

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'I Will Survive: A Viral TikTok Star's Journey through Acute Lymphoblastic Leukemia (ALL)'

Description:

Join us as we speak to William, a 23-year-old, three-time Acute Lymphoblastic Leukemia (ALL) survivor. In this episode, we hear about the variety of treatments William went through, his relapses and then subsequent stem cell transplant. Now one year out of transplant, he shares about his post-cancer journey – going viral on TikTok, becoming the face of the LLS Giving Tuesday campaign and then starting a podcast with another Young Adult Cancer survivor.

Transcript:

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

Edith: I'm Edith.

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

Today, we will be speaking to William, 23-year-old, three-time acute lymphoblastic leukemia, or ALL, survivor. After his initial diagnosis in 2018, he relapsed twice and then received a stem cell transplant. He is now in remission and back in school to finish his college degree.

William became a viral video star on the social media site TikTok during his treatment and in his continued journey as a cancer survivor. He recently used this platform to promote LLS on Giving Tuesday, and with William's continued passion to advocate for and connect with young adult cancer patients, he started a podcast called *The Illest.*, which is described as raw, unfiltered cancer stories by two young survivors.

Welcome William.

William Yank: Hello. Thank you. That seems like a list of accolades, but it's just another day at the office. But, yeah, thank you so much for having me. I really appreciate it.

Elissa: Of course. So, let's start with your initial diagnosis of ALL. What were the initial signs and symptoms that you had?

William: So originally when I got diagnosed, the only signs that I didn't know were signs before I got diagnosed were a lot of aching hand cramps. So, I was a very avid weightlifter and exercise enthusiast you could say, and long story short, I was curious on why my hands hurt so bad. And I was like, "Well maybe this is just pre-onset arthritis. Like, maybe this is just, you know, something weird or crazy." But at the time I was in D.C., and I was a young college kid. I'm not going to pay for an Urgent Care trip that isn't going to be something beneficial. I was like, "I'm young, I'm healthy I take care of myself. The chances of anything actually being wrong are very low." So I was, like, not going to worry about it. Just put it off.

And then one weekend I pretty much got a super, super bad sore throat, like, strep and my throat was almost swollen shut, that's where I was at. And so, I went to an Urgent Care finally. They told me I had mono. All they did was swab me. I don't think I had any blood tests or anything, if I remember correctly. And they're like, "Oh you got mono." They just gave me the Philadelphia mouthwash to numb your throat and then called it a day. And I was like, "All right. Great!"

Elissa: So, did the swab come back as mono?

William: I guess. That's what I was told. So, I was just like, "Okay." So that's what we did, and I laid in bed for the next four or five days and, obviously, continuously got worse. And then, yeah, I went to the ER, and it was just bad news from there on out.

Elissa: Oh my gosh. What was it like just hearing as a 21-year-old in college that all of a sudden you have leukemia?

William: Complete and utter disbelief. I was like, "There's just no way." And I vaguely remember just, like, treating the doctor that told me about it kind of, like, as a joke. I was like, "You're kidding." "There's no way this is actually true. I just have like the flu or something." That's what I thought in my head, right. But that was not the case and they quickly changed that reality around for me.

It was pretty terrifying though. You know, I went into the ER and kind of blacked out. And I've told that many times throughout many of my stories that I blacked out for like a week or two period where I don't really remember anything. I was still cognitive, but I was not able to interact or have conversations that I could remember and understand.

When I "woke up," quote/unquote, from that kind of time period, I was just like, "Whoa, this is not good."

Elissa: Now was that something that you don't remember that period or were your friends and your family seeing something that was just completely off with you during that two weeks?

William: During that two weeks, I mean I was in the middle of the PICU, and my parents were there. They came immediately after my boss had called them from my work and informed them of what was going on. Obviously, the hospital did the same thing. Not exactly the news you want to receive when you're, like, ten hours away from your kid, but.

Elissa: Right!

William: So, I got diagnosed in D.C. My mom beat me to Hopkins when they transferred me because as soon as she got the call, she drove with my stepdad to D.C. So, she beat me to Hopkins as D.C. was trying to stabilize me. The only way I know of what happened during those two weeks was at the time I was kind of, like, your avid, like, "I'm going to be a YouTuber blogger, blogger-

Elissa: Of course.

William: -guy thingy. I'm going to be famous. This is going to be great." But that was not the case, and I maybe had, like, 500 followers or something like that. But she knew that I liked to record stuff and so she made an effort to make sure she recorded everything just so I had a chance to remember it if I wanted to. So that was pretty cool.

Elissa: So, then you said you were in the ICU that whole time?

William: Yeah, yeah. So, for about a week and a half I think I was in the ICU as they were trying to, like, get me back under control, and then they took me up to the Peds/Onc floor.

Elissa: Okay. So, you did pediatric protocol then for ALL?

William: Yeah, yeah. They started me on ped, and I don't think they ever really had any intention of going to adult. As far as I know in talking with my oncologist, he thought it was best to go peds first. So, yeah, that's what we did.

Elissa: And then, as I talked about in the bio, so you've relapsed then twice after that. So, tell us about that.

William: Yeah. Relapsing is a pretty crappy experience. Not going to lie. So, what I did was I had the original induction consolidation chemo phases. They weren't really doing much for me marrow-wise because they were checking my marrow month to month. And they didn't like that outcome. And so then one day my oncologist brought up the opportunity of either CAR T-cell therapy, which is something I know LLS you guys backed and everything, or a bone marrow stem cell transplant. And what we could do is either CAR T then bone marrow, but you cannot do bone marrow then CAR T. So I was, like, "Okay, well, obvious chronological order here, let's do CAR T-cells and try that first. If that can get me there, great; if not, we'll just go onto transplant."

Do my first set of CAR T-cells. Pretty much all they do is you get hooked up to an apheresis machine. They take blood out one side, pull it out the other, take what they need, genetically modify the cells. Boom. You're in there. Couple months later you get them back from the lab and they infuse them. That put me into my first remission as of January I think it was 2019, and I was in remission for six months. So, it was pretty cool. I was very grateful for that. CAR T kind of worked numbers for me, so I was very happy.

And then I had enough cells to do two doses of CAR T, so when I relapsed again in June that year of 2019, I took another dose, and that got me another two months of remission to which I relapsed; and then in August/September 2019 going into 2020, we worked on transplant.

Elissa: Relapsing twice must have just been so difficult for you. I mean just having the rug pulled out from under you when you think everything's going okay. What was the emotional impact of that?

William: Yeah, it was really tough because I was just finally starting my senior year again. I had my room set up, my parents were excited to get me out of the house, put me back on my feet, get started for school. I was super excited. I was in a relationship at the time, and that was great. Like, things were just good in general, and I was like, "What could go wrong?" Oh yeah, everything.

And so, yeah. I mean as soon as I relapsed again, I mean it was just, like, the world falling back into my lap again, and I was like, "You got to be kidding me." I just, I built this tower with Legos and someone just kicked it over. And it was so frustrating, and I remember talking with my therapist about it and just being like, you know, "What am I doing wrong here?" I was someone prior to having taken such good care of my body only to have it rebel against me, and then we seemingly solved the problem only for it to rebel against me two times more. I felt like I was continuing taking the steps and I was doing the right things and taking care of my health, being

physically active, going under the protocol that the oncologists want me. I was trying to do everything right, and it's like even when you try to do everything right, you can end up with wrong. And, like, that's such a hard thing to swallow.

Elissa: I think that's what we hear from a lot of cancer survivors, and I definitely have thought that myself as a cancer survivor. And, just going through it, you almost take personal responsibility, like, why is my body not doing this versus why is the treatment not working? And I think there's so much blame and too much blame going to the patients when-

William: Yeah.

Elissa: -really, it's the treatment. You know, they're doing what they can. They're listening to the doctors, they're following evidence-based medicine, and it's the treatment and not so much you failing or your body failing.

William: Yeah. I think there's a piece of that where you, obviously, can't blame yourself. I mean I think, like you said, a lot of us take responsibility for ourselves because it's our bodies that's the ones that's going haywire, you know. And we're not going to blame the doctors. They're doing the best that they can. And so, yeah, I think it just comes back to, one, accepting the reality of the situation understanding that, okay, I can't change this and all I can do is my best. That's something my therapist had to pound into my stubborn forehead for so long. He's like, "Dude, all you can do is your best and that has to be okay. And you have to be okay with that and accept that so you can be able to move forward and that will be the only way you can actually heal this emotional mental stress you're giving yourself that's just worsening probably everything inside you."

Elissa: When did you start therapy during your treatment?

William: So my mom actually is the CEO of a mental health nonprofit in my hometown. And so as soon as I got sick, it was a no-brainer. She's like, "As soon as

you get home, you're starting with a therapist." And I was like, "All right, mom, I got you. No-brainer for sure." And so that's what we did. I get diagnosed in June 2018. I probably didn't see a therapist until maybe August/September of 2018. It was a couple months later when we actually got home, and I was able to see him in person. All pre-COVID, of course, so that's nice.

Edith: What's the name of your mom's nonprofit?

William: It's Family Services Society. They help women with domestic violence, mental health. They help troubled children, kids going through high school. They deal with all the school shootings in the area or, like, threats and stuff like that. So, she has a lot of weight on her shoulders that tends to be pretty emotional all the time, so I don't know how she does it.

Elissa: I'm so glad that she recommended therapy to you because I feel like so many cancer patients don't think about it. It's not necessarily recommended to them until they go into depression and somebody notices it, whether themselves or a family member or friend, and then they find out, "Yeah, I probably should've talked to somebody earlier than this and not waited till it got so bad emotionally."

William: Exactly. And one of my favorite things that one of my residents did at the time was he put me on antidepressants right away. He's like, "I know this seems trivial right now, and I know that at the start right now, you feel like you're fine and mentally you feel fine." He's like, "But these antidepressants will keep you even as you move forward because there's going to come a point where you're going to realize what's going on and then the world's going to crash down." And he was right. So, I was just like, "Well I really appreciate that," and, obviously, a mixture of medicine and, obviously, psychiatry or therapy is really helpful for people. So definitely recommend that.

Elissa: Yeah. And you said you moved back home too with your parents as well. I mean that had to be an additional emotional burden to move back home with your parents when you've been away and been in college and then you got to do that.

William: Exactly, exactly. My mom even jokes with me, so that she's like, "Nothing like being, you know-" – I'm 23 now – "Nothing like being 23 and still living with your parents, right" and gives me a nice shoulder check. And I'm just like, you know, I'm watching all my friends get careers, have families and stuff like that. It's definitely another emotional burden, but I'm very grateful for that at the same time. We were in Baltimore, kind of living there because I was getting treated there but then came back home two months in, to Indiana.

Lizette: When, when did you start realizing, because a lot of patients that we speak to say that they start realizing what they have been through when they get into remission. Like, you're in a fight mode while you're actually getting the treatment, but then you get into remission and you have that moment where you have the time to look back. Did you feel that way in your first remission?

William: Okay. If we're being honest here, in my first remission, so I will agree with that statement of definitely when you're in the moment, right, the cancer is there and you're fighting, you're getting treatment, it's definitely, like, life or death sort of thoughts. And that's what reflected in the conversations I had with my therapist a lot during that time.

During my first remission, I did not handle it appropriately. As a 21-year-old who didn't get a chance to celebrate their 21st, I went out, I had a lot of fun, I hung out with a lot of people. I really tried to socialize. The whole cancer thing was kind of an insecurity of mine at the time too, so it just didn't help that either. And so, I was probably more destructive than helpful to myself I would say. I also tried to do all these things at once. So, I tried to get back into school, I got my real estate license, I

tried to get a job. I was doing all this multitude of things that really didn't need to happen except me healing. That's what needed to happen.

I wasn't, like, going on a bingers of drinking or anything. I don't want to paint that picture or anything, but I was definitely just staying up late, you know, going out with friends, having a lot of fun, and everything. And so, yeah, in that first set of remission, no, I didn't think that way. But this remission that I'm in now, this survivorship, definitely, definitely mental health is hitting me like a broomstick right now, and it is tough, so.

Elissa: How far out are you from transplant now?

William: As of February 7, I am a year out, and I got my year-

Elissa: Yay!

William: -scan, in fact. Yeah, yeah, yeah. And right now, they're watching just, like, a very small population of cells. I got the clonoSEQ. I don't know if you guys have ever heard of that, but clonoSEQ is a super sensitive test for DNA makeups of your cells and all became egg cells. So, they're kind of watching that. I have, like, parts per million. They're very, very, very, very small populations of cells, and so I think I get my next test in May.

Elissa: Nice. Yeah, that's for minimal residual disease. And-

William: Yeah.

Elissa: -to check it there's those little pieces under the undetectable levels of a normal bone marrow biopsy.

William: Exactly. Creates a little bit of anxiety in my mind. I'm not going to lie. It makes you question, but I'm trying to have faith that, it's just little cells that my immune system will take care of.

Lizette: Well, the first time you were in remission, you were just being a 21-year-old, which is fine because that's something that as a 23-year-old now you want to look back and know that you celebrated your 21st, right?

William: True. True. Yeah, going through that whole kind of phase during my first six months remission definitely made me want to treat my second and third remission a lot differently. And so that's when during my second remission I think even I was still trying to make everything happen. You know, go back to school for my senior year, etc., and just the energy wasn't there, so.

Lizette: Sure. And usually with ALL, I know that, if a child is diagnosed, physicians will tell the child and the family, the caregivers, that the cure rate is really high for children. Then there's another ALL that usually occurs later in life for adults older than 65. That cure rate isn't as good. Not as many adults are in clinical trials than children, so we know more about the child pediatric protocol that you were on.

Now because you were on the pediatric protocol, and, like you said, you were a healthy 21-year-old, did you have discussions with your doctors, with your treatment team about how they anticipated treatment to go for you.

William: Yes. One of the interesting things that they told me when I originally got diagnosed was because I was as fit and healthy as I was prior, like, I'm talking your, your 5 AM wake up every morning, CrossFit class workout. I was a track athlete in college. I did all the jumps and everything. Ate very healthy. Never drank ever. Never smoked anything, etc. Just super focused. Regimented my schedule to where I was going to bed at 10 AM, waking up at 5 every single night. I scheduled out my entire day.

And they said, "I think that alone probably saved your life." Because when I got diagnosed, I had, acute organ failure, acute kidney dysfunction, cardiomyopathy, coagulopathy. My body was shutting down. And they said, "That alone saved your life." And they said, "Not only is that going to be what helped save your life, but the

fact that you were so physically fit prior is going to make your recovery and treatment processes go a lot smoother."

So, I was excited to hear about that because you never know what side effects you're going to get from chemo, and I think that's kind of for everybody. But at least for me I know I was pretty receptive to chemo and was able to get it in and get it out pretty quickly. So, I didn't have too many issues with chemo, which I was very fortunate with.

Lizette: And then your first relapse, how did you know that you were relapsing?

William: I didn't know. That's, the funny thing. So, I was in, like, my whole world of, like, "Oh I'm going to go do real estate. I'm going to go find a job, and, like, I'm going to do this." I went back to Baltimore for my six-month scan, and I really didn't even think about it. I was talking to everybody, the life of the party, like, "Hey, how's everybody doing?" Catching up with all my doctors and nurses. And then I come back home, I continue doing my thing, and then get the call. And they're just, like, "Hey you relapsed." I'm like, "What? I don't even feel bad right now. Like, I'm doing, I'm doing all right." And then I started to look back at myself, and I was, like, "I'm actually exhausted. I am really tired right now, and this is not how it's supposed to be."

Elissa: It's funny how you can look back and see those little, tiny changes. You're like, "Oh, yeah. Those weren't really right."

William: Yeah, yeah, yeah. I don't know why I ignored them. It could be fear. It could be just, yeah, ignorance. Ignorance is bliss. I think ignorance is bliss, you know, before you have cancer. And then once you have it, you kind of lose that.

Elissa: If you had started kind of all of these different things that you were doing after your diagnosis, did you know that relapse was much of a possibility, and did you think about it much?

William: I'm a very all-in or all-out person. I could tend to see things as kind of more black and white than gray sometimes. And when I got into remission for the first time with CAR T, I really thought that was it. I was, like, I just did this. Like, we were six months in. The scans were looking good up until that six-month point. But the things were looking good, and I felt good, and so I was like, "I could put this behind me. This is so great." And yeah. No.

Elissa: Yeah. That's tough. But you were in college at the time of your diagnosis. Were you still on your parents' health insurance? Were you able to stay on it and be covered through all of your treatments and your relapses and the subsequent treatments?

William: Yes. Thank you to whatever you believe above, yes, I was on my parents' health insurance, and I'll be on that till I'm 26. But it definitely created the realization that I probably can't be self-employed to start off my career because I'm going to need health insurance here moving forward, and I don't think that's something that as a young adult I really considered. My goal was always to be self-employed. I always wanted to work for myself. And then once this hit, I was like, "I can't afford my own healthcare. Are you kidding?" These scans, the costs of some of these tests that I'm getting, like, no way. So, realizing that I was another kind of bitter acceptance that I had to find.

Elissa: Right? I know. The Marketplace can be so expensive even though it does provide access to so many people. I remember when I finished, I had to buy my own healthcare, and I had to get, like, the top, top, top Gold plan. And it was so expensive just to be able to get the lowest deductible so that I could use that because all of my blood tests, all of the checkups, those were all out of pocket and went against the deductible. So, I had to get the lowest deductible possible.

William: Wow!

Elissa: And it can just be so expensive.

William: Yeah. It makes me jealous of my friends who don't even think twice about it. I'm like, "See I'm paying a car payment for my health insurance. You are paying for your new car with that money."

So, yeah. That's pretty frustrating. But, hey, I'm alive, so can't complain.

Elissa: Exactly. You know, one of the things I've appreciated is that LLS really tries to reduce that financial impact to patients through financial assistance and also the National Advocacy on Public Policy so that we can, hopefully increase access to care and make it affordable so that, people aren't having to walk away from being treated just because they're looking at these healthcare costs in front of them being, like, "Oh no, I can't afford it. I can't put that burden on my family." You know, whatever it is. And we've spoken to so many young adults who really struggled with the financial impact of cancer. And have you thought about what treatment would have been like had you not been on your parents' insurance at the time of your diagnosis or during your relapses?

William: Oh, what treatment would've been like is probably nonexistent. I really don't know what that would've looked like. I don't know how bills would've gotten paid, how that would even have worked, to be honest, because, yeah, like you said, I didn't have insurance. I didn't have anything, and I can't imagine being in that position. You know, my mom and I have had that conversations about that. Imagine being in my position as a young adult but let's say, like, in my 30s, more on your own, maybe less interaction with your parents, and being at the hospital alone. Maybe, maybe your parents have passed and, like you're trying to figure this out on your own. I can't imagine that at all. It would be gobsmacking, I think. So yeah, my heart goes out to those people that face it alone, and hence why I do half the stuff that I do is because I don't want them to feel like that. And I know I can't maybe help financially, but maybe I can let them know that they're not alone in how they feel.

Elissa: Yeah, definitely.

Lizette: And I know that you've mentioned before that you did have student loans during this time that you weren't in school. So how did you have to handle that?

William: Yeah. So, with student loans, you get a six-month deferment, I think straight out after you graduate. They let me use that deferment. And then after that, you could do an income-driven repayment plan. And, obviously, I was making zero dollars. I also put in that my health situation as another cause of why I couldn't pay back my loans. And that has deferred my loans until I'm able to pay them again.

Now, obviously, since I'm back in school, I'm not sure how the interest is compounding on that now, but, obviously, they're still growing, but I'm very grateful for that opportunity to defer that because I can figure out how to pay them off when that time comes, but, when you really just need to focus on your health and you really just need to take care of yourself first, yeah, you got to get that done before you can worry about all that other stuff.

Elissa: Now were you able to get on Social Security Disability since you didn't have much work experience behind you since you were in college? I know that can, prevent some people from getting on, but you also had an acute leukemia, which meant you couldn't work.

William: I remember my mom immediately as I was diagnosed – this was within, the first two months of being in Baltimore – since she had experience with her nonprofit and helping troubled families getting on Social Security and stuff like that, she immediately got the documents for me. We set that up. I got disability and everything, and I still get it today. And I denied my Medicare benefits though because, obviously, I'm protected under my parents' health insurance. So, I'm just getting that benefit still and that's kind of, like, what's keeping me afloat through college and stuff right now. So I'm very grateful for that, but yeah. Hopefully, I'll be able to return the favor to somebody someday.

Elissa: I love it.

Edith: So, let's talk about my favorite app, TikTok. For our listeners who don't know, TikTok is a social media app where users can create unique videos. You went viral during your treatment and continue to use it to share about cancer and LLS. What was that like going viral?

William: Yeah. What a question. It was really weird. When I consider the time that I went viral, it'd probably be the week before my transplant. I was kind of waiting in the hospital. I had to get the preliminary chemo and radiation leading up to it. And I remember just being, like, bored, impatient. And I was like, "Okay, I'm going to at least entertain myself somehow."

And I had gotten on TikTok just a month before going into full transplant stuff because of a friend of mine who was just like, "You should check this out. You're going to be bored anyway. Just watch something that make the time pass." And I'm like, "Okay." And so played with it and stuff and made videos, and, yeah, it was my seven days leading up to transplant. I was like, "I'll give you guys seven days of video each day of what's going on and then move on." And so, then I just kind of played on the whole cancer idea and played on songs that were trending at the time and popped off and went viral. I was like, "What the heck. This is so weird."

And then I found myself answering comments for hours on end and talking to people and finding out that I'm somehow helping people and all this stuff. And I'm just, like, "Okay."

Since then, I've really been trying to focus on the idea that, like, it's not about the follower count, it's just like helping one more person. I really try not to see myself as an influencer but more as an equal and just like someone who can help out the patient population because that's what matters.

Edith: That's awesome though because in the beginning you said you wanted to be an influencer, you wanted to be a YouTube star, an Instagram star. Little did you

know TikTok was, like, right around the corner, and, you know, you got to be it, and you're doing it, and that's really awesome.

William: Yeah. It's so funny because I joked with my friend David when I was back at college and I was like, "Watch TikTok just randomly be the app that I go famous on. Not even like the YouTube that I spent two years trying to make. Watch this be just randomly." And he's like, "Yeah, that'd be hilarious." And then, like, it actually happens, and he texts me. He's like, "What the heck, dude!" And I was like-

Elissa: 93,000-

William: -"I don't"

Elissa: -followers now.

William: Yeah. I was like, "I don't know what's going on. I'm just sitting here in my hospital bed," so.

Elissa: Oh my gosh. You know, it's funny as I was researching about your story, and I see an article from the *Daily Mail* in the UK pop up-

William: Yeah.

Elissa: -all about your story and your video dancing with the nurses. And I was like-

William: Yeah.

Elissa: -"Oh my gosh. His story made it to England." I mean-

William: Yeah, yeah.

Elissa: -that's crazy.

William: Yeah. I had, I had two articles picked up by the *Daily Mail*. So, you saw that one and then one during my first diagnosis and stuff. Somehow, they picked me

up as the model cancer boy because I did modeling prior to becoming sick and that got to the UK. Super small story that wasn't a big deal, but then it was this TikTok one that really blew things up. And then so many of my followers are from the UK. It's kind of crazy to think about I have a bunch of friends across the sea, which is kind of nice, but yeah. It was a really cool experience.

Elissa: That's so fun. And recently towards the end of last year, you utilized this platform to also help LLS with Giving Tuesday and you were kind of the face of our national Giving Tuesday campaign which was really fun. Did a video with you. And how did that go for you?

William: That was fun. It was fun to actually compile all of the video that I had taken with my mom and, like, videos and TikToks and pictures. I mean we had, my computer that I'm on right now is just chock full of just old photos and stuff like that of me going through treatment. And I was like, "What better way to finally use some of this stuff that I've just been kind of holding onto, I guess you could say, to actually, like, push out into the world and try to help a good organization, you know." And so, and especially with The Leukemia & Lymphoma Society actually relates to me. It's something I care about. It's a cause that I want to support, so kind of a no-brainer sort of deal.

Elissa: Yeah. It's great that you've just continued to share your story and get it out there. I feel like just looking through your TikTok that you're really just trying to help and really connect with other young adults.

You posted a video that really struck me as a fellow cancer survivor, and you talked about feeling like damaged goods. What prompted you to make that video, and how did you move past that feeling yourself?

William: Yeah. Wow! So that was a video I made during my first remission, and I kind of brought up the topic the idea that when you're in a relationship you can tend to feel as the cancer patient as damaged goods or someone who's not really good

enough. It also goes along with the idea of just damaged goods, kind of not loving yourself, I guess you could say, and kind of viewing yourself as a bunch of baggage and a burden-

Elissa: Yeah.

William: -to another person.

Elissa: You'll always have that cancer label on you.

William: Exactly. And I hated that, and I really didn't know how I could get, one, the cancer label off me, which is something that I've been trying to shift away from. I still want to help so many people, but I want to be known for more than that, right? More than just my cancer label. And that is something I really faced during that first remission.

And how'd I overcome that? I think it was really just like an acceptance that, and really a notice that after I opened up to people about my baggage, they probably had just as much baggage to come back with. And seeing that and hearing that, even if their experience wasn't cancer or life or death, you know, maybe they had an abusive father, maybe they had an alcoholism issue, maybe, you know, there's something along in those lines that they're facing within themselves that is just as valid as what I'm facing. And so, then when you realize, like, oh, you know, we're just two people we're both damaged goods, why can't we just come together and make each other better? I just kind of changed my perspective on the whole idea and was like, "I don't have to view myself as this way. Like, I am valuable. I do matter, and I'm not damaged; I'm just different. And that's okay."

Elissa: That's a good way to look at it. I like it.

William: Yeah. Thanks.

Elissa: So, in addition to being a TikTok star, you are a star, 93,000 followers. You have a podcast called *The Illest.*, which Edith brought up earlier that you host with another young adult cancer survivor. So why did you want to start a podcast?

William: Yeah. So, my cohost is Roni Bibring. We made friends over Instagram at first, and we kind of just talked during my treatment. She's been a survivor for quite some time, but she's had a lot of post cancer issues with her muscles and her body and her bones and things like that. And so, we would talk for hours. And we had a lot of humor. We shared a lot of conversations that we felt differently from a male and female perspective but the same about in general. And I was like, "Why don't we take these conversations and throw them online and have people listen to them. And maybe they can learn from our experiences and maybe we can help somebody else." And she was like, "Oh my gosh, I would love that." And so, I was like, "Okay, let me try to figure out how we can make this happen. And we'll just record a weekly episode and see what happens."

And so that's what we kind of did. We kind of made up the name. We made like a Google doc, jotted down, like, a bunch of different ideas, a bunch of guests we could possibly have, different names for the podcast. I don't know if you've seen, like, *Between Two Ferns*, the Netflix show with like Zach Galifianakis. He makes fun of celebrities. I was, like, "We could call it, like, "Between Two Poles," like, "Two Cancer Patients," and, like-

Elissa: That's amazing.

William: -you know, so, yeah. Like, we really tried to come up with cool, creative ideas and we settled on *The Illest.* because we like the idea that, you know, in today's usage, it's for young adults. It's kind of, like, a cool term, right. It's you're cool, you're hip, you're with the times, but we were also ill at one point. We just agreed that we had similar humor and that we knew we had something important to say and, yeah, went for it.

Elissa: That's awesome. What's the response that you've gotten so between the podcast and TikTok videos from fellow young adult cancer survivors and patients?

William: We've gotten a lot of messages and a lot of people have reached out and talked to us. And they've been really appreciative of the episodes and everything. If someone reaches out to me and they're like, "Hey, I just got diagnosed. This is what's going on," I really try to push them towards the podcast and be like, "Hey, listen to this stuff. If you have questions or things else that you may want us to hit on, let us know." Because, obviously, if I have this swarm of people all needing help, I can't individually help every single one myself. As much as I'd love to just give them all a hug and personally tend to all their needs, I can't do that. That would drive me nuts. So, yeah, I usually drive them towards the podcast.

The response has been great. I think on Apple podcast we have, like, 5 or 4.8 stars or something like that. We've gotten a lot of good reviews and stuff from different patients and people. I have patient friends who've reached out and they're like, "Oh my gosh, this is the best thing ever." I've had past nurses reach out who've-

Elissa: Aww!

William: -told their patients about it and, like, they've listened to it themselves because they're excited to maybe hear their name in the episode. So, it's like, it's really funny to get everybody kind of involved. But, yeah, the response has been overwhelmingly good.

Elissa: That's awesome. I think there's something in particular about young adults with cancer that they just crave that connection with other survivors, and they crave that knowing other people are going through the exact same thing and that somebody-

William: Yeah.

Elissa: -else has experienced this particular thing or this particular thing. And you want to know that you're not alone in all of this.

William: Yeah. Another big thing was the clothes. I'm wearing a hoodie right now. Even just selling the T-shirts and stuff I think really helped make people feel more involved as well because - as soon as we released the merch, I felt like there was a lot more people who were, like, "Oh this is actually, like, a real thing. Maybe we can actually talk to them and ask our questions and they'll respond," and stuff like that. I think oftentimes we get faced with people that are very popular and, they're not going to treat us like humans. They'll just ignore us.

Elissa: Right.

William: But that's not really, like, Roni and I's case. Like, we're literally trying to talk to everybody and help wherever we can. And we take their questions into consideration and try to put them into episodes.

Elissa: That's really great.

Lizette: It could make you feel more connected too. Just, like, you see somebody on the street wearing something that you know, you're like, "Oh my gosh, you know, we have something in common."

William: Yeah, yeah, exactly. Exactly.

Elissa: Always trying to pick out those other cancer patients or survivors, like, "I want to be their friend. I just want to go and talk to them because-

William: Yeah.

Elissa: -they're like me."

William: There's so many Facebook groups out there that are patient centered, like, "We'll help you. We're a supportive group. We love, love, love." I joined a bunch of them, but I wasn't, like, loving the experience. I didn't like the idea of me having to type everything out and tell everything. I really liked the more video/audio format of podcasts, of TikTok, of Instagram. And so, I've really kind of shied away from the

Facebook group idea, though I think they are a very positive influence to some people, and I think they do help a lot of people. But, yeah, that was just my take on all of that.

Elissa: I don't know if you've been to CancerCon yet put on by Stupid Cancer. It's a young adult cancer conference for cancer survivors and patients from around the country, all different kinds of cancer, but about 40% or so blood cancers. And it's just so much fun to be in that room with 500 or 600 other survivors and patients who have been through the exact same thing. And you can talk to them and say something with so few words, and they just get it. They understand it, and you're like, "Aw, you know, night nurses, like, ugh!" "Ugh, yeah. Oh yeah." They're just, you know, and they'll just like go off about them.

William: Yeah, yeah, yeah. Go on a rant. Yeah.

Elissa: You just say one thing, they're like, "Yeah."

William: No. Yeah. I've not been to CancerCon. That's definitely a goal of mine. I have a friend, her name's Shannon, and she has been pushing me to go, and I just need to take the time and buy a ticket and go. So, I'm going to try to-

Elissa: Definitely.

William: -make that happen.

Elissa: Yeah, next time it's in person, you definitely got to be there. And LLS will be there so you got to go to the blood cancer seminar.

William: Heck, yeah.

Edith: On our patient, on our podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer journey, what would you choose to complete that sentence, "After diagnosis comes?"

William: Reality.

Edith: That's a great one.

William: Yeah, reality. Just realizing that you got to pick up all the pieces from where you left off, and the world is not going to hold your hand for that. And that you've had a lot of help along this way, but it's up to you to take responsibility for your life moving forward and every step of the way forward now that you're done with treatment. Cancer is something that happened to you, yes. It's something that happened to your life. It is monumental, it is life-changing, it is perspective changing, but try not to use that as a crutch. Try to use it as something that can help propel you forward and shoot you forward.

Elissa: That's great. Well, thank you so much, William, for being with us on the podcast today and sharing your story. And, also, thank you for all that you have done for LLS. We appreciate it. We love having you as kind of the face of our Giving Tuesday. This was great. And we're excited to see where you go with TikTok and your podcast and just anything in the future of your life.

William: Thank you so much for the opportunity. And, honestly, if there's anyone out there who gets to work with LLS in the future, seriously do it. It's an amazing opportunity to try to help more people, and the people you get to work with they're just as fun. So, thank you.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families. To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes. This is your opportunity to provide feedback and suggested topics that will help so many people. We would also like to know about you, and how we can serve you better. The survey is completely anonymous and no identifying information will be taken.



We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. You can also find information specific to young adults at LLS.org/YoungAdults. All of these links will be found in the Show Notes.

Thank you again for listening. Be sure to subscribe to *the Bloodline* so you don't miss an episode. We look forward to having you join us next time.