it was acute. You kind of have to get them in and you have to get home. and so I, you know, the day that I found out, I mean, it was just—it was just devastating because it was just a, you know, everything—everything that I knew in my life was—had essentially just—it was a—it was a break in time, essentially. So, it was, like, there was before cancer and I knew that there was an after cancer now or during cancer. And there's a whole new part of my life now and everything that I knew is now different.

Shona: Hmm; hmm.

Elissa: And it's a hard thing to think about that you know that, from this second, everything will be different.

Shona: Right.

Elissa: Everything in your life. And, while I was going through it—I'm a fairly happy and positive person, so I felt like I stayed pretty positive and-- kind of just breezed through it. I remember my—one of the nurses in the hospital—he's like, "you're just kind of here and just kind of doing it". And, I was like, "I don't know what the alternative is?" I mean, just sitting here being miserable is...

Shona: Right; right.

Elissa: ...is essentially the alternative. And I mean, during—the time, again, like I was lonely. I lived with a roommate, who didn't really talk to me and you know, it—on the times when I was neutropenic, I was just at home. I could barely even go to the grocery store and my one goal for my day was just to be able to cook for myself. That was it. That was all I wanted to do was to walk downstairs and cook for myself. And so, you know. It was hard going through that and, I felt empty when I was not around people. And I loved being with my friends. I never felt like I was fake with my friends or family. I genuinely loved being around them, but it was hard. And losing my hair probably was the hardest part. It was worse than—I think that was worse than chemo. That was worse than diagnosis day. That was the hardest part and, again, it's hard to explain to people because they're like, "oh, you have, like, such a cute head. Like, you look great bald."

Shona: A cute head.

Elissa: "You look great with short hair". And I was, like, but I don't look like me.

Shona: Exactly.

Elissa: At the end of the day, I want to look like me.

Shona: And you mentioned before, you are already going through so many changes. You are already, like you said, there's a before-cancer and after-cancer where, you know, you thought your life was going to go a certain way so there's a certain amount of grieving process that kind of goes along with that—like, look, things are going to be different from here on out. And then when you look in the mirror, it's like a reminder, a visual reminder, of how things are different. You know, how this isn't something you can just put away in the back of your mind. It's more real.

Elissa: Oh yeah; it was a daily visual reminder. And it still--it almost still is, to some degree, with my hair growing longer. It is now a little bit below shoulder length, but I gained a lot of weight during, with the leukemia—and it would cause weight gain and with water retention. And then, the chemo caused weight gain. So, I got a double whammy there. And, then, steroids cause weight gain. So, you know, my face was fat. I was, you know, I gained everything that I lost that year before—all gained back in, mostly, water weight. And ah, I could see it in my face every day. Every single day, I could see it in my body, in my arms and it's a daily reminder. I mean, there's no getting away from it. When you don't look like you did, before the cancer. And watching my hair grow. I actually got—I got extensions. When my hair was 3 inches long, I found one person in Portland that would give me extensions. And it was so nice to be able to, like, really look in the mirror finally and be like, "okay, it's like I feel a little bit more like me." I have longer hair again and this is about as close as I'm—as I'm going to get to feeling like me, but it is still—it was still a daily reminder.

Shona: Right. And I think it's important to talk about, you know, I hear people say, you know, I do a lot of work with our online patient community and they'll go through things like losing their hair, or certain oral medications can, increase edema around their eyes, or they just don't feel like they look like themselves anymore. And then, they almost feel guilty for caring about that especially if they're doing rather well, especially if they're on a medication that's prolonging their life, they almost feel guilty that they're consumed with this thing that they think is vanity, but you bring up an excellent point. It's okay to feel—it's okay to look in the mirror and feel sad that you don't look like yourself.

Elissa: Yeah. I had—I met an AML survivor, who's in her fifties, and she was 3 years ahead of me and I remember I texted her one day and I was like, "I need to—I need to talk." I call her, like, my AA sponsor. So, I called her on shave day. I called her on, you know, when I saw some article about fertility that I was upset about. I called her—and I called her with this—that my hair was short. I was working with a foundation that does photo shoots for cancer patients. I was on the Board of that and they wanted to start using adults. And so, they asked me to be in a photo shoot and, ah, I was so stressed about my hair. I think my hair was about an inch and a half at that point and everyone was like, "but it's so cute. I don't understand why you don't like it." And I just—so I called my friend and I was like, "I just don't understand why nobody gets it". Nobody understands and I'm—and I'm tired of explaining this to people and I just—I just wish they would know what it was like.

Shona: Right.

Elissa: And I think why this, again, this community is so nice 'cause they totally know what it is like. They...

Shona: They 100% understand.

Elissa: Yeah; yeah.

Shona: So, while you were going through treatment—diagnosis and treatment—did you go any place for education or support throughout the process?

Elissa: So, during my actual treatment, I—probably about a couple of months—I actually didn't know much about LLS. And I think that, you know, well overtures was stuck into a huge 2-inch packet of papers that they gave me when I entered the hospital—and, I mean I saw that pack of papers and I just told my—I told my Dad—I was like, "please just go get a folder and put them in. I don't want to read any of it. I don't—I have no desire to look at any of this." So, I didn't know about any of the programs, which, I mean, looking back, it's kind of frustrating. And then, about probably 2-3 months in, I was really kind of feeling like I wanted to, you know, pave forward and help cancer patients. I don't why I was thinking that I could, like, go ahead and start volunteering at, like, 2 months into my treatment, but I reached—I decided to look up LLS and said that I was interested in volunteering, and got hooked up with Laura Brown, in my chapter.

Shona: She's amazing, isn't she?

Elissa: Yeah; she's so amazing. So, she, after I had started talking to her, she was actually coming to Portland because she's based in Boise, and so, I met up with her and kind of talked to her all about it; and I was excited. Frankly, I was like signing up to be a First Connection volunteer, which again, like, now I look back and I am like, "oh gosh, why did I—why did I sign up to be a First Connection volunteer while I'm still in treatment?" You know, if anything, I need to be talking to a First Connection volunteer, you know.

Shona: Exactly. And for those—I will talk more about our resources that we offer at the end of this podcast, but I will go ahead and explain that First Connection is a program that we offer. It's a Patti Robinson Kaufmann First Connection program where you are matched with someone of a similar age and diagnosis; and you can talk with them over the phone and get support and advice and just talk to someone who's been through it so you know what to expect.

Elissa: So, after the rest of it, I mean, I just—I kind of found my own way. And, I had to look up things on my own. I had to find wigs for myself. I've been a health care professional for a long time so, like, I knew about nutrition and I knew about this stuff, and exercise, but, yeah; so I finished my treatment in early November, on November 5th, and you know, we're coming into Thanksgiving time—and I love Thanksgiving and Christmas—like, love Thanksgiving. So, I was excited to be with my

family, you know, but at the same time, I was like, "I'm not particularly looking forward to it". And, as I'm getting closer to Thanksgiving and thinking like, "I'm still, like, not really excited. I'm not looking forward to it. I'm looking forward to being with my family and that's about it.", and then Thanksgiving passed; and then we are into the Christmas season. And, I mean, I am one of the freaky people that, like, love Christmas—I mean, more than Thanksgiving. Frankly, as far as I'm concerned, I could start decorating after Halloween. It's like...

Shona: Right.

Elissa: If the person I was living with was OK with this. And just skip Thanksgiving altogether.

Shona: You see the Christmas decorations in the store in September and you're like, "yeah".

Elissa: Exactly. Like, I love Christmas. And I noticed, after Thanksgiving, that I was finding no joy in the Christmas season. And I was at that point, I was like, "this is a problem."

Shona: Right.

Elissa: I don't know what's going on. And, again, I felt genuinely happy when I was with my family and friends' and then when I was by myself, I felt completely empty inside. And so, at that point, I reached out to the social worker on the inpatient floor that I had been on and —I was telling her about it and she was like, "oh yeah, it's totally normal for patients to be strong and positive throughout their treatment and then, once it's done, then they break down."

Shona: We see this so often at LLS. It's one of the things that I am constantly seeing and have a great interest in because you wouldn't think it would go that way, right? But, it's--you almost go into survival mode when you're in treatment. You're like this warrior and then, afterwards, you have all of this' kind of' fallout to deal with; and sometimes it manifests almost as PTSD for some patients. It's- so, so common and I am glad that your social worker normalized that for you because it's something we see all the time that our patients go through.

Elissa: Yeah; and it was so good. And, she had referred me to a counselor and, once I started seeing her, I mean, things just got so much better. And, at some point, she's just like, "listen; you never—you never actually emotionally dealt with any of this. you got diagnosed and you just went through it and you never processed anything." And so, she had me start writing in a journal, putting pictures in there. So back in October, like when things started happening and I started getting worried, and again, put

pictures of my trip, put pictures of, like, all the different points in there, and write about how I felt about them, and write about how I felt about each moment that I was writing about. And, finally, processed, like, of every bit of it; and that was so helpful for me. I was still getting fairly regular triggers as well, you know, I remember I came in one day and I was like, “yeah” so, I got triggered with this one thing and I just kind of totally pushed it away and she was like, “no, no, no”. Please don’t ever do that. Don’t do that. Don’t push it away.” She’s like, “that’s why you’re here; that’s why you’re here because you push everything away.” And she’s like, “when that stuff comes, I just want you to feel what you are going to feel. Just let it ride and it will be done.”

You know, and I remember this one—it was the worst trigger that I had, and I had been invited to my aunt’s church to watch, to watch a movie and—God bless them—but , they didn’t think about to give me a warning, , because there was somebody in the movie dying of leukemia. And they didn’t think about it and I, you know, I felt bad so I actually never brought it up with them and I’m sure they’re going to hear this—sorry Suzie! But you know, they—this moment, I’m sitting there, and I’m watching him, and there’s this key moment in the movie and everybody else is crying, you know, and he’s—I mean, he dying and, in the hospital, and I mean, I just—I not only started crying, but it was like flashbacks. It was just like boom, boom, boom! I mean just like one after the other, after the other. And I was sitting there thinking like “I was just—I can’t deal with this. I just want to get out of here.” Then, I was like, “I don’t want to cause a scene.” And like, I wanted to jump out of my seat and run out. I just, like, it was the worst that I’ve ever had—like with the flashbacks and you know, because up until that point, I was like, “I’ve dealt with this fine. No problem.” And then that happened and I told my therapist about it and she was like, “you know, that’s what you need to do though. you just need to feel whatever feelings come and it’s okay; and then it will be done.” And she was right. It was eventually done and then I moved on with my day. And so that was so—that was so helpful for me, but kind of going back to what the social worker had said to me, if it’s so normal, it’s, frankly, shocking that it’s not in every care plan—every survivorship care plan. Once you’re done with treatment, you should be—counseling should be recommended. It should be highly recommended.

Shona: 100%. Absolutely.

Elissa: It was never brought up to me. I was like, I shouldn’t find—have to find my way there. That should be like, to me, this is totally normal for you. You should—go to counseling. It’s probably going to be hard. If anything, I feel like counseling should have been brought up like, you know, throughout this thing...

Shona: On day one.

Elissa: You know, I remember I came in when—I got my biopsy results telling me that I had no evidence of disease and was cancer-free and, I mean, I was crying. And my doctor had walked out of the room and I was there with his nurse manager and I was—and I was just like I’m—I don’t know how to—I don’t know how to deal with this. I should be like so excited, but I don’t know how to deal with this. And again, this is the middle of December, right when I’m’ like’ feeling, you know, kind of depressed and he came back and he was, like, “I don’t know why you’re sad.” I was, like, I don’t know what to say. I don’t know, I mean, but I feel like they—it should be so normalized if it’s something that’s so common and it’s a normal thing to happen, that that should be part of every single, every single care plan—really for any age. I don’t know about for little children, but like, you know, anybody who would need help, like, processing this stuff ‘cause I’m sure this happens to almost everybody.

Shona: Right. And, you know, what you’re talking about, like I said, we see it all the time in patients and it almost seems as if, you got the information that you, , were in remission and then you didn’t know what to do after that. It’s almost as if there’s no road map for, like, what your new normal is supposed to look like after cancer treatment. I feel like the world maybe thinks that you’re supposed to be fine...

Elissa: Yes.

Shona: ...like you’re better, you survived, but that’s not the case and there really isn’t one road map for every person for what that new normal looks like. Your new normal involved volunteering for, like, Light the Night. Could you talk more about that and how you—how you came to that volunteer?

Elissa: Yeah; so actually, I had moved from volunteering, I was kind of stayed on as a First Connection volunteer, after I talked to Laura that initial time, and never got meshed with anybody throughout that time; and then, about one year into remission, I started feeling like—I’m feeling like I’m missing my calling a little bit and I really want to—I feel like I need to—I need to transition to working with—in the cancer world, preferably with blood cancer, but I don’t know—and I called Laura up and I said, “what, you know, this is kind of—I’m looking into maybe like patient navigation or something.” And she was like, “we don’t have, you know, we don’t have paid positions for this, but there are volunteer positions.” So, I signed up to do the Patient and Family Outreach volunteer, and went through all the training and everything; and then a job for LLS popped up with Light the Night. And I had been to Light the Night as a participant that previous year in 2017 and just loved it, and so I ended up getting the job and—and it was to do logistics for the event, which is 6,000 people, and a pretty big event; and then also work with teams for fund raising. And so a little bit about Light the Night.

So, Light the Night, it's our biggest campaign of the entire year and it's the community event of the year. All the other ones are kind of very specialized. Light the Night is the community event. That's where we are bringing out the survivors, as a—my personal goal is to get more survivors and patients to this event. It was something that was so impactful and emotional for me. So, it's an evening walk, and you walk with illuminated lanterns, and there's this beautiful lighting ceremony and, generally, a firework show, in most chapters, at the end of it. And, all the survivors get into this circle and they all light up their white lanterns and raise them high; and then surrounding them, the supporters with their red lanterns and those people that have lost somebody, with their gold lanterns; all turn on their lanterns. And so, you have—you look around and you see all these other survivors and patients, with their white lanterns, proud to be there. And then all your supporters around them. And that is why it is so special. It was special for me to look back and see my family, you know, 5 feet away from me with their red lanterns—my supporters. And, ah, it is such a cool moment. And then, you go for the walk and we came back and—and had the fireworks show. And it is just so special and I hope that, you know, more survivors and patients can experience that. But, you know, that's Light the Night in a nutshell.

Shona: So, I have to ask because now, you know, I'm so invested in your story—you were saying earlier that, you know, you felt fulfilled when you were around friends and family, but when you were by yourself, you felt empty and you didn't know why. Has your work with LLS and working with Light the Night, has that helped that feeling dissipate at all?

Elissa: Yes; definitely. So, it has been so special to work for LLS, you know, paying it forward, in a sense, and I have loved, loved working with—being able to work with current patients and survivors and talk to them and you know, share stories and connect with them in that way. I'm the only survivor in my chapter and, at our chapter office, and it's been so special to do that, but also know that I'm making a difference with raising money. AML has a very low survival rate. The survival rate right now, I believe, is around 29% overall; and I have a 70% chance with my age and my gene mutation, which was a highly favorable one, but I know other people aren't as lucky. I know that I responded very well to the conventional treatment that has been around for 40 years, but a lot of people don't. And, you know, I—I think about this all the time that, you know, that those people need a chance. They need something that is going to work. I've told a lot of people that I've met here that I'm like if there's that one thing out there that you're waiting for, you know, maybe it won't come in the next year or two, maybe it will come in 5 years, just—just hang on. Hang on until then. Something is going to come out; something is going to work at some point. And you know, I think that is all that we can do is hope that—hope that, you know, if something happens that there will be something that works out there. I hope, for selfish reasons, if I ever relapse that something will work for me.

Shona: Hmm; hmm.

Elissa: And you know, I think it's been so meaningful to not only work with patients, and survivors—but also—also really feel like, you know, the money that we are raising now in 10 to 15 years down the line is going to save a lot more people.

Shona: Right.

Elissa: And that is so—it's so special to feel that. So, yeah, I love—I love what I do. I love working with LLS. Light the Night is the perfect thing for me to be working on 'cause I can make it doing logistics. I can make the walk more special for survivors. We started a survivor tent this year and—and had a reserved seating tent for our less-mobile patients. So, you know, it's—thinking about it on a patient level, and you know, we worked with—I started recently with our patient access team to start Bingo up on the blood cancer floor at one of our local hospitals. And it's just so much fun. It's so much fun to be involved in that and bring smiles to their faces; and also going into them on the same floor that I was treated on as a survivor and say, "you know what, there is life after 14K. There is life after cancer." And I saw the smiles on their faces when, you know, I told them that and we had a patient access volunteer there, who was also treated on that floor and she told them that. And it was a really—it was a really neat moment. So, to bring those kinds of programs to the people that are fighting it right now, it's really special.

Shona: It sounds like you really found your calling throughout this whole ordeal.

Elissa: Yeah.

Shona: Before we back up, are there any other pearls of wisdom you would give to other young adult survivors or those currently going through treatment? what would be the take-away that you would want them to know?

Elissa: Oh my gosh! I mean, you know, at the end of the day, I think that--that connecting with other people that have gone through that is so important. It's so important to reach out and get the help—get the help that you need. Ah—I would, you know, I would hope that more young adults would come to this thing, and I--and as I lead the social—I run the social media pages for our chapter and I am trying to, you know, kind of increase the young adult movement in my town, but you know, I would hope that there's—there's more resources and more opportunities out there for young survivors to meet other people. And meet somebody who has survived. Like, you know, a few years, I mean, that is so inspirational to not only talk to people that are going through it right now, but people that are a few years out. It was like, I'm looking at them and saying like, "they've made it. They've made it. They've continued on with their lives and, you know, I can do that, too."

Shona: I agree that support and connection are so important. This is the perfect time for me to plug some of the resources that LLS offers as far as support and connection for our patients. So, I have already mentioned the Patti Robinson Kaufmann First Connection program, but we also have online chats that are moderated by an oncology social worker so you can go on and you can talk about, they are separated by disease groups and also there's a young adult chat for our young adult patients. We have an online patient support forum, called LLS Community, and that kind of works as a social media site. We publish a lot of educational resources in there, but it also mostly functions as a platform for patients to talk to each other. We have patients from all over the world on "The Community" and, again, we have a young adult group. You will be auto-joined to your diagnosis group, but you can also find groups that interest you as well. So, if you want to talk to other young adult patients, you can go there as well. And we also, of course, have in-person support groups and then we also have our Information Resource Center, where you can call and speak to a masters' level social worker or nurse who can help you navigate some of the trickier aspects of cancer such as financial support and other resources. All of this stuff can be found on our website at www.LLS.org. Please, for those of you who are listening, feel free to browse around and look for the support options that work for you. We have so many available and we want to be there for you.

Elissa, thank you so much for joining me on this episode. It was wonderful having you on here and sharing your story. So, I am sure all of our listeners at home appreciate it as well.

Elissa: Thank you. This was wonderful.