

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'How CAR T-cell Therapy Saved My Life: Chuck's Story'

Description:

On this episode, Alicia and Lizette speak with Chuck Colletti, a two-time survivor of Stage 4 follicular lymphoma. Chuck was diagnosed in early 2016 when he underwent 7 months of chemotherapy which put his cancer into temporary remission. Unfortunately, 7 months later, it returned in a more aggressive form. With options dwindling, he was accepted into a CAR T-cell therapy clinical trial. Listen in as he describes how this therapy impacted his life both emotionally and physically, the side effects he experienced and the hope he has in this therapy's ability to save many more lives.

Transcript:

Alicia: Welcome to The Bloodline with LLS. I am Alicia.

Lizette: And I am Lizette. Thank you so much joining us on this episode.

Alicia: Today, we will be speaking with Chuck Colletti, who is a two-time survivor of Stage 4 follicular lymphoma, which is a non-Hodgkin lymphoma. Chuck was diagnosed in early 2016 when he underwent 7 months of chemotherapy which put his cancer into temporary remission. Unfortunately, 7 months later, it returned in a more aggressive form. Then, after 4 weeks of infusions of a cancer drug and options dwindling, he was accepted into a clinical trial on February 26, 2018 and has been in remission ever since. Congrats and welcome, Chuck.

Chuck: Thank you ladies. Thank you for having me here today.

Lizette: Thank you for giving us your time. We really appreciate it.

Alicia: On today's episode, we will be speaking to Chuck about his treatment journey involving CAR T-cell therapy which many have probably heard much about, as it has become very popular as a hopeful option for many cancer patients. And for those who may not be familiar with CAR T-cell therapy, CAR stands for chimeric antigen receptor and it is a new form of immunotherapy that uses altered T-cells from a patient's own blood to more specifically target cancer cells. These CAR T-cells are expanded in number and reinfused to the patient and when these CAR T-cells are reinfused into the

patient, the receptors may help the T-cells identify and attack cancer cells throughout the body. Chuck, as one doctor said, "it almost seems like sci-fi."

Chuck: Yes; yes. It definitely is something out of the movies.

Alicia: Now, currently CAR T-cell therapy is being FDA-approved as the standard of care for some forms of refractory non-Hodgkin's lymphoma and pediatric relapse, acute lymphoblastic leukemia and is available through clinical trials for other forms of blood cancer. How were you diagnosed and, what were your emotions around that time? Were there any specific life events that you were in the midst of?

Chuck: Alright, that question's, a little bit of a longer answer than I was diagnosed on this date and went into treatment. I was a healthy 49-year-old, just turning, you know, 50-year-old, guy and had no health—underlying health conditions. Actually, I had just—my fiancée and I had just witnessed the birth of our daughter. My daughter was about six- months-old so I waited in life to have children. And, so my daughter was born and it was around September of 2015 and I had a lump on the side of my neck and I had that lump for, oh, maybe a year or so. It was like, you know, just something that was there. It never bothered me. It had, you know, no other red flags coming up and, being a guy, you know, guys don't go to doctors.

You know, I'm 50-years-old. I go to the gym every day. I just had, a beautiful baby, you know, everything was going great and I felt no need. So around in September of that year, it was still there and it looked like it got larger. It was about the size of a marble and my fiancée, Brandy, she, you know, said, "Chuck, will you please go to the doctor and get it checked out?" I'm like, "I'm alright." And to give a little bit of a quick background on Brandy, she's 17 years younger than me, but she had just experienced her father, grandmother and grandfather in a 5-year period dying to cancer...

Alicia: Wow!

Chuck: ...lose their lives in the battle of cancer and right, right. So, not that we had any inkling that I had cancer, but you know, she was doing what, I guess, what your spouse does is "hey, you know, get your butt to the doctor." So, to humor her more than anything, I went to the doctor—my PCP. He looked at it. We did some blood work. We did some CT scans. He says, "Hey, Chuck, listen, you've got a couple enlarged lymph nodes" he goes, "but your blood work is clean." He's like, you know, "I think it's your allergies. You've got the vitals of a 30-year-old; no high blood pressure." He says, "you're perfect." He goes, "I'm going to put you on Claritin and, you know, we'll call it a wrap." So, I'm like, "alright, you know." For me, it was a good enough answer. So, I went home. We accepted that and went about our business. Well, through the course of the next couple of months, you know, I had a

few more people point that out to me on my neck and they said, “man, it doesn’t look right.” I said, “hey, I had it checked. My doc says I’m good, you know, it’s allergies.” Well, around December, I noticed some lymph nodes in my groin and for me, I told myself, I said, “you know what? Something is not right here.” So, I went back to my PCP doctor and, you know, I told him what was going on. He’s like, “Chuck, you don’t have cancer”. He says, “let me put you on steroids”, and I’ll send you to an ear, nose and throat doctor just to be sure.” So, went to—in January of 2016, I went to an ear, nose and throat doctor. He looked at it. He says, “yeah” he goes “looks a little suspicious”. He goes, “we could either, you know, schedule you for a full biopsy or we can do a needle biopsy right in here.” So, I said, “why don’t you do the needle biopsy?” He did the needle biopsy and about a week later, he called me and he says, “hey, listen,” he goes, “we have malignant cancer cells.” And I was like “okay; what does that mean?” He goes, “well, we are not sure. We are going to have to do a series of tests to find out exactly what’s going on.”

Needless to say, my fiancée had me down at the hospital the very next day and before I could say “what’s going on”, they were taking bone marrow from me, scheduling me for a PET scan and also a full biopsy. so, that was kind of like—people always ask, “well, what did you feel?” Well, it happened so quick and it was, like, that day he just like—I thought I was going down to talk to the doctor and—I knew there was something going on, but we weren’t sure, you know. So, seeing the oncologist that very day, getting all these tests done, we went home. And, you know, deep down inside, I say, “okay” because they told me. They go, “Chuck, it looks like lymphoma.” So, what do I do? I go home. I google lymphoma and it tells me...

Alicia: Oh no!

Chuck: ...yeah, okay; right, right. You’re probably going to die. Okay and so, you know, I took that and, after I freaked out for a little bit, I settled down and I said, “let’s wait to hear what they say. Let’s get all the tests back.” And I figured, you know, it was going to come back. And I figured maybe I had a touch of cancer, if that sounds, you know. I was too healthy. I was too healthy. I wasn’t sick. I was, you know, there was no reason for me to freak out. So, again, approximately about a week later, you know, I got the phone call and it was my oncologist and she had said, “Hey Chuck”—this was like on a Thursday. She says, “I am going to give you a bunch of information and then, on Monday, I want you and Brandy to come down and we are going to sit down. You’re going to tell me all your questions and then we are going to schedule to put a port in you.” I didn’t even know what a port was, okay, so, my head started spinning. The first words out your mouth. She’s like, “Chuck, you have Stage 4 non-Hodgkin’s follicular lymphoma.” Now, all I heard was Stage 4. I didn’t hear anything after that at the time. And my immediate reaction was “Dr. Osborne, is there a Stage 5?” She says, “no Chuck, unfortunately, there is not.” So, the rest of the conversation was kind of numb. She gave me, you know, what kind of drugs they

were going to use? What kind of therapies they were going to do? When they were going to do all this and, you know, all this stuff. I was actually at work that day and so I drove home and had to share the news with Brandy, which was heartbreaking because here she had just lost, you know, 3 people in her life and, now, she is dating the old man and the old man's got cancer. And she's, you know, it was something I couldn't even—I can't even, you know, describe how she felt, but I understand cancer affects more than just the person. So, I was diagnosed officially in January of 2016 with Stage 4 non-Hodgkin's lymphoma so that is how I got there.

Alicia: Wow!

Lizette: I was just wondering if your doctor went over with you that really the staging for lymphoma is a little different than other cancers.

Chuck: I remember sitting down with her. And so, Brandy and I sat down and she goes, "okay; before I go into what I am going to tell you about non-Hodgkin's lymphoma and our treatments, what do you have to ask me?" So, Brandy jumped in because she runs the house over here and not only Brandy does, but my soon-to-be 4-year-old daughter does, too, so...

Alicia: Of course.

Chuck: ...and then my dog, Cooper, comes and then Chuck comes so...

Alicia: Right.

Chuck: So, just so you guys know, you know, the operational structure around the house.

Lizette: Well; that's the recipe for a happy family, isn't it?

Chuck: That's what they tell me. Yes; yes. We're getting married in July. We have been putting it off because, of course, my illness, but you know, we're finally getting married in July so I think once I get married, maybe I can maybe move up on the food chain above the dog. So, we'll see what happens. I will keep you guys posted, though.

Alicia: Yes, please.

Chuck: But so, when we sat down with Dr. Osborn who I have to, you know—she's wonderful. She-- I wouldn't even know if I had somebody else to start this journey with, I don't think I would be where I am at so, you know, kudos to Dr. Jennifer Osborn. But anyway, at UPMC Hospital. Anyway, so the first question Brandy goes "is

he going to die from this?" And she looked at us and she says, "listen; he's in great shape. He's got a great attitude. It looks like he's got a great support system. I believe if he does what I say and tell him to do that we are going to get him through this. And he's probably going to be more likely to die with his lymphoma than from his lymphoma." So, that was, you know, that was—initially—I mean because you come in. You are all amped up. You've got all these questions your—we were going to go to 8 different doctors. We were going to fly around the country, you know. I wasn't going to die from cancer.

So, after that question, I jumped in and because of my Google research over the weekend, I said, "well, Doc, what if I don't do chemotherapy", cause, you know, you read a lot and, you know, you hear different stories and you hear about chemotherapy; and chemotherapy is a poison. I mean, there's no two ways about it. It's not a pleasant treatment, you know, so I figured if I don't ask the question, I won't get the answer. I asked it and she goes, "I don't think that would be a wise decision. You have what they call Stage 4." And that is when she went into the staging of it. And what Stage 4 meant is that, basically, it is in your—it's above your diaphragm, below your diaphragm. And, you know, she basically said, "if you don't do this, you know, there's not a good prognosis for you. It's pretty progressed." I said, "but listen, I'm not sick." She goes, "well, you are going to become sick. You know, you are going to become very sick with or without the chemo".

So, we agreed to it. We went through our questions and so that is when she did go into the staging where, you know, if you have 4 stage pancreatic or 4 stage lung cancer or breast cancer, it is different than having Stage 4 blood cancer, but that doesn't mean at all, well, it's the good cancer. You know, someone explained to me what a good cancer is. Cancer is cancer.

And through my journey in 3 years, I've met a ton of people that had only blood cancers and, unfortunately, you know, some of them, who I can call my friends because we have developed good relationships, are no longer with us. so, with that being said, yeah; the staging is different, when it comes to blood cancers.

Alicia: So, at this moment, you get this news. You're like, "oh my gosh, I am so healthy. I do all the things I think I should be doing in regards to fitness, and health, and all that so where did you go for support at that time? You mentioned your healthcare team was a great source of knowledge. You mentioned you went on Google which can be your best friend or your worst friend. Where did you go to get more information about this disease?

Chuck: People deal with diseases and illnesses differently. I'm an "A" type of person. For me, it's better to talk about it; better to educate yourself about it; better to reach out so, you know, I go home. We settle in. We kind of, you know, do our sadness

part where we cry on each other's shoulders a little bit and then, you know, I looked at her and I told her, "hey listen, we are going to do this. I am going to do this. Don't worry about it. We're going to go on and we are going to beat this." So, I immediately went onto social media and, again, you know, I am a sales guy. I am an upfront type of person. I believe, you know, the proof is in the pudding. So, I put out that, you know, that Brandy and I had been, diagnosed with a cancer, you know, a Stage 4 cancer and we didn't know much about it. I said what it was and, you know, I had like 800 friends on Facebook, probably a hundred of them I know at that time. I put it out there and, you know, you get all the, you know, you are in my thoughts and prayers and all the stuff that normally comes with when you have something bad happen in your life. Well, one of the e-mails or texts that I got back was from a girl I went to high school with and I haven't seen her in twenty some years, and she's messaging me on Facebook and she says, "Chuck, you need to call me." She goes, "I am the Executive Director of The Leukemia and Lymphoma Society down in South Florida. And I didn't even know—I never heard of The Leukemia and Lymphoma Society.

Alicia: Wow!

Chuck: Right, because I mean, I've heard of leukemia. I really never heard of lymphoma, and you know, I knew about breast cancer. My Mom had died of lung cancer. She was a heavy smoker, but you know, I just, you know, again, my ignorance—I just didn't even know there was a Leukemia and Lymphoma Society.

Alicia: I completely understand because if someone doesn't get this diagnosis and someone doesn't know anyone, you know, in their close circle of friends, or family, that has this diagnosis, it's really not one that you go out looking for so that's completely understandable.

Chuck: Oh exactly. And you know, so needless to say, she got off. I called her on the phone. We scheduled a call. We were on the phone for 2 hours and she explained so much about LLS. And she goes, "here is what I am going to do. I am reaching out to the girls in Pittsburgh. I am going to put you in touch." The next day, I was down there, okay? So, I was down there the week that I had my port put in. And that was so helpful. The Leukemia and Lymphoma Society, when I went down there, they started putting me in touch with people that had gone through this. I started talking to them. I started reaching out on social media. There are support groups out there. So that—I took action, okay? What I think one of the main things I think for anybody that goes through this, and I know it's easier for some people like myself to do this than others and I respect that and I appreciate that, but you have to do for you. I would have loved to just sat back and had everything come to me, but when someone tells you that you have a Stage 4 cancer, for me, time was of the essence. So, I

immediately went and I joined 8 support groups online, okay? And I started talking to everybody across the country and in different countries.

And, within about 2 days of all that information overload—it was overloading, but you know what, I could breathe. I was, like, man, there's people living with this. There are people that have, you know—it's incurable, non-Hodgkin's is incurable, but there's people that have been in remission for 20 years, okay? There are people, you know, that had Stage 4, and for me, it gave me not only a peace of mind to relax, but it gave me that shot in the arm and said, "hey, listen, get out there and beat this. Every—there's other people that have done it." So, that was like one of the main things—I guess I did for myself, and there's people like some, you know, medical doctors will refer you to support groups and things of that nature, but I basically, within the first couple of days, before I even—before I even had the first drop of chemotherapy in my body, I think I had probably talked to maybe 20 people and it was very reassuring and, cause you're like, "does chemo burn?" You know, you hear chemotherapy. It's a bad thing, you know. There's are so many different things. You know, am I going to get sick? Am I going to lose my hair? and there's so many questions and, again, it is something that I want to stress, especially at the very beginning. No matter how many stories; no matter how many people you talk to, they're their own personal experience. Chemotherapy and cancer effects people differently. So, don't expect your journey to be like the guy next to you or the lady next to you. Your journey is your journey. Make it your journey. Do what you do for yourself. Do what makes you feel good and do what with you're comfortable in doing. So, you can't say, "well, he did this or he didn't make it." It doesn't matter. It's about you!

Alicia: Right. That's such a great point. And the program that you are actually referring to is our Patti Robinson-Kaufman First Connection Program because we do understand that there is so much comfort and strength in community and this program connects patients and families over the phone with individuals who have personally experienced the challenges of dealing with a diagnosis; a blood cancer diagnosis. So, I think it is so important that you stressed the point of, you know, at this point of your life, it's not going to look like somebody's else's journey, it's your own journey and all you can kind of gather from that is how you are going to move forward with what you know and connect to those who have been through it so that you can know that there are others living with this thing.

Chuck: Exactly.

Lizette: And it's so true that, you know, nobody's journey is the same so somebody else with follicular lymphoma, even though they have the same type of non-Hodgkin's lymphoma, , may not have the same treatments, , but just the comfort of knowing that somebody else is going through, , the experience of being told that they have cancer and you're not the only one, that is very powerful.

Chuck: Yes; yes. And you know, to give you a great example—a personal example is that, you know, again, I talked to people that went through—chemotherapy that had such a hard time with it, okay? And so, I was preparing myself for the worst. The medical professionals, you know, suggested well, you can go on disability for 6 months. You can do this. You can do that. I decided not to and I decided, and I made a promise to Brandy, that I was going to live as normal as possible. We had a brand-new baby and I wanted her not, she just had to deal with 3 people that went through, you know, this journey and, unfortunately, didn't make it and now, at the happiest time of her life, her partner is going deal with this. So, I tried to make it as normal as possible and, for me the first 7 months of chemo that I went through, I missed about 3 days of work, I lost 2 pounds. I didn't lose my hair. I would sit in the chemo—they called me the Energizer Bunny down there.

I would sit and take chemo and sandwiches and have people bring me food in; never lost my appetite. I think I couldn't drink coffee for, like, maybe 2 months. That was a weird thing. I did end up, in the third month, in the hospital for a week with neutropenic fever because of the heavy doses—because I was so advanced in my cancer, they really hammered me with Bendamustine and Rituxan and so I did end up in a week with, you know, no immune system so I ended up in the hospital, but beside that, I work as a business development professional and they have been tremendous, too. They told me, "don't worry about work. Worry about yourself. Get yourself better." people going through cancer treatments and cancer diagnosis, we have a lot to worry about, and so, if you have an employer. And I think more employers need to understand this, too, is that hey, there's a reason you employed this person. You know, get him better. Get him back to work. Give him the support so I was very lucky through my first round, through 7 months. Then, at the end of 7 months—I mean, at the end of 3 months, they told me I was in full remission, but they wanted to continue the full cycle because they didn't have any, you know, data on, you know, somebody who just did 3 months. So, I did do the full time and I ended up in full remission after that chemo.

Alicia: Wow! That's a great point for employers to hear as well. That's true. When was CAR T introduced as treatment?

Chuck: Okay; so, you know, January 2016, I do the chemo and it takes me through, probably I believe, it was July or August of '16 where I went into remission. I stayed into remission for—until about July of 2017 and I started having some symptoms. Well, when I went back and they said, "hey, you know, your CT scans are showing some lymphoma. We did PET scans." You know, it was coming back. They did some biopsies, yeah; it was coming back. They did a bone marrow biopsy and everything was—as quickly as I had popped out of it, I was back in it. And, but what-- something else I will stress. When you get a cancer diagnosis, it changes you. And whether your cancer is a cancer that they can cure, you know, clinically, or if you have a cancer that,

you know, is clinically incurable, you'll never stop being a cancer fighter, okay? So even when I went into remission, it's not that I walked around and said, "hey, look at the cancer boy", but I kept my contacts. I kept educating myself on treatments, on ways to take care of yourself, everything I could to fill, you know. And sometimes, I maybe would go over, you know, a little and Brandy would say, "you don't have any cancer. Why are you reading this?" And I said, "well, you never know." said, "believe me, I'm one of the most positive guys you will ever meet, okay?" I said, "But, like this is, unfortunately, this is going to be part of my life from here on out. And, I, you know, we don't have to sit around and talk about it at dinner, but at night, you know, when we are getting ready to go to bed and I want to—and you want to read a book or you want to work on your computer, I'm going to read about the latest in immunotherapy." So, I had stumbled across CAR T and thought it was really amazing. So, I kind of knew about that.

So anyway, when I got back in, my doctor, you know, says, "hey, it's coming back and, Chuck, I think we are going to have to do a bone marrow transplant on you." And, that just—I knew what it was. I cringed at it. My daughter was, you know, 2-years-old—2 ½-3-years-old, and in daycare, and I'm thinking, "oh, how is this going to work, okay?" I was really, you know, believe me, people always say, "Chuck, you're so positive. You've got this, you know, superman attitude." Well, you know, Chuck has down times, too, and there's nothing wrong with that, you know, you can be—you can get angry. You can get sad. You can get mad, as long as that's a very little part of your journey, and that's what I try to keep it at so, you know, when I heard that, I was not too happy. And I am like, "are you kidding me? You know, this is going to be a rough one."

So, she had sent me to a specialist, over to Hillman Cancer Center, a lymphoma specialist. So, we sat down with him and, immediately, he, you know, threw out. He says, "I am going to give you some options." He goes, "bone marrow transplant is definitely an option." He goes, "I don't think we need to do that right now. We can always come back to it throughout chemotherapy—more different chemotherapies, some new immunotherapy pills"; and then he said, ", I may be able to get you into a clinical trial called CAR T." And he goes, "what CAR"; and I said, "hold it right there." And I explained to him what CAR T was. Brandy looked at me like I was crazy. She was like, "how do you know about this?"

The doctor, Doctor Ho, he looked at me and he was just like—he's like, you know, speechless; and I said, "I have been following this for about 6 months." I go, "are you guys doing this here?" He goes, "yes, we are." And, I mean, you want to talk about I was just—it was so like, you know, it was so great that something I had been following and had—and this was like even before, you know, I—even before my cancer came back, I was following it. And, I was so happy because I knew that it was going to help, you know, thousands of people out there and now, here, I get to, hopefully,

experience it. So, he goes, "okay, but we have to do—because it's in a clinical trial, we've going to have to do another—traditional regimen of treatment because you have to fail 2 in order to be qualified for it." So, we went and we did 4 more weeks of heavy infusions of Rituxan to try to stop or slow the growth of the tumors. And, fortunately, it didn't work. I know that sounds crazy because, you know, that was another thing. You go—cancer—it brings you through so many different twists and turns. I didn't know if I wanted the Rituxan to work because I already did Rituxan and it came back and I knew how promising CAR T was. So, I didn't know if I wanted it to fail or if I didn't want it to fail. You know, it was weird, but eventually, it did fail and so I went and did all the pre-testing and I was accepted into the CAR T program. So, that happened February of 2017.

Lizette: So, when you were told about the CAR T and it looked like you were going into a clinical trial, I know that going into a clinical trial can be a little bit intimidating, especially, , when they are giving you the packet for you to sign to tell you everything about that clinical trial so it could be a little bit overwhelming, , but at the same time, exciting because you are getting this new treatment in CAR T. How did you feel and how did you start with the clinical trial?

Chuck: You hit it right on the head, you know, that packet they give you where it says "you may die", okay? And I had friends come up to me, "clinical trial, what are you, a guinea pig? What—you could die." I go, "I got Stage 4 cancer." I mean, you know, I—I thought I was at the Improv for a minute there, you know. I did my research. I understood about this and my—Brandy is a pharmaceutical sales rep and she knows a lot about clinical trials; and it's not like Frankenstein where they're hooking up, you know, these cables to you and waiting for lightning to strike a pole and see what happens. I mean, CAR T had been around for a number of years in the trial basis, they learn what the side effects were. They learn how to handle those side effects. you know, there's still people that were, you know—may die on it, , but again, you know, when you have, you know, this terrible, terrible disease that, you know, just consumes your body and you have a chance, okay? And it's like to go back to the very beginning of our conversation here, ladies, you know, when I Googled it, they said I had a 40% chance or something I read of living like 5 years; and they thought that was good. And I'm thinking to myself, "5 years. My daughter was just born. I don't want to—I want to see her go to high school. I want to see her get married. I don't want to see her go—to graduate kindergarten." So, you know, you get that packet and, of course, you read it and, you know, it's like anything. You go get your tooth pulled and they put you out and you may not wake up so I—I believe, you know, that you have to go with your heart and your gut. And Brandy and I had talked about, you know, we discussed it in detail of, you know, the pros and cons of entering into this. so, I signed all the paperwork and then we started the process.

And the process begins with something they call pheresis and, basically, what they do is you go in and they put a line in your neck. And, they cycle blood out for about 4 hours in a machine similar to a dialysis machine. And what they are doing, they're collecting these T-cells, okay? And so, it's not too bad of a process. It's uncomfortable. I mean, you've got a line jammed in your neck. You've got to sit still for 4 hours. You know, for me to say it's pleasant would be a lie, but it's not, you know, it's not too bad. So, you do that. They collect the T-cells and you get this bag of blood. You know, it looks like just red blood and they ship it off to a medical place out there that genetically re-engineers your T-cells and puts a receptor on these things. So, once they isolate the T-cells, re-engineer them, put the receptors on, then they take them and multiply them, you know, like 700 million times, okay? And so, that takes about approximately—it took me about 2 weeks. In the meantime, you go home. I went about business as normal. I got the phone call that my T-cells were ready. So, what they do is when your T-cells are ready, I went in on a Wednesday, Thursday and Friday and I did 8 hours of what they call conditioning, preconditioning chemotherapy. And, it's not like getting a bone marrow chemotherapy. It's more to knock down your immune system and create some room for all these, you know, what I call Ninja fighter T-cells to come in.

And they definitely need some room. So, I did it 3 days of the chemotherapy. Again, it wasn't pleasant, but, you know, I handled it pretty well, and they send you home on the weekend to rest. And that included me probably cleaning the house or whatever list Brandy had for me because she knew that I was going to be laid up for a while, but I did, I did go home. And, on Monday morning, Brandy and I went back to the transplant ward and lo and behold, I had this little bag, just a small bag, clear bag, and they said, "yeah, here's your re-engineered T-cells. There's like 700 million in there." And I look at this little bag and they were like "it's going to take about 5 minutes to go in and, you know, after that, the protocol will be, in about 2 days, we'll take you to the ICU because that's when your side effects will start kicking in and you will be there for, you know, 3 or 4 days; and then you will be in the Transplant Ward for a day or two; and then you will be released and, you know, went about." And again, these are all things that we had known. We had read, and I was aware of. So, the cells went in, had a little reaction to the cells. They gave me some Benadryl, but the cells went in in about 5 minutes and Brandy went home to get our daughter and she said, "I'll see you tomorrow. I'll come back and see you after I drop Gigi off and, you know, we'll wait for your side effects to kick in." Well, she went home and about 3 hours later—it was about 8 o'clock at night and, you know, I had finished my dinner. I'm watching TV laying on that very comfortable hospital bed, and I got up to use the restroom and I got a chill. And I was like, "oh, that's not right." So, I got back in bed after and the next thing you know, I started shaking, and shaking, and shaking. So, I buzzed the nurse. They come in. The next thing I know, I'm down in ICU. They're like, "wow, your side effects are kicking in right now." And, you kind of look at their eyes; you're trying to read them and they're like, "yeah, this is the quickest it's ever happened."

So, I ended up in ICU for 6 days, or 7 days, and it was pretty intense. There're 2 major side effects that you get with CAR T, cytokine storms and neuro-toxicities. I don't remember all of ICU because, like I said, it is pretty intense, these side effects, but when I was in ICU, the first thing that happened was, of course, I spiked a fever. That's why I went down there; a pretty high fever. I think it was around 104, 103, 104, 104.5, you know, something around there. And I had—I got a tremendous headache. I had a massive headache for about 5 or 6 days that even, like, the morphine, or whatever they would give me, it just—the headache would not go away, and they would come in every 2 hours and they would give you neurological exams. so, they would have you fold a piece of paper; write your name; who's the President; what day is it? and, as my side effects got worse, they started administering the drugs to counteract which, you know, they knew what they administered. So, it was a rough 6 days. I am not going to lie.

You know, I look back at it, , and it was the first time in my journey that, you know, when you've got oxygen on you and, you know, you can't speak at times or you can't, you know, function. It was the first time in my journey that I ever really thought that, "hey, I may die. This may be—this may be it for me! Maybe this was the crazy, you know, clinical trial. Maybe I am that person that will die in this." But, you know, I got through it. They have a—they use a scale with these side effects and it goes like from 1 to 5 with, 1 being, you know, being barely anything, maybe a fever, and 5 being death. I think I scaled out at a 3 1/2. I didn't go into a coma, but I was, you know, I did have some neurotoxicity and I did have the tremendous cytokine storms. And, one of the good—and again, I want to reference to people—I had talked to people that went through CAR T prior to this, especially in the 2 weeks, even when I was in the hospital, I was, you know, texting or, you know, Facebooking people and I talked to people that went through this; and they said, "man, it's—you're going through the storm. Just bear the storm.". And so, even though I was scared and even though, you know, I did have that little bit of weakness in me, you know, there was still that part of me that says, "hey, listen; this is just like they told me. It's bad. It's rough, okay, but I can get through it."

So yeah; I got through it, and then I was released from ICU and they sent me over to the transplant ward for about 2 days, and I was beat up. I was definitely beat up. Had a hard time standing, walking, you know, all of that. And so, I believe I had a total time—8 or 9 days, I was in the hospital total. I was released to go back home, but I had to stay within an hour of the hospital, which our home is, and I had to be watched 24 hours a day. I couldn't be left alone for 30 days. I had to have someone with me 24 hours. So, I had a couple of aunts come in from out-of-town to stay and help out with the house and me. And, you know, it was hard. My appetite wasn't there. I lost a good amount of weight. My muscle tone just—I was beat up. I couldn't stand in the shower, tremendous heartburn, had trouble remembering things, speaking, you know, holding conversations, which Brandy, because I am a talker,

Brandy said, “man, I’ve never seen you so quiet.” And you know, trying to get a laugh out of me, you know. So, she was always there trying, you know, to get me to—because like I said, it was very unpleasant, but I was able to go back to work 45 days after. And they wanted me to stay out for 60 days. They wanted at least 60 days, and I told them I would, but—and again, I work in business development sales so, it wasn’t like I was a labor guy doing something where I had to lift because I had no strength. I had no strength almost—very--still very weak. I had people drive me to work just go I could go into the office to just try to function normally, but then around day 70, I believe it was, day 70 because it was like not quite—it wasn’t 3 months, but I started working out at home and, , I started getting my muscle tone back. Then, I believe at 90 days, I was back in the gym and I was real careful, you know, because my immune system was being, you know, when I say I was back in the gym, I may have gone to the gym, walked around for 15 minutes, picked up a weight, but you know what, it felt normal and that was part of my recovering process.

So I would say, 90 days for me; and I went and I met with people that went through CAR T and they looked at me, and again, this is why I tell everybody with chemo, CAR T—people looked at me in 90 days, they didn’t believe I did CAR T because I was moving around so well. I talked to a lady who I met, and it took her over a year. I mean, she was in a wheelchair at home for 2 months, you know, so you have to remember that, you know, I’m here—I’m here to inspire and motivate, but I am not here to set a standard. You know, I am not here to state, “well, hey, this is where you need to be.” You know what, only you can tell yourself where you need to be and, for me, I put my goals—and sometimes I reach my goals and sometimes I fell short, and you know what, I was alright with falling short because, you know what, I was alive. And, tomorrow’s always—you’ve got to tell yourself—tomorrow is always another day so you may have wanted to go and walk around the block or may have wanted to walk on the treadmill, or you may have wanted, you know, just to sit up today, but you didn’t feel like it, that’s fine. You know what, this isn’t a sprint. It’s a marathon.

Alicia: Absolutely. Was there a specific day or time where you said to yourself, “I think I’m going to be alright?”

Chuck: Once I got home, and even though, again, I said I was beat up—I knew I was beat up, and I had read enough about the intensity and how quickly my side effects had started so I was pretty confident, because I wouldn’t do a PET scan for 30 days. So, I was pretty confident that I could feel my cancer being beat up. I mean, I was confident that this CAR T was working, okay? And being out of the hospital and being able to, you know, be at home and not on oxygen and my blood pressure was fine, and you know, playing with my daughter, I mean, even though I felt like crap, and even though, you know, I didn’t look like myself and I slept all the time, I, in my heart,

I was, like, I think this is working. To answer your question, and again, everybody's different, but man, when I got home and I really felt that "hey, I think this treatment is going to work and I think I am out of the woods", cause they tell you, you know, these neuro-toxicities can—that's why you have to be watched. They can hit you, you know, 30, 60 days out so you have to be really careful, and you know, I would never take anything for granted, but, in my gut, I was like, "you know what, I think this is going to work".

Alicia: So, having gone through this experience and looking back, are there any questions that those who may be listening who may either be considering it or may be, you know, about to begin their journey of CAR T treatment, is there any question that you think would be beneficial to that person to ask their healthcare team?

Chuck: I think any healthcare team—like when you're going through cancer and, you know, when you're going through a battle, you should always ask your health provider, your team, your doctor, your oncologist, whoever—you should always ask them, you know, about options; if they know about clinical trials because, I mean, I'm talking about CAR T cause, you know, like I want to be the poster child for CAR T because I believe in it so much, but they're developing every day. They're developing things. I still believe CAR T—is definitely a game changer here, but I think you need to ask—your team, you know, what do they recommend. You know, what do you think is right for me? Because they may not think CAR T is right for them. They may not need CAR T. you know, and there is so much going—there's so much confusion right now with CAR T and, you know, what's approved? What's not approved? What, you know, insurance—like insurance companies wanting to cover it, I mean, and something we haven't touched on that I definitely have to bring up. One treatment of CAR T is like \$500,000, okay?

You know, that used to be something that angered me, you know, when I started this journey 3 years ago about the cost of medical treatments, and things of that nature because—and again, all you people that are listening out there that are, you know, supporters, or survivors, or battling it right now, you know, cancer affects you mentally, emotionally, socially, but it affects you financially. It changes you, okay? But my Dad gave me some good advice. He says, "Chuck, you can't put a price tag on being alive." He says, "worry about it later" and he's right. Twenty-five years ago, 30 years ago, I may not even be talking right now, okay? I may be done, but because of the way chemotherapy has evolved, , and hopefully, we can get rid of chemotherapy one day, , because I do believe that the more toxicities you put in your body, you know, the bigger chance you're going to have of getting secondary malignancies down the road, but I do believe, with the research and the monies—and that's why organizations like LLS are so important. That's why I am running for Man-of-the-Year because I want to raise money because they donate so many monies to these trials.

Everybody is a little bit different so, you know, is CAR T right for you? It may not be. You know, there's just so many variables right now because it's in that transition mode of, you know, some of it's approved, some of it's not, some of the insurance will do it, some won't, you know but, that's just something you'll have to discuss with your medical providers, and insurance companies, and your family.

Alicia: Absolutely.

Lizette: Right; and it is so exciting to speak with you just to know that you've gone through such an innovative treatment. Our cells—our blood cells can recognize, you know, colds, but at this point, they can't recognize cancer cells to kill them and, now, with CAR T-cell therapy, re-engineering these cells so they can go back into your own body and kill these cancer cells is—is just amazing that, you know, our own bodies are able to kill these cancer cells. So, it's just really exciting talking to you that, you know, you've gone through this and I just wanted to know, how are you doing now? What are the doctors saying about your follicular lymphoma?

Chuck: Well, I'm doing really good now. Yeah, I've had a pretty, you know—February 26, this year will be, and by the time of this broadcast, it will probably be past, but this February 26, 2019 will be one year.

And, I actually go back on that day for a PET scan, and blood work and tests. So, you know, as I right now, I am in remission. I've learned, you know again, I created my new normal, okay? I mean, this morning, I was in the gym before work. You know, I was running--I ran three miles on the treadmill, lifted weights, and went to work. You know, I had to adjust things and I found out things that, you know. My body has been through a lot in 3 years; and a lot of people that go through treatment, our bodies take abuse. And sometimes it takes, not just months, but it takes years to get back. Sometimes it will never come back. you know, so what I found is that I found that I keep myself, and by no means am I this guy that won't eat a pizza, or drink beer, or have a glass of wine, or you know, I love that stuff. I'm a foodie, okay? But I also, you know, it's like "O my God" don't eat red meat or no, no, no, no!

I do everything in moderation, but what I've done, I've done a couple of things. And even though I have kind of kept fitness part of my life, you know, since I've been a kid--and that was one of the reasons, too, and I'm sorry I didn't bring this up sooner, is that, one of the reasons they think I did so well during chemotherapy and, actually, with CAR T was that, you know, I kept myself pretty much a healthy individual. I was able to, you know, like again, not indulge, like I believe in moderation and everything. You know, I worked out and watched my diet to a point, so it helped me in my recovery, or in my battle with it. But what I found out in my recovery and, you know, I had a—I said, "what, I'm just going to run to the gym now and I'm going to work out

and I'm going to get back to where I was." Well, hey, put the brakes on. You know, your body's beat so I had to dial that back.

Something I've never done in my life was supplement, because these treatments and these drugs they put into you, they deplete your body of so many nutrients and I don't care how good you eat. I mean, my Brandy makes me a smoothie every morning with kale and this and that. I have been doing this for, you know, a long time, but no matter what you do, you need to supplement, and, you know, I never did that. I didn't believe I did, you know--needed to. So, I had to change up some things, you know, so now I go to the gym. And I, also, take nutrients every day that have really, really helped me and I was the guy that didn't believe in nutrients You need to, you know, create your new normal, because prior to cancer you were one person. It doesn't mean you're going to be a totally different person coming out of it, but there are some aspects of your life that you're going to have to change. So, if you can do that, I think you'll have a, you know, a good shot at overcoming this illness.

Alicia: And I think that's was such a great point when you mentioned that, you know, this new normal is one of those—it's a weird situation because many people think to themselves, I want to be my old self. I want to do the things I used to do, but the reality is that there is a new person that comes out the other side and to, you know, just to kind of get comfortable with that and really approach that with ease and with some sense of idea that this is who I am now and I can't change it. What I can do is work with it and your new normal is what you create that helps you get through each day and really feel like you have control of the situation.

Chuck: Oh, exactly; exactly. And, you know, that was tough for me because, again, you know, I had it in my mindset from day #1. I'm just going to go around and just act like nothing's—like cancer is not part of my life, but unfortunately, it was and as much as you don't want to change some things, you do, but it doesn't have to change who you are. And I guess at the end of the day, I always live by the motto, "cancer does not define me. I define cancer."

You know what, listen, you get that phone call, "Chuck, you've got Stage 4 cancer." You've got 2 ways of dealing with this in my mind. You deal with it on cancer's terms or you deal with it on yours--your own terms. And, you know, because it's there, okay? You can't pull the sheets over your head and I just said, "regardless of what happens, I'm going to deal with it on my terms." So, you know, if that helps anybody, you know, just deal with it the way you want to deal with it. There's no right or wrong way either.

Alicia: There's no guidebook for cancer. Who knows...

Chuck: No; no.

Alicia: ...what to do.

Chuck: No; no. It isn't. hopefully this information has helped people. I, you know, if anybody's that's interested or has, you know, questions for me, CAR T, about CAR T, or whatever, I actually developed a website for informational purposes and I don't know if you guys could put that out there, ...

Alicia: Sure.

Chuck: ...at the pod—but it's www.collettisurvivorsquad.org and you can--there's an area where you can send a question to me. I can give you my personal experiences. Again, I advocate for The Leukemia and Lymphoma Society and I am always, like, goggling or researching so if I can do anything to help anyone out there, you know, I would be more than happy to do that.

Lizette: Thank you. We do appreciate it. Yeah; it's really helpful to hear from somebody and, at this point, there's not a lot of people that have gone through CAR T. So, it's very helpful for all of the CAR T participants to actually be able to talk to others, because there's not a lot of people out there yet and I think, you know, in the near future, hopefully, there will be more. Hopefully, they will and they have been looking into CAR T for possibly second-line therapy. So, like, Chuck, you had to fail second-line therapy before you can get CAR T. Hopefully, somebody else that comes behind you doesn't have to go through that second therapy that you had to go through before CAR T. Hopefully, they can get it at that point, hopefully, they can get it as a second-line therapy.

Chuck: Exactly; and you know, eventually who knows. When it does become an out-patient procedure, maybe be don't even do chemotherapy anymore, okay? You know, maybe this becomes, you know, the new norm.

Alicia: So, I understand, Chuck, that there are many who are interested in your story. Can you tell us more about who you had the opportunity of sharing your experience with?

Chuck: There was a company that came out and did a documentary on—a short one. It's about 15 minutes long. It can be found on my website. I believe there's a link on there. And basically, they followed me out of CAR T, probably I would say 45 days out of CAR T, and it's a pretty interesting thing. Healthcentral.com is a—a company that follows people with chronic illnesses that lead a normal life. So, I did that. I was actually the Father-of-the-Year for The Leukemia and Lymphoma Society. This past Father's Day, they did a nice little write-up on me. I was interviewed by Parade Magazine and parade.com., it's a pretty—a pretty nice interview, all these can be found on the website. And the USA Today did a special insert on September 20 of 2018 on

blood cancers; and I was one of the people that was interviewed and the interview was in the USA Today, so I did that.

And so it's been, hopefully, you know, again, I know there's people out there, you know, that don't, because I've come across people that have contacted me and they are, like, I can't talk about my illness or, you know, I wish I could, you know, tell people my story and inspire people like, you know, hopefully, I'm inspiring people, , but you know, the owner of my company told me something 3 years ago when I got diagnosed. He said, "Chuck, there's a reason a guy like you got cancer and there's a reason a guy like you has endured for 3 years." And, you know, you go through what you go through, but then you promote it, and then you put it out there, and then, you know, you try to educate or inspire. I spoke at a blood cancer conference here in Pittsburgh a few months back and I had people come up and give me a hug afterwards. And, you know what, I mean I worked my whole life, you know, and I've always been a guy that, you know, a hard-working guy and, I want to make sure I get everything in line and I used to get great satisfaction out of that. You know, I consider myself a hard-worker, but I've never got as much satisfaction—as I've gotten since I got cancer. For me to be able to, you know, when I'm sitting in the chemo ward and sitting next to the lady who's got Stage 4 breast cancer that's just doing end-of-life care and I can make her laugh. I mean, you know, for me to be able to do that there's no words. There's no reward. There's no check you could ever get to say, "wow", you know, you made her smile today or made her laugh today. You know, you get that hug and people say, "I love you for what you're doing." you know, listen, cancer is still a tricky business and doctors are great, and medical professionals are great, and The Leukemia and Lymphoma organization, the pharmaceutical companies and—you guys are all great, but survivors and people who are battling this, we have so much to give to other people that are going through it, okay? And, you know, I think that, you know, by doing this, by doing things like this, for me—that's why if I get a phone call and they say, "will you do this or will you do that", of course I will, because even if there's only one person that listens to this today, and if there's one person that takes one thing from this today, it was well worth my time here today. So, yeah, I, you know, again, I love doing these things and I love putting the word out and trying to help others so

Alicia: Thank you so much, Chuck.

Lizette: Yeah; thank you. It was meant to be for you to share your story. You've helped so many people. Really, thank you.

Chuck: Well, thank you ladies. It was a pleasure being here today.

Alicia: And it's one thing to read about CAR T, but it's much different to hear someone's story and understand what they went through; the emotions they had, how



they were feeling so thank you so much for joining and sharing your story with us and our listeners.

Chuck: No problem.