THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Dating with a Diagnosis: Stephen and Rebecca's Story'

Description:

Join Alicia as she speaks with young adult leukemia survivor, Stephen and his wife, Rebecca. This episode was recorded onsite at the filming of The Leukemia & Lymphoma Society's young adult reunion video, which you can access here. As Stephen prepared when he would introduce Rebecca to his parents, he realized that he was experiencing shortness of breath which prompted an emergency room visit. While in the ER, he received the shocking diagnosis of acute lymphoblastic leukemia (ALL). Having dated for only four months, it was in the ER where Rebecca met Stephen's parents and where both Stephen and Rebecca knew that they had found *the one*. Listen in as they share their story about dating, fertility and the importance of advocating for the needs of a patient.

Transcript:

Alicia: Okay; so, I am sitting down here with Stephen and Rebecca. Stephen was diagnosed with acute lymphoblastic leukemia and Rebecca is his wife; thank you guys for joining me.

Stephen: Well, thank you for having us. We're very happy to be here.

Alicia: So, tell us, why are we here?

Stephen: We're here to reunite with some friends and also to give an update on how we've been over the years since the last time that we did the LLS video shoot. It's so good to see some of these folks here again and to see how everyone has been doing well.

Alicia: It's such an awesome experience to come back and see everybody again; especially when having children and being married

Stephen: Yes; definitely things are very different…

Alicia: Yeah

Stephen: …now than when we did the video originally.

Alicia: Yeah.

Stephen: When we did the video

Rebecca: We were married. I was pregnant.

Stephen: We had just found out and we hadn't told people yet so people at the video shoot didn't know that she was pregnant at the time.

Rebecca: But it has been such a special process because I feel like we've all gone through the different stages of life together. He was diagnosed in 2010, but we started coming to the meetings in 2011. And it was just, you know, we were young, and single, and, I guess, we all sort of…

Stephen: Yeah; it certainly evolved…

Rebecca: Yeah.

Stephen: from that point; and, certainly, when we were doing the video, who would have thought that we would be here now with two kids and you know and a happy ending and, most importantly, healthy.

Alicia: Looking back five years ago when we first did this first video and looking at us now, does any part of you think, "oh my gosh, I never would have thought that this is what it would look like in five years."

Rebecca: I mean it was, the whole process for us, you know, we had been dating four months when Stephen got diagnosed.

Alicia: Hmm; hmm.

Rebecca: And, then you know, initially, when they give you a diagnosis of ALL..

Alicia: Hmm; hmm.

Rebecca: …you have a four-year protocol and it's like the four years is just daunting. You know, it's just how long and everything that he went through. And for us, at least for me, it was just so special the day that we found out I was pregnant was his last chemo.

Alicia: Oh my gosh!

Rebecca: And it was sort of, like, the next chapter in our lives and the fact that, you know, we were able to get pregnant, and have two healthy pregnancies, and two healthy kids.

Alicia: Their kids are beautiful, by the way.

Rebecca: Thank you! We just feel very blessed.

Alicia: Yes; oh my gosh! when he was diagnosed, you guys were dating for four months.

Stephen: Yeah.

Alicia: So, how was that being the partner? Were you okay with being thrown into this crazy world of what do I do next? Or, was it just kind of this thing where you were, like we're going to do this together.

Stephen: It was funny actually. She met my parents in the hospital so…

Rebecca: In the emergency room.

Alicia: Oh wow!

Rebecca: We were scheduled to meet them in like a few weeks.

Alicia: Yeah.

Rebecca: He was going to take me to introduce me to his parents and then, you know, he started having shortness of breath and we went to the emergency room and that, sort of, was when everything happened so…

Alicia: Wow, that is quite the experience.

Rebecca: But no; for us, I mean, you know, I always—there was never a question in my mind that we were going to get through it together.

Alicia: And how much does attitude play a part in getting through something like this?

Stephen: Certainly, it plays a huge part. I was fortunate in that I had a very strong support system. She was by my side throughout the entire process and I had my parents, as well; and other family and friends and it was certainly inspiring and I had people around who were very much routing for me. So, I mean, it helped me to get through it.

Rebecca: Yeah.

Stephen: …because it is a tough experience. There were many, many dark days. We were in and out of the hospital. I was probably in the hospital almost twenty times over the stretch…

Rebecca: Hmm; hmm.

Stephen: … and some for long time periods.

Rebecca: Yeah.

Stephen: I spent a Christmas in the hospital. it was a very tough experience, but with having a positive attitude and, positive people around you, it absolutely helped to get me through it.

Rebecca: Yeah. And seeing others that can come out from the other side.

Rebecca: …you know, went through the same rough treatment from this group, but now—completed all the treatments and just moving on with life, I thought was very helpful for us.

Stephen: Yeah; I mean, at that point, I had thought that "alright, well, this is going define what my life is", but after having gone through it and passed it, I don't think about it much at all.

Stephen: It is part of my history that has helped to inform me, you know, we're thinking on forward, but certainly it is not something that defines me and it has definitely been an interesting learning experience, but I am glad to be well past it now.

Alicia: We were talking to one doctor and she was saying, you know, this is one of those clubs that nobody wants to join, but once you are in it that you have to have the attitude of…

Stephen: Right; right. I mean, you know…

Alicia: …we are going to get through it. We have to.

Stephen: it's one of those clubs that, you know, like alright, you know, it's okay, I'll take a pass on that one.

Alicia: Yeah; yeah; and that

Stephen: But once you are in it, though, you've got to enjoy it.

Alicia: You have to make the best out of it, right?

Stephen: Yup.

Alicia: And that's the thing, I mean, at LLS, you know, we have —I don't know if you are familiar with LLS community. Have you guys heard of that?

Stephen: No; actually.

Alicia: No! Okay; so, LLS Community is an online social platform. And people create profiles. They have questions of the day. People can answer it and interact with each other, but it's created because we know that people need that community. And, sometimes when you get a diagnosis, you either kind of shut yourself off because you just don't know how to handle the gravity of the situation…

Stephen: Right.

Alicia: But it is so important to know that these resources exist so that people can tap in and ask questions and be around other people who pushed through and can actually give you, a success story. So, community is so important when it comes to something like this.

Stephen: Absolutely; absolutely. You know, and that's why this group, has been fantastic. Like Rebecca said, I mean, this is—just being around some of these folks and speaking with them and learning about their experiences, their reactions, their ups and downs that they've gone through, it certainly helps.

Stephen: they have inspired me.

Rebecca: Yeah, and I know that when he was going through treatment, and you go to the hospital—and you go to the hospital and, a lot of times, it's the older patients that are there so you look around and it's, you know, a different type of patient. You're not seeing somebody that looks like you, that's going through the same stage in life and has the same questions. I remember we got excellent education here as far as fertility questions; how to address fertility questions. And, you know, it was not something that was addressed initially with the first doctor that he went to, but we got a lot of resources here about it.

Alicia: So with the first doctor not mentioning, because that is actually an interesting point--we were speaking with other young adults and they were saying sometimes they go to that first doctor who doesn't bring it up so they think, "okay, well, he didn't bring it up, then I guess that's not something that."

Stephen: that's what happened with us. The first doctor never mentioned anything about that to us and—so we took the initiative. We actually got up out of the hospital bed and went a place to have that taken care of.

Alicia: Yeah.

Rebecca: I don't know if you remember that, but when she walked into the room to diagnose you

Alicia: Hmm; hmm.

Rebecca: …she said, "okay, you have acute lymphoblastic leukemia and that there are a lot of side effects"; and she turned to you and she's like, "but you're never going to have children."

Alicia: Oh wow!

Rebecca: Yes.

Alicia: Wow!

Rebecca: Yes. Actually…

Stephen: And, I know, then at that point…

Rebecca: We started doing research.

Stephen: …my brother found a place that was nearby, and after I told him that, he said, "no; you can go do something about it."

Rebecca: Yeah.

Stephen: And we did.

Alicia: And that is so important to hear because, again, people get that news and they're, like, "well, the doctor knows better", but then there's this this quote, I remember in one of my podcasts where a doctor said, "there are two experts in the room. There's the doctor, but then there's also you who know what you want and know how you feel"

Stephen: You absolutely have to be informed and responsible for your own care. You always have to ask questions. You always have to understand, what's happening and what your options are.

Alicia: Yeah.

Stephen: And you always have to make those decisions based upon, your own thought process.

Rebecca: Yeah.

Stephen: So, you have to be your own expert there, too.

Rebecca: Your own advocate…

Stephen: Your own advocate, absolutely.

Rebecca: …because even the second doctor where we went. He had only had one round of chemo with the first doctor and the very first question (and that's why I loved him) was, you know, have you taken precautions, you know, there's still, even though you've had one round of chemo, you can still go to a sperm bank and, there are different resources. And we told him what that first doctor had said and he got so angry.

Alicia: Because that is a horrible thing to say.

Rebecca: He's like, "I don't know that. Nobody knows that. Nobody knows that." You can go through several rounds of chemo and you still can, you know, you can still procreate. there's no scientific evidence that it's conclusive. Nobody can say that.

Alicia: nobody knows so to have that be the stance initially is frustrating.

Rebecca: But, you know, a lot of times as a patient, you do take what the doctor says.

Alicia: Exactly.

Rebecca: They know best, you know, I am not going to question them, but I think, so that's why…

Stephen: Especially for the younger patients.

Alicia: And that's also why, like you said, it's important to be informed that you know that you can ask those questions.

Stephen: Yeah, sure.

Alicia: That's a really great point. So, we are actually talking today because we will be filming the, the next video; kind of where are they now reunion. So, for those listening to this podcast, as a patient and as a caregiver, as a husband and wife, what is one thing that you want to leave with the listeners when it comes to being diagnosed, getting the news that you get and how to push forward?

Stephen: Being your own advocate, being positive throughout the process and surrounding yourself with people that have that same attitude and are supportive, definitely ask questions. I would stay away from the internet. I mean, it is just…

Alicia: It is like your best and worst friend.

Stephen: Yeah, I mean I would I wouldn't do the research through the internet. I would certainly talk to people.

Alicia: Right; a controlled search.

Stephen: Right; and if you have the opportunity to participate and talk to other people that either have gone through it or are going through it, I think that is one of the best things to do…

Alicia: Yeah.

Stephen: …because then you see that you are not in this by yourself.

Alicia: And that's a really good focus of our Patti Robinson-Kaufman First Connection Program. And what it is, is someone will call our IRC, you tell them exactly what you are looking for, and they'll connect you with somebody who is in a similar situation, that's now a volunteer, that can then share their story and ask the question, "what would you do at this point?" What questions did you ask? It allows people to have that connection and not feel like they are lost and they don't know—because a lot of times you are diagnosed—we were talking with one of the guys here and when you are diagnosed, you may be the only one in your group of friends that even knows anything about a blood cancer, so to have that resource when they can say, "okay, so I'm looking for somebody my age, diagnosed with this, four months in, and then have that conversation, I think is really—is so important.

Stephen: Absolutely.

Rebecca: No; I agree. I think just know that it is something that's happening to you, but there is life beyond cancer. And yes, you know, some things may change once you had cancer and you have to adapt, but you get a whole new appreciation for life.

Alicia: Yeah.

Rebecca: And you just have to look forward to what you are going to do beyond that.

Alicia: Yeah; absolutely. After diagnosis comes hope, right?

Rebecca: Yeah; absolutely.

Alicia: Well, thank you guys so much for sitting down with me.

Stephen: Thank you for having us again.

Rebecca: Absolutely.

Stephen: And you know what. I wish anyone listening to this all the best of luck and keep on fighting.

Rebecca: Absolutely.