

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: "The Only Way Through It, Is Through It": Tim Card's Story'***

#### **Description:**

They say hindsight is always 20/20. Looking back, Tim Card remembers how his body may have been sending signals that something was wrong, but how he often attributed them to his active and busy lifestyle. Tim received his shocking lymphoma diagnosis after logging onto his medical portal, while awaiting test results. Tim is Penn State Cancer Institute's *first* chimeric antigen receptor (CAR) t-cell therapy recipient, diffuse large B-cell lymphoma survivor and a father of 7. On this episode, Tim describes how he was diagnosed, when CAR T-cell therapy was introduced as a treatment option, side effects he experienced after CAR T-cell therapy, the importance of caregivers, and how humor helped him during the most challenging time of his life.

#### **Transcript:**

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

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

**Alicia:** Today, we will be speaking with Tim Card, a CAR T-cell therapy recipient, diffuse large B-cell lymphoma survivor and a father of 7.

**Lizette:** Plus, a dog.

**Alicia:** Yes; 7 kids and a dog. Thanks for joining us today, Tim.

**Tim:** Thank you so much for having me. I'm glad to be here.

**Alicia:** We're super excited to talk to you. We know that you were diagnosed with diffuse large B-cell lymphoma, which is the most common type of non-Hodgkin lymphoma. So, when you were diagnosed, what was happening? How were you feeling? How did you get that diagnosis?

**Tim:** Yes; so, when I was diagnosed, at the time, I owned a gym. I owned a cross fit gym and...

**Lizette:** Oh Wow!

**Tim:** ...when you're the guy in charge, you're, kind of, always telling everyone, "alright, do this, lift this, do it again, do it faster." You don't really run the class by doing the exercises with them, like you're in front of a spin class, but you're walking around and telling people what to do and all that stuff. And, I was—I just had this pain, like this nasty pain in my side for about a week. It just—it just wasn't going away. And I thought I had pulled a muscle, which is really not unusual considering my line of work; a pulled muscle happened. I had done it before; probably will do it again, but it just felt odd. It just felt weird. And I was coaching one of the classes and one of the other coaches there, she looked at me; and she's, like, "Tim, you need to go. Something is wrong." You know, I was all pasty and sweaty. I was sitting down a lot. I didn't have a lot of energy. "Go to the hospital. I'll close this up. You need to go. Something's wrong."

So, I went to Urgent Care and they told me that "yeah; you either pulled a muscle or you've got gas." You know, so which one of those would you like us to treat? So, I said, "yeah; please, treat the pulled muscle because going to Urgent Care because you've got gas is just embarrassing." They said, "sure, we'll do that." They said, "take some Flexeril and some Advil and you'll be fine by morning. Everything should be okay." So, I did that. That was about 9 o'clock and by midnight, it hurt so bad that I drove myself into the E.R. I couldn't take it anymore.

**Alicia:** Wow!

**Tim:** And when I got there, they did all the CAT scans and all that stuff; and that's when things started to, kind of, get out of hand. They didn't tell me what the CAT scan showed initially, the E.R. doc was, kind of, dodging around the whole thing; and I said, "well, what's going on? Why do I have this pain?" He said, "well, you know, the E.R.'s job isn't to diagnose, it's to fix the acute problem and get you to your doctor; and *you should really see your doctor.*" I said, "okay, I will, but why am I in so much pain? Like, I don't have cancer, do I?" He said, "well, *you should really go see your doctor.*" So, the next day I did and there were checking me for Lyme disease and all these autoimmune problems and all this stuff that I knew wasn't right. Like, I knew that wasn't it, but I didn't know what it was; and I was still a little worried that something was really, really wrong because it was such an unusually bad pain. Like, I never felt anything like that. And, they tested me for all the stuff and then said, "well, we'll figure it out when we get the results back." And that was Friday; and then Saturday, I was able to log onto the hospital's health portal and pull up my records; and I saw that the CAT scan—the read of the CAT scan, right there, like first paragraph, huge, you've got a big, massive lymph node on your left side. Our primary concern is lymphoma; secondary concern is testicular cancer? So, I was a little upset that the doctor, like, knew exactly what we were dealing with and...

**Lizette:** Right

**Alicia:** And nobody called you.

**Tim:** ...I found out that I had cancer on the internet. It's just not why people go on the internet at all.

**Alicia:** Hmm, hm.

**Tim:** So, that's kind of where I was. I went back on Monday to my doc and kind of chewed him out, which was unfair, because he didn't have any more information than I did. And I apologized, but it was a terrifying time to find out. Like, you know, that one thing you never want your doctor to say, you know, is "you've got cancer". Like, there is not a whole lot worse thing you can hear from your doc and, so, I was terrified. I was terrified of what was happening. I didn't know what to expect. I didn't know anything about lymphoma or—other than my uncle had it; and he didn't make it out. So, that was my basis of knowledge for lymphoma was my Uncle George didn't make it. So, I was completely terrified. I had no idea what was going on.

**Alicia:** So, I find that so wild, Tim, because usually we hear someone say, you know, "a doctor then called me and said come into the office tomorrow or go into the E.R. tonight", but you found out

**Tim:** Right

**Alicia:** ...off of your own curiosity to log into your portal.

**Tim:** Yes; yes. Super morbid curiosity.

**Alicia:** Was it persistent pain or was it pain that was, kind of, coming and going?

**Tim:** It was all the time 'cause this mass of--and this is unusual for lymphoma. You know, lymphoma is usually systemic, right? It's all over the place. It doesn't usually get all jammed up in one spot, but this one mass of lymph nodes, it's about the size of a lemon, and that was pushing against stuff in my left side. You know, it was against some organs in there, my spine, my stomach, like all that stuff...

**Lizette:** Right.

**Alicia:** Wow.

**Tim:** ....and that's what was causing the pain. And if it didn't, like, who knows how long I would have gone before I went to the doctor and said something doesn't feel right. You know, because, I mean, looking back, I see things that were probably symptomatic, but I could also explain away. Like, I would sit down and fall asleep. Well, of course, I'm going to fall asleep. I have 7 kids. I've got a business, a real

estate practice, a dog. Like yeah; I'm tired so when I sit down, I fall asleep. Like, that's not unusual, but I was falling asleep, like, at the drop of a hat and, like, people were worried about it. Patricia was worried, but thought, "well, he's just—he's working hard." So, that was one thing looking back.

Looking back at the gym, like, we recorded everything. You know, we kept records of everything. We wanted verifiable, measurable, repeatable results. So, I had about a decade's worth of workouts in my log and I knew what I could and couldn't do. And there were times where I was way off. Like, orders of magnitude off where I know I should have been and—but had no good reason for it. But then, the next day, I was okay.

**Lizette:** Wow.

**Tim:** Yes; it was just—it was weird. It was just weird, but yeah, the pain was persistent and it just kept getting worse, and worse, and worse.

**Alicia:** You said that the only time you really heard of lymphoma was through your Uncle George and you didn't really know much about it. So, had you heard of The Leukemia and Lymphoma Society? What questions did you have? Where did you go to for that information?

**Tim:** I didn't know about LLS at all. I didn't know about them until Marcia and Hannah...

**Lizette:** Oh Wow!

**Tim:** ...from the Central Pennsylvania chapter reached out to me. That was after I was diagnosed. They wanted me to be the honored hero for the Light the Night walk this month. I didn't know anything about them until they said, "hey, we'd like you to be our poster boy." Okay; sure. Let's do that. So, I went to Google. You know, I went to talk to Dr. Google, which is never a good idea.

**Alicia:** Oh! Like your best friend and your worst friend all at the same time.

**Tim:** Right. Like, just give me all the information without any way of ranking, like, this is good information and this is bad information. I was trying to go to the American Cancer Society, or Web MD, or things that seemed like they might be more up and up than others, but there's just so much. And there's so much, you know, you get down in the weeds of the cancer diagnosis and there's so many different kinds of just lymphoma. Dozens and dozens and dozens of different kinds of lymphoma. And I didn't know what kind I had yet. I mean, I've already learned more about the lymphatic system than I ever thought I would ever know...

**Alicia:** Right.

**Tim:** ...by Saturday afternoon.

**Lizette:** Sure. Yeah; and that's a point a lot of people don't really understand that there are so many types of non-Hodgkin lymphoma, even that there's Hodgkin and non-Hodgkin lymphoma.

**Tim:** Right; right; yeah.

**Lizette:** So, it's difficult. And your type of lymphoma is an aggressive form where there's aggressive forms and chronic forms, which are slow-growing forms and, basically, for your type, they really try to cure you.

**Tim:** Yeah; they want to knock it out as fast as possible.

**Lizette:** Yeah; so, what did they explain to you when they figured out that you actually had diffuse large B-cell.

**Tim:** It took a while to get to the diagnosis. They had to do, I think, 4 biopsies to figure out what it was because it was being weird...

**Lizette:** Okay.

**Tim:** ...because it wasn't behaving like a typical lymphoma would with a big mass and all that stuff. Like, it wasn't how lymphoma was. They took one biopsy and they said, "we didn't get enough so we've got to do it again." They took another one, and that didn't work, they've got to do it again. I got 3 biopsies in my back before I finally had a solid diagnosis of what I was dealing with.

**Lizette:** Sure.

**Tim:** My docs in Lancaster were consulting with Penn State docs, and some other docs, to try to figure out what was going on. So, it took a little while to finally get a diagnosis, but they figured it was non-Hodgkin lymphoma. They just were, kind of, just bickering about what particular flavor.

**Alicia:** Right

**Tim:** So, you know the first thing they say "we're going to give you 6 rounds of this chemo called R-CHOP; and it's a little cocktail. And you are going to come in on Wednesday, in the morning, and we are going to pump you full of poison and then you're going to go home. And then, 3 weeks later, we're going to do it again and we're going to do that 6 times." And, they told me that, usually, this is something like

an 85% success rate. So, we are really fully expecting for this to be knocked out by the time we get to February. You know, everything should be fine by then or, at least, statistically, it looks like everything will be good. So, I was looking at it, kind of, like that—like this is going to be like Lyme disease. This is going to be inconvenient. I'm not going to like it, but in 6 months, I'm going to be fine.

**Alicia:** Right.

**Tim:** I went into my first round of treatment with that kind of attitude. Like, this will be inconvenient, but I'll be okay.

**Lizette:** And I know that you have so many considerations, too, with treatment just having, you know, a large family.

**Tim:** Right.

**Lizette:** And a business to oversee.

**Tim:** Yeah; two of them.

**Alicia:** Two, right.

**Tim:** I'm in real estate, too, so I was trying to get that running, trying to get the business going. You know, the plan was to get the real estate, kind of, on-ramped enough that I could sell the gym and make a smooth transition from one to the other. This kind of threw a wrench in things.

**Alicia:** Right.

**Tim:** I really thought that—I had hoped anyway—that I would be able to get my chemo on Wednesday, and then, you know, take Thursday and Friday off; and then get back to work Monday morning. You know, just jump in; 5:30 in the morning, I'm at the gym, run my classes, do my stuff, do the gym work. In the afternoon, 1 o'clock, start doing real estate. You know, work into the evening, get home, do the kids, all that stuff. I really thought I would be able to do that, and I did that one day, and that was the end of that.

**Alicia:** Wow!

**Tim:** I just couldn't do it. I was just so completely wiped out.

**Alicia:** You mentioned that you were waiting for the results with the doctors going back and forth amongst each other. What was the time frame?

**Tim:** So, I went to the E.R. at the end of September. I finally talked to the oncologist, like, the first week of October. So, that didn't take very long. I got my port put in on Halloween and had the first round of chemo on November 1. So, there was about a month...

**Alicia:** Yeah.

**Tim:** ...of hemming and hawing. It was a long month. You just feel so frustrated like there's nothing that I can do.

**Alicia:** Right.

**Tim:** I just have to sit here and wait for—for smarter people than me to figure out what my next step is.

**Alicia:** And we hear so many patients say, when they hear that diagnosis, they say, "okay, well, let's start. Let's get going..."

**Tim:** Yeah. Let's go.

**Alicia:** If someone says, "we know it's NHL, but we don't know which sub-type. And then a whole month goes by, I can only imagine what you're thinking during this time. How that waiting period must have been and how stressful it must have been.

**Tim:** It was pretty tense. It was not my favorite part.

**Alicia:** Yeah.

**Tim:** Yeah, it was a lot of appointments. It was a lot of trying to figure out what to do with all my stuff. Like, how do I keep these businesses running; or can I keep these businesses running, and what's going to happen, and how am I going to take care of my family? How am I going to put food on the table at this time, how am I going to be able to take care of the kids and help out around the house; and spoiler alert, I couldn't take care of the kids, or help out around the house.

And that "P" in R-CHOP is prednisone and that makes you quite a bear.

**Lizette:** Yeah.

**Tim:** And that didn't help.

**Lizette:** Right.



**Tim:** Actually, the third round—the third or fourth round, I was—I had just gotten the stuff—it was Wednesday—it must have been Wednesday night, or Thursday, and I was starting to feel, kind of, rotten and my sister came out. My sister and my parents live in New Jersey, where I grew up; and it's about a 2 ½ hour drive from where they are to where we are. My sister was out this time and I was hiding in my room, like, in my big leather chair. You know, the lights are out, just trying to—just calm myself down and be okay, and not throw up, and watch TV or something; and everyone's running around, like, dinners got to get cooked and kids have to be fed, and bathed, and watered, and homework has to get done and I got to get them to bed. Like, it's just a chaotic time, right? It's just from 4 or 5 o'clock until about 8 o'clock in my house, it's just a million moving parts all at the same time. It's just—it's wonderful love and chaos, but it's still chaos.

**Alicia & Lizette:** Right

**Tim:** And I'm just sitting there trying to, like, block it out and just be okay. And my sister comes in and says, "hey how about when I leave tomorrow, why don't I take you back to Mom and Dad's and you can ride the weekend out there. It will be quiet. You can do that. You'd be okay. And I immediately thought and said, "I don't want to do that. Like, that's so unfair to Trish. I could leave her here all alone with the kids, and all the house stuff, do everything on her own, and all the driving. No way. I can't do that to her." And Howie says, "no, no, you're not understanding. This was Trish's idea."

**Lizette:** Wow.

**Tim:** "You're leaving. Pack a bag. I'm trying to make it feel like it's your idea, but it's not." So, "we already called Mom and they can't wait to have you. Like, get your bag packed. We're leaving tomorrow".

**Alicia:** Wow! That actually brings up a good point, though. That there are needs that both sides have.

**Tim:** Yeah, for sure. Yeah, but it's definitely a very different experience.

**Alicia:** Uh huh

**Tim:** It's seems like the patient is trying to express to the caregiver what it is that they are going through and the caregiver is trying to express to the patient what they're going through, but that's really not the conversation they need to have right now. That's a conversation to have, for sure, but in the thick of it, like, the caregiver's job is to help me survive. That's—that's the conversation we need to have. And the patient's job is not to piss off the caregiver. Do all we can to be not—to be thankful and appreciative and not piss you off too much which tough. Like, I wasn't really good



at not pissing off my wife before I was sick. So, you throw all this other stuff into it and it's a real challenge, but there is a lot of clashing because we are both looking at the same situation from very, very different points of view.

**Lizette:** Right; and you're thinking she needs, you know—she needs you there to help her out. You're, like, "oh, that wouldn't be great for me to leave and she..."

**Tim:** No.

**Lizette:** ...and she's, like, "oh".

**Alicia:** "I wish he'd leave."

**Tim:** I wish he'd go away now. I don't want to make it sound like she was being mean or anything. She really wasn't.

**Alicia:** Of course.

**Lizette:** Of course not.

**Tim:** I think it was a good idea for me to get out where it's quiet at my parents' house. Like, there's not a lot going on there and that's okay. That's exactly what I needed and that gave my parents a way to feel that they could help.

**Lizette:** Sure

**Tim:** Because they want to help, too. They really want to be—like, they were furious that they couldn't be donors for bone marrow. Yeah, but gosh, you know, you're old. I'm too old to donate bone marrow. You're definitely too old. So, they were looking for ways to be as helpful as they could which is a great way to do it.

**Alicia:** Yeah.

**Lizette:** Yeah; that is a great way. And it's really hard sometimes to, you know, allow those long-distance caregivers to really help out; and you're right, long distance caregivers don't always know what they can do.

**Tim:** Yeah; and that was part of what I was feeling terrible about. Part of the guilt that I was carrying around was, like, yeah, they're driving 2 ½ hours, like, every week for a couple of days. They go home for a day or two, and then they turn around and come back; go home for 3 or 4 days, turn around and come back. My sister was pregnant and she's still driving back and forth. Like, I felt terrible that I can't really do anything; and all these people are upending their lives to help me through this patch.

I felt awful. I felt useless and I felt like such a burden to everybody around me, which wasn't helpful in the whole healing process.

**Alicia:** Right. There are so many psychosocial things that take place in addition to physical effects of just...

**Tim:** Yeah; right; yeah.

**Alicia:** ...diagnosis. Yeah.

**Tim:** Yeah; exactly. There's a lot of mental loops to jump through. They're not great.

**Alicia:** Right. You mentioned you were given R-CHOP again, a drug combination therapy to treat NHL, when was the conversation regarding CAR-T introduced?

**Tim:** Sure. So, after 3 rounds of R-CHOP, we took another scan and everybody said everything looked great, but I wasn't feeling it. I told the docs. I told Trish. I told everybody, like, I think something's wrong. Like, I don't think this is catching anymore. It felt different and I couldn't put my finger on what it was. And I thought maybe I was just being paranoid or, you know, whatever; and the doc said, "you've got to let the medicine do its work. You've got to give it time to do things. Everything looks good now." And it was. The thing had shrunk from the size of a lemon to the size of a grape. Like, on the outside, it looked like things were going fine, but internally, I really felt like something was wrong. I felt like something's not clicking anymore and I don't know what it is, but I feel like something might be off. Everyone kind of "no, no, no, you just let the medicine work and we'll see what happens." Then, I got my last round of R-CHOP on Valentine's Day, which is a very romantic way to spend Valentine's Day. It was great, we had a date night. We got to spend the whole day together watching bad TV in an infusion room. Very romantic.

So, I got the last one on Valentine's Day and got another scan, I think 3 weeks later, or a month later—and the doctor's office called me, like, the next day and said, "hey, can you come in and see doc, like, right now?" And I knew, like, immediately, like, that's not good news. Like, there's no way the doc is rushing me to tell me good news. So, well, I mean "I can get there pretty soon." She said, "how about 2:30?" "Well, it's 2:15". "Yeah; can you get here at 2:30?"

**Alicia:** Wow!

**Tim:** "Okay".

**Lizette:** That's such a different experience than when you were first diagnosed.

**Tim:** Yeah. This is, like, this is almost a worst fear than “I wonder if I have cancer.” Like, that’s a bad one, right? But I wonder if the really strong medicine didn’t work. That’s really bad because they tell you, like, the 85% success rate is true.

**Alicia:** Uh hum.

**Lizette:** Yes

**Tim:** But that means 15% of the people don’t—don’t recover, but—and they you get, in my situation, a refractory disease, right? This is growing in spite of treatment, right? So now, I’ve got, like a 15% chance....

**Alicia:** Right

**Tim:** ...of a long-term survival. That’s a scary number to read. That’s a scary number to hear.

**Alicia:** Absolutely.

**Tim:** So, when they figured out that, you know, the stuff came back and it was as big as a lemon again. Like, it had been growing for the last six weeks--this thing had been growing again; two months of growing. They said, we can’t treat you here in Lancaster, we’re going to send you to Penn State/Hershey and see those docs there. So, that’s when the CAR T conversation came in. Initially, my initial oncologist said, “you are going to need a bone marrow transplant and we do not do that in Lancaster. We do that in Hershey.” So, he sent me over to Doctor Amin over in Hershey and we started that conversation about a bone marrow transplant. And he’s telling me about all the different kinds, and how I was going to have to get someone else’s blood. And there’s a whole list—there’s a hundred to a couple of hundred thousand people on this list and we have to match them up and, you know, it’s not just finding the same blood type. You’ve got to get all these protein markers you got to line up, like. I think there’s 300,000 people on the list, and I got 2 matches, and he was ecstatic.

**Lizette:** Wow! Yeah!

**Tim:** I got 2. Two is a win. Two out of 300,000; those aren’t great odds, but we found 2 of them. And then, he says, “but also we’ve got this other thing. Like, we’ve got this, like, side door issue we want to talk about, too”.

**Alicia:** You’re probably, like, what else?

**Tim:** Oh, there’s another option—cool! So, Penn State hadn’t done any CAR T procedures yet at all and they were all ready to. They had all the doctors, and all the training, and everything was ready, but they were looking for an ideal first candidate.

They really wanted someone they could make a success story out of; and it ended up being me. I was relatively young. Before I got sick, I was in phenomenal shape. I didn't have any other underlying health issues. Doctor Amin called me "annoyingly healthy".

**Lizette:** It's from the cross fit.

**Tim:** That didn't hurt. You know, that really helped a lot. I built into a lot of the health and wellness stock of my body so I had some reserves to lean on.

**Lizette:** Yeah.

**Tim:** But so, they were really looking for a good, first candidate, and that's when they brought it up. They said, "would you be interested in being that?" I was a little nervous. Like, I know the first time I do something, it's almost never the best time I've done something. So, I was a little worried that, like, you know, do they have all the kinks worked out? Have they ironed out all the procedures yet? But, I also figured, you know, these guys are just going to wing it. You know, they've got all these people who are going to be looking at it and all these—I'll probably have more eyes on me, in this situation, than I would in a bone marrow transplant which is, at this point, kind of run of the mill because there's nothing really exciting, or new, or cutting edge about a bone marrow transplant. They've done thousands of them—thousands and thousands and thousands. You know, this is a first. So, I know I am going to have a lot of people following this and making sure that I'm okay. So, that's how I learned about CAR T. Would you like to be a guinea pig? Okay.

**Alicia:** So, Mt. Joy resident becomes the first patient at Penn State Cancer Institute to receive CAR T?

**Tim:** Yeah; it worked out well for them. They're, like, right up the street. Very convenient. I checked off a lot of their boxes.

**Alicia:** Right.

**Tim:** So, we had to get the hospital to approve it. We had to get my insurance company to approve it. There's a lot of things that had to all line up. And, in the meantime, while all this was happening, we're still going through the bone marrow transplant process because they ran parallel. Until had to make a hard decision, one or the other.

**Lizette:** Sure; sure.

**Tim:** So, in the meantime, I'm getting salvage chemo. I had to get a week's worth of radiation at one point at the end of July, the beginning of August. Yeah, so things

were still progressing. I'm still very sick. Yeah, but nothing's getting done that's actually going to cure me until September. You know, so, this is May or April that I went to go see him first. So, April to September, it was just "keep him alive until we figure out what we're going to do".

**Alicia:** Wow! And I want to actually address something that you said. When you said "doctors aren't going to wing it", I think that's also something important to note because at LLS, we always want to educate, patients, caregivers, and really anybody that clinical trials isn't something where they just came up with yesterday.

**Tim:** Right.

**Alicia:** You know what I mean?

**Tim:** It wasn't some mad science, like, ooh, ooh, let's try this!

**Alicia:** Exactly; exactly; It is, I mean, clinical trials, they are used to determine the most effective and safest treatment for a disease; and like you said, it is understood that because it is a trial, you are being watched more because—they are really trying to figure out every single detail of—of that trial; yeah.

**Tim:** This was beyond clinical trial phase. I was just the first one to get it in Hershey.

**Lizette:** It's important that even before it got there...

**Alicia:** Right.

**Lizette:** ...that they spent years in clinical trials.

**Tim:** Yeah; getting ready, yeah. Like getting stuff set up and ironing it out—ironing out a lot of those kinks.

**Alicia:** Right.

**Tim:** The other reason that we decided to go through—because, really, he left the choice up to me. Either one, you can do. They've both got their pluses and minuses. They're both about as effective as the other. There is not a lot of long-term, studies on how long—on how well CAR T lasts for 20 years because it just hasn't been around that long.

**Lizette:** Right.

**Tim:** So, the initial effectiveness looks to be about the same; 40-50% in that ballpark, but what I was trying to do, and what--the way he presented it, what I was trying to

do was manage the worst-case scenario. So, if I get CAR T—what if I get a bone marrow transplant, tried and true, like, everybody does this. If I get this and it doesn't work, what's my next choice? What's the next rung down the ladder? And that would be CAR T or something else on the clinical trial, but either way, they couldn't do that at Hershey because if I get bone marrow transplant, I could not get CAR T treatment at Hershey if the bone marrow transplant didn't work. I'd have to go somewhere else; and anywhere else would be disastrous. Even Philadelphia would be extraordinarily difficult for my family and myself to do that. In CAR T, I'm in there for 3 weeks, and then I'm back and forth to the hospital every other day for a month after that. There's a lot of driving back and forth. Like, it could have been Philadelphia. It could have been Nebraska. Who knows? Like, you don't know where it was, but if I got the CAR T and that didn't work, I could still do a bone marrow transplant at Hershey.

**Alicia:** Right.

**Tim:** So, I could keep the same medical team. I could keep the same, you know, familiar hospital with the same nurses and the kids know where I'm at. It's only a half hour away. Like, there's a lot of benefits to the down side if we did it in this order. The other side of it is the recovery time for CAR T is dramatically less than it is with a bone marrow transplant; and that was a big plus for me. Like, I'm young. I want to get back to doing the things that I want to do. I'm only 42. I'm not that old.

**Lizette:** Laughing.

**Tim:** I've got stuff I want to do and the thought of taking off another 2 years just to recover from this treatment was not appealing.

**Alicia:** Yeah.

**Lizette:** Well, first of all, to be given a choice of different options, is something great for patients. Not every patient has the chance to have different treatment options at different points of treatment. So, just to have that, but you are right, there's so many considerations that you do have to take. It not just, you know, what treatment am I going to do? It's what treatment is the best for me and my family at this point in time?

**Tim:** Yeah.

**Alicia:** You mentioned recovery. I want to talk about the effects of CAR T therapy.

**Tim:** Sure.

**Alicia:** So, once you got it. How were the days, weeks after that for you?

**Tim:** Yeah; they were—they were kind of awful. So, when they took the cells out of me, at the beginning of August—the middle of—I think it was like the first or second week of August, they took the cells out. And that took all day. They hooked up their pheresis machine. They put, like, a drinking straw-sized catheter in your chest that pulled the blood out. It's a disturbingly large straw that they stick, like, right into your jugular.

**Alicia:** Wow!

**Tim:** It's really, really big and they leave it there for a couple of days; and then they pull it out. They pulled it out of my chest with no anesthesia whatsoever. They just yanked it out

**Alicia:** What?

**Tim:** Oh, yeah. It hurt really bad. A hose was really what it looked like, but they put that in. They ship them off to California and I wait. I wait about 3 weeks. I came in on the 9<sup>th</sup> of September. They gave me one last round of chemo to try to wipe out as much of everything as they possibly could before they put the cells in. They wanted to take care of as much as they could so when they put the new cells in, there's less friendly fire. You know, let's just focus on the cancer cells. So, it was weird because, you know, I'm the first one, right? So, when they put the stuff back in, the whole hospital room—there must have been a dozen people up there...

**Lizette:** Wow!

**Tim:** ...like, all watching this. It was really odd. So, I'm lying in the bed, and Trish is sitting next to me holding my hand, and they're pumping this stuff into me and it smelled really, really bad. Like, the scent was like—it was burnt garlic and creamed corn.

**Lizette:** Wow.

**Tim:** It's a really bad smell. I guess that was the antifreeze or whatever it is they use—the thawing agent because they brought it in, like, frozen and they had to thaw it out real quick to put it into me. The thawing agent smells like burned Thanksgiving.

**Alicia:** That is very vivid and I appreciate that.

**Tim:** And everybody's standing around watching me and they said it was going to take half an hour, but I'm a cross fitter so I do everything faster, so I got it done in 6 minutes.

**Lizette:** Six minutes! Wow!



**Tim:** Yeah; it didn't take long. It's not a—it's like a sandwich-size Ziploc bag full of stuff. It really wasn't—there's millions of cells in there, but they're all very, very small. So, there really wasn't a whole lot of actual physical material; just a lot of very small cells. And then, I just hung out. Everybody filtered out and I watched Dead Pool on the TV and I felt fine. I had the first dose. I go, "oh, this isn't so bad. I guess I'll get through this okay." Trish was there for most of the day. She left for dinner—or after dinner and I hung out that night. I watched a movie on the I-pad and fell asleep. The first day was fine, but then, the next day is when the fever started; that cytokine storm; that cytokine release syndrome (CRS)...

**Lizette:** Yeah.

**Tim:** ...where your immune system realizes that we just pumped in a bunch of cells. Even though they were from me, they are now different enough that your body's going to fight them which is why they pumped me full of chemo the day before. Alright, so that fight was pretty weak, but my fever still got up to over 105. The highest I remember was 105.6 which is pretty high...

**Lizette:** Yes.

**Tim:** ...like brain-boilingly high. Yeah; they were coming in and putting ice all over me and trying to pump me full of stuff to get the fever to come down; and it wasn't working. And it was probably for a day or two that the fever was that high like that. It finally broke and it got down to, like 102, and naturally when I felt uncomfortable at 105, I think your body just stops caring. Like, we can't—there's no way that feeling bad is going to make this any better. I felt okay. A little spacey, but I didn't feel bad. When it got down to 102, I really started to get uncomfortable. But then, after that, is when the second thing came in and that's the neurotoxicity. And they warned us about these things. They told me that you're going to get a flu and you're probably going to end up—you're going to get this neurotoxicity. Ninety-some odd percent of people get both of these side effects. We're ready for it. And the way they kept an eye out for the neurotoxicity, they had me fill out a little questionnaire every day and then sign my name. Yeah, like who's the President? What day is it? Where are you? Who's this sitting next to you? Like, very simple questions and then my signature. And my signature is usually a pretty big, bold signature; and they showed me the paper and, like, I watched as the days went by, it got smaller and smaller. Now, it's just a little tiny chicken scratch thing and then there was just N.A. Like, no signature required for about 6 days I was in the ICU.

**Alicia:** Wow!

**Tim:** Trish was saying something was quite right with me and then they looked at my signature and said something's wrong. They rushed me down to the ICU. They thought I was having seizures. I'm not sure that I actually was, but I was acting like I

was. So, they had me in the boots to keep my toes from getting locked pointed down and all the sensors all over me. I couldn't eat. I don't really remember much of those 6 days in the ICU. What I do remember is unpleasant.

**Alicia:** Yeah.

**Tim:** I remember my Dad being there and I remember just, like, holding—just leaning on him. Like, I can't do this anymore. This is too hard. I can't do this, but there's no choice. It's not like they can take this stuff out.

**Alicia:** Right.

**Tim:** The only way through it is through it.

**Alicia:** Right.

**Tim:** But I remember that. I remember, at one point, Trish was there playing my guitar for me. Actually, the hospital—did a film, a video, of this whole process because they wanted to document the first one. So, they got me from almost the moment that I walked into the hospital, in the very beginning in April, all the way up through this. They showed me some of the raw footage of me in the ICU. It was really bad. At one point, when I first got there, they put a catheter in me and I yanked it out which is not a good way to remove a catheter.

**Alicia:** Oh Gosh. Do you remember doing that?

**Tim:** No, I don't, but I remember it hurt for about a month afterward.

**Lizette:** Wow!

**Tim:** And then they put mittens on me because I was trying to pull everything else out, too. So, I was like—I was, like, trying to watch a drunken 3-year-old. I was just—it was that bad—I couldn't really

**Alicia:** You were like the Hulk in there, huh?

**Tim:** Yeah; right. Aahh! I didn't know what I was doing. I didn't know where I was. I remember, one lady—This is funny. I had to have a 24-hour babysitter. If there wasn't a doctor there, someone had to be there. So, I had these patient care advocates who are wonderful people and, you know, their job is to hang out overnight. You know, just to make sure I don't do anything silly. And this one lady—I can't for the life of me remember her name, but if she hears this, I'm sorry! I just remember yelling at her. Like, "what are you even doing here? What is your job?" Because all I wanted to do was take my pants off. Like, that's all I wanted to

do. I don't know why, but I just wanted to take my pants off; and I scared her and dropped them, and, like, "Tim, put your pants on." "Fine. Why are you here? Go away". So, I don't know who that was and I was really sorry that I was so mean.

**Lizette:** Ahh!

**Alicia:** If you are listening here today, Tim is sorry.

**Tim:** I'm sorry. I'm really, really sorry.

**Lizette:** Now, I know that usually for CAR T, they really do try to prepare you for these things because most patients have these after-effects; and most of the time, you know, in close duration after the actual procedure. They told you about this, but can they really prepare you for something like this?

**Tim:** Nope. That's the short answer. No; they can't. There's really no way to—it was good that they knew it was coming and they told us it was coming. That was good, but, you know, sometimes, like, the doctor says you're going to get a shot and it's going to sting a little bit; and then you get it and it really wasn't that bad. This was not that. Yeah; this is the opposite of that. This is so much worse than we thought it was going to be because not everybody gets it to the same degree. The guy who had CAR T after me was in the ICU for a day. His response was not nearly as bad as mine was.

**Alicia:** Right...right.

**Tim:** But no, it was hard and I lost 30 pounds in the 17 days that I was in the hospital. I hardly ate anything. You know, I came out just—I passed a kidney stone.

**Alicia:** Oh wow.

**Tim:** You know, because all this medicine, like, bunched up and created this what they call "renal sludge". That's what they called it.

**Lizette:** Oh.

**Alicia:** Yeah

**Tim:** Then, there was a kidney stone, too. As a matter of fact, I didn't feel it because I was on so much other pain medicine that I think it just got mixed in with all the rest of it.

**Lizette:** Wow. And for people who have had that, that's painful in itself. I must say.

**Tim:** Yeah; I've heard.

**Lizette:** It really is...

**Tim:** I'm glad I missed it.

**Lizette:** Yeah; I'm glad you did, too, because it's painful and they say—because I—I've had—and they say it's even more painful for men. So, I am glad that you do not remember that part.

**Tim:** Yeah; I've heard that kidney stones are almost as bad as a man cold and those are so bad.

**Lizette:** A little worse.

**Tim:** I don't know. Have you ever had a man cold? I was pretty sick.

**Alicia:** You mentioned there was a moment when you said to yourself, "I don't know. I don't know if I can do this." But then, to your point, you have to. There's no way for them to take it out so now it's your body fighting and, kind of, you're just going through what you need to go through. So, when was it when you said to yourself, "I think I'm going to be fine! I think that I've gotten through the worst bit of it and I'm going to be okay." Was there, kind of, a prominent time when you were able to think that?

**Tim:** I think when I got out of the ICU, I went back up to the 7<sup>th</sup> floor where the cancer ward is, I felt like, "okay, that's probably the worst of that." But getting through the treatment, and feeling like I'm going to survive the treatment is a different time for me feeling like I am going to survive this disease. Yeah so, I felt like once I got out of the ICU, the treatment wasn't going to kill me.

**Alicia:** Right.

**Tim:** But I was still concerned about the disease and I really didn't know; and we wouldn't know if this worked. I think they said you don't know if this worked until it works.

Either the cancer goes away or it doesn't. And then they initially said, "and it's going to be about 2 years before we know whether or not it worked". So, I was really, like, geared up for 2 years of angst. You know, just not sure what's happening and not knowing if I'm going to be okay, but then we went to the doc a couple of months later and he said, "hey, you know, the good news is that all of the current studies of CAR T show that if you make it 6 months, the chances of it coming back dramatically fall off.

So, if you can get to 6 months, you'll probably be okay." And that was in, like, 5 months.

**Alicia:** Oh, wow! Okay, so you're, like, one more to go. Let's see. Let's see.

**Tim:** Whew; this just got a lot easier. But then, what I didn't know is that—there's a brain-blood barrier, and also a bulb-blood barrier, where your body has decided that those are the 2 very important parts of your body and we're not going to let poison get into them. So, a lot of times what will happen with CAR T because you put it into your blood, it doesn't get into your brain, it doesn't get into your testicles. So, the cancer will hide out there and wait; and kind of wait for things to simmer down for a couple of months and then pop up again. That happened to someone else at the hospital that I knew. I found that out, you know like, 5 months later—or 5 months away from my treatment. Like, oh man, I didn't know that that was a possibility.

**Alicia:** So, where did you go for support? I mean, again, I mean, you come out of the ICU. I'm assuming that you still want to know what's going on in regards to this therapy and any new developments. Where did you go to get the support from those people who could actually relate to what you were going through, whether it be someone who may also be in the midst of CAR T or just somebody who has the same diagnosis that could shed some light on questions you may have had?

**Tim:** Yeah, the first person when I first got sick—there's another woman at my gym who also had just gotten through cancer and you know, I just found out and I was terrified. And she sat me down and she looked me right in the eye. She said, "welcome to the club." And I--and I never thought of it that way. I never heard it expressed that way because I was never in the club, but here it is. Now, we're all a part of this. So, like, I knew there was people out there that were sick, who had been through stuff like this and were here to help, but I didn't really need a whole lot of those folks until I was in the hospital and I went to the first support group there. I didn't lean on a lot of sick folks. Now, we got a lot of help. You know, you said who did I lean on for support? As far as, like, taking care of stuff at home, we had a meal train set up within a couple of hours of finding out that I was sick. The gym ran itself. The coaches stepped up and said, "you get better. We'll take care of this." They ran it while I was sick and I didn't have to go in at all. They just took care of everything. Then, when I found out I was still sick, I sold it to one of the coaches. You know, one of the people that had stepped up and helped us. I said, "I can't do this anymore. You want to buy it? And they said, "yeah, sure". So, I sold the gym to her. People from the gym; people from our parish here in Mt. Joy in our Church, people from the community, they really stepped up; and my family to help out with the day-to-day stuff. But as far as cancer folks, I really felt pretty alone. That's part of why I'm doing what I'm doing now, you to let people know, especially people who are new to this, and new to this whole cancer Club, that you're not alone. Not out there alone. There are people out there who can help you. There are organizations, like LLS, that I didn't

even know about that can help in tremendous ways besides just, you know, helping out with the research side of things. There's very practical day-to-day stuff that you can help with. There's support groups that are out there. There are people who have been through this. Like, there's—there's ways to not feel alone because that was—that was a big struggle was just feeling very isolated from the rest of the world.

**Lizette:** I just think it's important to make those connections and we do hear from a lot of our patients, and caregivers alike, that keep saying, you know, I felt like I was the only one going through this.

**Tim:** Exactly.

**Lizette:** And they'll meet each other and they have similar stories; and they can't believe it because they really felt like, you know, nobody else is ever going to feel this way.

**Tim:** Right.

**Lizette:** And you hope nobody does.

**Tim:** Yeah, but the truth is there are, unfortunately, millions of people that do.

**Alicia:** Right.

**Tim:** Yeah; there's millions of people that have cancer right now that are in the thick of it or have beaten it. Yeah; right now. So, we're not alone, but it's very—it's a very isolating feeling.

**Alicia:** Hmm; hmm.

**Tim:** And that makes the physical—we were talking earlier about the mental side of it, too. Like, feeling alone is not helpful for feeling better.

**Alicia & Lizette:** Right.

**Tim:** And even though I was surrounded by people. You know, surrounded by friends and family that love me. It was a different type of loneliness that I never experienced before.

**Alicia:** I think that's why it is so important, like you said, for people to find what is out there and connect either locally, or whether it be an online platform, here at LLS, we created weekly chats. We created this podcast. We also have LLS Community, which is a community of blood cancer patients, survivors, caregivers and they create a profile and they are able to, and converse with each other, ask questions, answer

questions that are posed to the entire community; and then really, really have that fluid conversation about whatever the topic may be. And it is because of the belief that no one should have to face a blood cancer diagnosis alone.

**Tim:** Yeah; sure.

**Alicia:** Because it is not good for you. You know, stats have showed that being in isolation and then kind of being in that mindset of “I am alone” will do nothing to help.

**Tim:** No nothing at all. It does no favors.

**Alicia:** Yeah; yeah.

**Tim:** I’ve been really blessed in the last couple months since I’ve been out to be able to talk to a lot of patients at the hospital. Like, they’ll have people that are going through CAR T call me. You know, I mean, they always ask, but I always say, “yes”. “Yeah, please have them call me.” I walk them through that, through being in the honored hero with you guys in central Pennsylvania. I’ve been able to speak to a lot of people, raise a lot of money to help out with you guys and all the work that you’re doing. I am on billboards with Hershey, which is kind of weird. There’re probably a dozen billboards around here that have a picture of me all bald and scary on my bike in my garage. It’s very odd. It’s very, very odd. But it has opened a lot of doors for me to be able to be that person for somebody else. I really feel strongly about doing that. About being able to help initiate the new members.

**Alicia:** And meeting new people. I heard that you have a new friend that you met that you have created a new resource with.

**Tim:** Yes; Oya?

**Alicia:** Would you like shedding some light on what that is.

**Tim:** Oya and I met in the hospital. He was in the middle of his bone marrow transplant. He has myeloma. Yes; he’s got that one. He was getting his bone marrow transplant. I was in for one of my rounds of salvage chemo and, somehow wandering those halls, we ran into each other and just hit it off. We’re an odd couple. We just had a very similar sense of humor and we bounced things off each other. And, in the middle of all this, we’re just laughing. We’re just laughing at all of this ridiculousness; and we stayed in touch. I saw him there. I left before he was out. I touched base with him a couple of times. He said, when I walk into his hospital room, like, “who’s this white guy that’s not the doctor coming in here to talk to me?”

So, that’s the story of how we met. I wandered into his room. And we exchanged numbers.



**Alicia:** Not creepy at all.

**Tim:** Not at all. Not at all. “Hey, man, you look terrible. How are you?” And I went back and he was there again. We saw each other. We had lunch and we just chatted back and forth; and then somehow, along the way, The LLS was at that support group at the hospital and they asked if I could be there; and I had been since I was in the hospital, I’ve just—I’ve never really been a support group guy. They’re wonderful things. I just never—it just never really was my thing...

**Lizette:** Hmm.

**Tim:** ...but—and I’m starting to see now more and more that, probably, it is my thing. I’m just being stubborn about it.

**Lizette:** Okay.

**Tim:** But they asked me to come and hang out; and I said, “yeah, sure. I haven’t seen those guys in a while. I’ll go;” and Oya walks in the door. So, my, look at that, because he lives, like, a long way away from the hospital, too. How about that? So, we started talking, again, and we were laughing with Hannah; and Hannah says, “hey, you guys should, like, start a podcast”. “Well, hey, that’s not a bad idea. You want to do that?” He’s like, “yeah, let’s do that.” So, we did.

We’re calling it “Dying Laughing”. Going through this and, kind of, looking at our ways of being able to reach out to people that are in the middle of it and feeling less alone. Like, how can you know that you are not doing this by yourself? How can you laugh at this a little bit because there is some funny stuff that happens in all this. You’ve got to find it. Some of it’s dark, but it’s funny and we’re going to exploit that. So, it’s really trying to figure something that we would have liked to listen to while we were sick. Now, we’re sitting in the hospital room and these guys get it and are giving us a little bit of hope through all this. Not just us, but also our caregivers and the other people that are around you. Like, just a perspective of the patient that’s not from the perspective of the patient that you’re specifically dealing with. Sometimes, it’s a little close. It’s a little too close. You’re, kind of lost. You can’t see the forest through the trees if it’s your patient that you’re dealing with. You know, you hear someone else say it that might carry a different weight. That’s what we’re trying to do. We’re trying to make people laugh in the face of all this and feel less alone.

**Alicia:** I think that’s such a great resource for so many people. It’s one thing to read it, but the it’s a whole other thing to actually hear it from a person going through it.

**Tim:** Right. Like, I’ve been there!

**Alicia:** Yeah; like he knows what I’m talking about. He’s not giving me an example.

**Tim:** Right. This isn't the Webster Dictionary definition.

**Alicia:** Right; and a quick shout out to Hannah because she connected us with you.

**Tim:** Yeah; she's great.

**Alicia:** Yeah; yeah. So, Hi Hannah in our Central Pennsylvania chapter.

**Tim:** Hi Hannah! She's going to be in the podcast, too. I just talked to her today.

**Alicia & Lizette:** Oh, that's awesome.

**Tim:** So, we've got her. We've got another patient—another cancer survivor that I met through cross fit. He's going to come on. I'm trying to get some of the nurses from Penn State to get on and get their point of view of what it's like. Oya's got another patient that he met—another survivor that he met—we're going to record that show on Thursday. So, we've got—we've got a whole bunch of episodes lined up. We're going to see where this thing rolls. We're really excited and hope to help out a lot of people.

**Lizette:** That's great.

**Alicia:** Nice, we'll definitely be listening as well.

**Tim:** Please do! Everybody should.

**Alicia:** Yes. What's the website?

**Tim:** The website is [dyinglaughingpodcast.buzzsprout.com](http://dyinglaughingpodcast.buzzsprout.com).

**Alicia:** Awesome.

**Tim:** And you'll be able to sign up for RRS feed or get it from iTunes and all that stuff.

**Lizette:** That's great. Congratulations!

**Tim:** Thank you.

**Alicia:** Yeah, it's so exciting.

**Tim:** Yes; it is.

**Lizette:** It's really great and it's still important, I think, that you, as a patient, know how important it is to let newly diagnosed patients know that they are not alone because of what you felt.

**Alicia:** So, as you know, Tim, I mean, those listening—I mean, the target audience for this podcast is patients and caregivers. So, for those listening, what advice would you leave with them today? When they are listening to this episode and they are, like, "wow, Tim's an awesome guy, can't we just subscribe to his podcast?" What advice would you have for somebody who may be just getting a diagnosis or may be in the same stage as you? What would you say to them?

**Tim:** One thing would be to be as kind as you possibly can to your caregivers; to thank them profusely for everything that they are doing 'cause it's—it's hard on them and you may not see it, at the time, because you're going through your own stuff. They really try to be as kind, and loving, and patient as you can be in the situation. Find some good resources to look at. I know that The LLS has a bunch of resources. Like, don't just go goggling around and reading medical journals 'cause it's dense. It's dense, and a lot of the information doesn't pertain and you don't know the language. Unless you're a doctor, it's like reading a foreign language sometimes.

And that's the other side of it, is find a doctor that you really like, and can talk to, and trust. Like, get another opinion. If you don't like a doc, go find another one.

**Alicia:** Right, such great advise.

**Lizette:** It is. That is. You know, we shop for, you know, what's the best deal on a car. We shop around for so many things, but I feel like we don't know that we can shop around for a doctor that communicates with us well. You know...

**Tim:** Yeah.

**Lizette:** ...and everybody communicates differently. So, you know, the best doctor for me may not...

**Tim:** Yeah, it's not like one doctor is good and one doctor is bad. Exactly.

**Lizette:** Yeah.

**Tim:** Shout out to Dr. Amin in Hershey. He was fantastic.

**Alicia:** Nice.

**Tim:** He was a great doctor. He was a great doc for me. We got along very well. There's a lot of laughing in spite of all this stuff. Our sense of humor lined up very well which made all these very difficult conversations just a little bit easier.

**Alicia:** Yeah. And something that you mentioned earlier that I think is also very important is you said, you knew how you were feeling and, even though people were saying, "oh, you know, the treatment's working", but it was you that said, "no, I think something's off."

**Tim:** Yeah.

**Alicia:** And I think it is so important for patients to hear that because we always say when a patient is sitting with a doctor, there are 2 experts in the room. There's the doctor and then there is the patient, and the patient knows exactly how they feel.

**Tim:** Right. So, don't be afraid to be your own advocate.

**Alicia:** Exactly; exactly. Many times, people will say, you know, the doctor knows it all. They know more than me. Let me just sit here and listen, but you know if something - something feels off, you know...

**Tim:** Right.

**Alicia:** ...it's your body and it's so important to know that that's exactly the time and place to get all your questions out.

**Tim:** Right.

**Alicia:** And, if you can't get your questions out or you do feel uncomfortable, so many doctors tell us, "that's not the doctor for you."

**Tim:** Right. Find a doctor you can talk to.

**Alicia:** Exactly. That's exactly right. So, how are you feeling now?

**Tim:** Now, I feel pretty good. I ride my bike 60 miles or so a week.

**Lizette:** Wow!

**Tim:** I have a nice, little garage gym set up in my garage. I'm not back at my cross fit gym, but I do work out with some folks in the garage and I throw some weights around and have fun.

**Alicia:** Tim, on our home page on thebloodline.org, we have a phrase, “after a diagnosis comes hope”. If you were to finish that sentence, what would you say? After a diagnosis comes...

**Tim:** After a diagnosis comes the rest of your life.

**Alicia:** Nice, that’s a good one.

**Tim:** Right; because a diagnosis isn’t necessarily a death sentence.

**Alicia:** Right.

**Tim:** Right. You’re still going to keep living, for a while anyway.

**Alicia:** And nobody knows.

**Tim:** Nobody knows.

**Alicia:** Even if there’s stats or there’s—nobody knows. We were talking with this young adult. She is a model; and she was reading these articles and everything said “the 5-year mark” or “life span 5 years”. And she said that she became so obsessed with this 5-years that everything she did was “okay, well in 5 years.” And, then, she had to say to herself, “stop”. Nobody even knows if that’s true for me.

**Tim:** Right.

**Alicia:** It may be true for 10 other people, but it wasn’t true for another group and so what makes we think that I’m going to fit into that group as opposed to the other. And it’s the truth that nobody knows; and you really have to take it day by day.

**Tim:** Even if it is true; like, alright, so maybe you have 5 years. Well, get on with it.

**Alicia:** Right; right.

**Tim:** Like, do the things that you want to do.

**Alicia:** Yeah.

**Tim:** You’ve been procrastinating. Now’s the time to get to it.

**Alicia:** Right; right.

**Tim:** But I think having a diagnosis like this kind of puts that in perspective anyway. Like, I think you should do what you want to do.



**Alicia:** Hmm; hmm.

**Tim:** Like, there's things you want to accomplish in your life. Get to them regardless of whether or not you have cancer. Cancer, kind of, gives you a little bookend or a little exclamation point to the whole process, but you should be doing what makes you, you! You know, get about the business of doing that.

**Lizette:** It's true.

**Alicia:** Right. We couldn't agree more. Well, Tim, thank you so, so much for joining us on today's episode.

**Tim:** Absolutely.

**Alicia:** It's been so amazing just to hear your story; and thank you for your willingness to share your story and be a resource to so many patients and caregivers.

**Tim:** It is my pleasure. Thank you so much.