

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'A Young Adult's Journey Through Two Leukemia Diagnoses'***

#### **Description:**

Join us as we speak to John Falco, who was diagnosed with chronic myeloid leukemia (CML) in 2019 and then later diagnosed with acute myeloid leukemia (AML) in his brain in 2021. This incredibly rare second diagnosis changed the course of John's treatment and thankfully led to him achieving a complete remission after a stem cell transplant.

As a young adult professional, John was at the heart of his career at the time of his diagnosis and felt the pressure to return to normal, which meant returning to work quickly. He shares advice with other young adult cancer patients to slow down and enjoy life, while also listening to your body and advocating for yourself.

#### **Transcript:**

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

**Jesse:** I'm Jesse.

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

**Elissa:** Today we will be speaking to John Falco who was diagnosed with chronic myeloid leukemia, or CML, in 2019 when he was 29 years old. After diagnosis, he was given chemotherapy and oral medication, which he tolerated until a seizure brought him back to the hospital. At that time, he was diagnosed with acute myeloid leukemia, or AML, in the brain. He received an allogeneic stem cell transplant in October 2021 and has been in complete remission ever since.

Following his initial diagnosis of CML, he felt pressured to return to normal as a young professional in the staffing industry and went back to work not long after his diagnosis. However, after his diagnosis with AML, his career was once again put on hold due to cancer.

In this episode, John will share his struggles with work and career while being treated for two different leukemias. Welcome, John.

**John Falco:** Thank you. Thank you for having me, Elissa.

**Elissa:** So let's start with your diagnosis of chronic myeloid leukemia or CML. What were the signs and symptoms leading up to your diagnosis, and how did you end up getting diagnosed?

**John:** The way that I found out that I was diagnosed for CML in 2019 was severe pain in the chest on my left side and my shoulder and neck. I was on vacation. I flew home early because I was feeling terrible. I didn't sleep on the flight. It was a coast-to-coast flight, which I normally would sleep. And then when I got home, I called my mother, and I was like, "I'm in so much pain that if I don't go to the hospital right now, I feel that I'm afraid I can't call 911."

And so, she came and picked me up. We went to MGH [Massachusetts General Hospital] Emergency Room. And I remember just saying like, "Hey, I have chest pains." I couldn't even speak. They had put me in the Emergency Room and then eventually got me my own room.

What was causing all the pain was my spleen was enlarged and white blood cells were basically attacking my spleen. I stayed there for ten days as they diagnosed me for leukemia. But I was on a leukemia floor at MGH, so I kind of knew where things were going.

**Lizette:** Wow! And what treatments did you end up getting for your CML?

**John:** So, there I got a bone marrow biopsy, I got a lumbar puncture while I was there, drugs for pain for the spleen, and then I was given dasatinib to help. And that worked for about two years. I went back to normal routine after that.

**Lizette:** Sure. And that's an oral medication, right?

**John:** Yeah. And that's something to my knowledge that was within the last 10, 15 years.

**Lizette:** Yes, the first TKI, tyrosine kinase inhibitor, was approved in 2001 and that really transformed the treatment and life expectancy for CML.

**Elissa:** So you started with CML. How long did you have just CML before your diagnosis of AML?

**John:** I would say 2019 to 2021.

**Elissa:** Okay.

**John:** So, two years.

**Elissa:** Now let's move on to your subsequent diagnosis of AML. This came about after you had a seizure.

**John:** Yes.

**Elissa:** Could you tell us about the seizure? Was it the AML in the brain that caused it?

**John:** Yeah. This is all during the pandemic too, so I think that was part of the problem, right. I was getting TeleMedicine. I wasn't able to physically go in as much to MGH. Unless you had COVID-19, it was very hard to go in there. And I was having severe headaches and it was a pain in the middle of my eyes. It would cause my eyes to water. And this started in January. I would go to sleep almost at like 6:30, 7:30 at night after I finished work. I feel like I have a genuinely high pain tolerance, and I knew that it was something severe. And I think that's good advice, too, is like, you know, you always have to be your biggest advocate what your body feels.

So, I just kind of continued to reach out, but eventually I had a seizure on July 4<sup>th</sup>. I was staying at my mother's house. I didn't go out because I wasn't feeling well, and I

don't really remember the seizure itself. I was in my bedroom, and then I went into my bathroom, and my mom's fiancé said that I was talking gibberish and even combative. He had to knock the door down and noticed that I was having a seizure.

Took me to Lowell General Hospital. They did a spinal tap or a bone marrow biopsy, one of the two, and saw that it was cancer. Then I went to MGH and was checked back in for ten days where they ran a bunch of tests, and I went back to the leukemia floor that I was originally on in 2019.

**Elissa:** Wow! Had your oncologist known that you had been having headaches for months?

**John:** Yeah, they did. Yeah.

**Elissa:** And was there just kind of no explanation for it? I know a lot of times with young adults, we seem to have all these different symptoms and it's hard to get a diagnosis because, again, you are so young. So, what were their thoughts?

**John:** Because of how rare this is, it was kind of an afterthought. It wasn't something that was frequently diagnosed. The last person that they had was in the '70s, and they chalked it up to stress and sometimes the preventative drugs cause headaches; sinus, it was that time of year, the winter; the blue light, you're staring at Zoom a lot longer than normal because all your meetings are online. So, I just think it got put on the back burner, unfortunately.

**Jesse:** First I want to say sorry to hear what you've gone through. After they determined you had AML, did they discuss with you how that happened since you already CML? And could you please explain what it means to have AML in the brain?

**John:** Yeah. So, AML is acute myeloid leukemia. I think of it as a more aggressive form than chronic. And for it to go to the brain, that's all the pain that I was feeling. I don't know how it went from my blood to the brain. I remember having headaches

that were so bad and trying everything, cold compress, anything you would think of, Tylenol®, different stuff and it was definitely hard fighting through that.

**Lizette:** Right. And were there any treatments besides the stem cell transplant planned to treat the AML?

**John:** No. They were pushing me towards that. I sought a second opinion at Dana-Farber [Cancer Institute]. That was the advice that I was always given was to seek out second opinions. And they concurred, "You're not going to live long. You're not going to live 6, maybe 12 months."

**Elissa:** That must have been scary as you were 30 or 31 when you were told that?

**John:** Yeah. Yeah, for sure.

**Elissa:** Yeah.

**John:** I was shocked because I felt so good and then I also went through ten days in July and then I was back out working, hanging out with my friends. But the way that they articulated it to me was it was "If you want to live to your 80s and 90s, you need to do this stem cell, otherwise, you probably won't live within the year."

And even selfishly speaking, at the time, I was like, "Well, stem cells aren't always guaranteed and that's a lot to go through. Am I better off just being on a beach for the next 12 months or something like that?" I know that's kind of a dark thing to say, but your head is in a million different places. And I could see the person when I was talking at Dana-Farber, they were upset by that type of idea of not taking action. Like noticeably upset, crying and stuff.

I ultimately decided to do the stem cell. Did a Be The Match® program, which my company was nice enough to let me do at work, so a lot of my colleagues did the cheek swab.

**Elissa:** So, you did a donor registry event at work.



**John:** I did a donor registry event, yeah.

**Lizette:** Wow!

**Elissa:** That's wonderful.

**Lizette:** That is.

**John:** Yeah. There's a woman from-

**Elissa:** Aw!

**John:** -Rhode Island that came, and we actually had another young child come who needed it too. The two of us spoke in front of everyone and that was me also letting my company know what I had been dealing with. Some people knew, but that was me really letting the cat out of the bag. And I ended up using one of my cousins because of the timeline. I needed it as soon as possible.

**Elissa:** And your cousin was a good match.

**John:** They're considered a 50% match.

**Lizette:** Okay.

**John:** Which is funny because a stranger can be an 80%, 90% match, which is strange. So it's your parents are 50% and then first cousins are 50%. I'm an only child myself, so, obviously a brother or sister would be a good match as well.

**Elissa:** Wow! Now you brought up a little bit about the rareness of AML in the brain. Could you share with our listeners how rare AML in the brain is and what happened to you and what the response was from your treatment team?

**John:** Yeah. They were very transparent in how rare it was because I was, obviously, upset because I had been reaching out since January with headaches and when they're looking at the playbook, they're like, "We're not even really considering that."

Now I hope they are. I hope everyone is. That's such a rare thing that it wasn't something they were thinking that it could be a possibility at the time.

And I asked about examples or is there anyone I can talk to, and they hadn't had anybody that had gone through that. They were looking at books from the 1970s case studies and stuff like that and medicine has evolved so crazy. The stem cell is pretty recent to my knowledge. These drugs are recent. So, even if someone did something in the '80s, it's not necessarily how we would approach things now. So, I also looked at that as a little badge of honor of, "Okay, cool. I'm not only doing this for myself now. This is something that I hope will give someone hope. So, I looked at it as like a higher responsibility to go through.

**Lizette:** Sure. And how did the transplant go? It's usually very intense and-

**John:** Yeah.

**Lizette:** -there is time after the transplant, around 100 days or so, where you're really watched closely.

**John:** Yep.

**Lizette:** So, how did that go for you?

**John:** Yeah. So, what got me interested in the podcast in the first place, you did a I think it was like Dr. Holtan, and it was a podcast from a medical professional's perspective on what the stem cell entails. And I was like, "I got to talk from a patient perspective because I went into it, pretty blind I would say." I got diagnosed with it in July. I came out. I went to work for a little bit. And I knew that I was getting this procedure done in October. And what was crazy too, I had three matches that were strangers in the US. And they said, "No." And I was like, "What do you mean no?" "That's crazy. Can I talk to them? Can I interview with them? Like what's going on here?"

**Jesse:** Yeah.

**John:** I know when you typically you swab your cheek, you're doing it for a specific individual that you know. But just know that you may get that phone call one day and just be prepared for that.

**Lizette:** I can agree with you because I did the swab at The Leukemia & Lymphoma Society's Light the Night event one year.

**John:** Yeah.

**Lizette:** And I have been waiting for that call, and somebody just told me the other day that they might have taken me off the list because I'm so old. I actually didn't know that you can age out of being on the list.

**Elissa:** And they also say it's actually only 1 in, I think, 430 that are matches for people that will-

**John:** Right.

**Elissa:** -get called. But I think it is important what you said is that if you are signing up for this, definitely think about what you're doing because that is, what's going to save people when you do get that call. It's a little bit of your time and easy enough procedure to go through, but it is important, and it is saving a life.

**Lizette:** Yeah.

**John:** 100%. And I don't want to sound selfish, but it's not a kidney, people can do it. If you're in good health, you can do it. And I was just a little bit rattled by that. I was like, "Wow, three people." One person was like "Is it a kid?" And I'm like, I'm 30. You know what I mean, like I feel like a kid. I feel like I got a long way to go.

**Lizette:** Right.



**John:** But, anyway, so I knew I was getting that in October. And you would think you're going to Europe or you're doing stuff. But it wasn't like that. I had rigorous stuff getting me prepared for that. For example, I had to do radiation. I think I did eight rounds of radiation, which was pretty intense. And that was on my brain. I'm sure there's side effects from that. That was intense because you're in a mask and you can't move for, I think an hour. And it's just a sad place to be.

I remember when I went, I saw, children. And that also motivated me, "Okay, this six, seven-year-old is tough." And they were confiding to their mother like, "Mom, I'm going to be okay," I'm like, "Okay, I can handle this." Same thing goes for people that are 75, 80 going through this. So I looked to them as I got to be the strong individual coming in and out of this.

I went there for ten rounds, and I also did ten rounds of a spinal tap, which sucked. When they poke you in the back and they take cells out of your body through your spine, that was really, really hard. That was something that I never, ever want to have again, never want anyone to go through. I would listen to music, meditate, zone out. They give you a couple little drugs for anxiety. You could feel nerves in your legs. It was a weird sensation, but they basically clear the cancer out of you, they do the radiation, and then you go in for your stem cell. And the stem cell they told me would be about 30 days. And I went into that a little bit unprepared as far as expectations go for sure.

**Elissa:** So now that you've had the transplant what's going on with the CML? Are you still getting treatment for that?

**John:** Yeah. I'm taking ponatinib.

**Lizette:** And how are you doing with the ponatinib?

**John:** Good. I'm doing real good. I mean initially after the stem cell, I was taking a lot of stuff that has to do with graft versus host, but I'm not taking that stuff anymore.

**Lizette:** Sure.

**John:** So it's just this. And my platelets are at 140,000 right now. A normal person is at 150, from what I was told, 150 to 750. And sometimes that medicine can knock those down, but mine's been going up, so.

**Elissa:** Do you have to end up getting a platelet transfusion?

**John:** I had a couple. When I went in for the first time, I was at 6,000, so I got a couple then. But they're hard to come by, so that's a good point. If you can donate platelets, do that. My mother wanted to donate to me, and they told her, if you donate these, there's too many other people that are higher priority that it would go to. So, it seems like they were like a scarce resource, to be honest. So, yeah, if you're able to donate platelets, definitely. And now I'm in remission.

**Elissa:** That is wonderful that you are in complete remission. Now I'm sure that was quite the experience to have two cancers. Now as a young adult, you were in the heart of your career at-

**John:** Right.

**Elissa:** -the time of your initial diagnosis. What was the timeline in going back to work after finding out you had CML?

**John:** So CML, nobody even noticed. I was in Arizona for vacation and then I was in the hospital for ten days, so people probably just thought I extended my trip. And then I came back, and I told a couple people. I was really close to a lot of my colleagues, so I had visitors. They knew. But, yeah, I didn't look different. I went about my business.

And eventually it started to leak out. It was a company where everybody was really close. It started to inspire a lot of people, which I thought was really good. I went back to work, business as usual.

My platelet count was still pretty high. And I felt great. It was the best I felt in probably a year because I was dealing with this undiagnosed for probably a year. So, I was always kind of feeling lousy. And you don't know if that's depression or if it's exhaustion or what, it sounds weird to say, but I was relieved when I was like, "Oh okay, that's not how I should normally feel,". And then once I got this pill to knock that down, I felt like a million bucks when I went back to work.

**Elissa:** Now young adults often are really wanting to feel like they're returning to normal.

**John:** Yeah.

**Elissa:** Did you feel like that? Did you feel pressure to get back to work?

**John:** Yeah.

**Elissa:** "I've gone through those initial dealings with the starting treatment and now I just need to get back to my life." What was that like for you?

**John:** For sure. And I think, in my 20s, I was always grinding. Like I said, I was in sales. So there is parts of my time where it was like it was a badge of honor not to take time off. You work 7 to 7. We're in Boston where we don't even see sunlight. And everything that I was doing was for John Falco in his 40s to have financial independence, to set my future family up to go to private school if you want to, take vacations if you want to. And I felt like my 20s were dedicated to a grind.

And when I was given that card of, you may not live till you're 32, that changed my whole perspective of there's got to be a happy medium here. There's got to be some travel. There's got to be, shut it down when you want to shut it down. When you don't feel good, it's okay to rest. Coming into work sick, all that type of stuff and we learned that all, obviously, with the pandemic too, but my priority shifted.



When I thought that my life would be cut short, the two things that I was really thinking about was, I've always wanted to start a family. And I did a bunch of things to check boxes like buy a house, financial independence. And if my life were to be cut short, I wouldn't've had the most important thing and that's the people that are involved in that.

And I hardly traveled because, like I said, you're grinding. Now I'm very much more conscious of that.

Same thing with exercise, too, making time for my health throughout the day what I'm eating. Not overdoing it when it comes to drinking and all that other stuff.

**Elissa:** Yeah, that grind tends to start to look a little different with something like this. I think young adults in particular, in their 20s and 30s, think that they have so much time and they can set themselves up for retirement in their 60s and 70s, and they can go live their life then. And for right now, it's setting everything up, grinding as hard as you can, not taking as much vacation. And then something like this happens.

**John:** Yeah.

**Elissa:** And it changes your entire world view that, wow, I didn't think that there was even a possibility I might not make it past my 30s. And what have I done with my life? How do I live my life now?

**John:** Yeah. What would people say about me was one of the biggest things I thought of. What would people say? That I was good at my job? Did I hold the door for people? Did I do something from a philanthropy perspective that really made an impact on someone? Did I teach someone something? And that's kind of how I've been thinking about life now.

The why behind what I'm doing, where I am, how important time is, where you spend it, who you spend it with. Less about chasing. One of my friends says, "chasing the

dragon," but anything that's trying to get likes or materialistic stuff. That stuff just doesn't matter.

**Elissa:** Yeah. And as an AML survivor myself, I would say one of the best things that I learned is to really take the time and stop and smell the roses.

**John:** Yes.

**Elissa:** And find ways to enjoy your life and just slow down. Slow down and enjoy the everyday things that this world has to offer. I think it's really important.

**John:** Yeah, and when I got diagnosed with CML, the way that I articulated it from a young adult perspective is on any given day, I would be stressed about probably 25 to 30 things. And that could be the dog, the house, what I'm paying for, my car, my friends, my dad, my mom, a girl, maybe a text or how my friends are doing. And then you have another 10, 15 things that come with being in the staffing industry that cause stress.

When you're diagnosed with something like that, everything just shrinks; and there's only about five things that are truly important. I just try to keep that in mind. Don't let stressful stuff, negative stuff, really get into your mind and bog you down. I feel like a lot of young individuals deal with that, cancer or not.

**Jesse:** As a person who worked in a similar industry as you, I can relate to everything that you're describing – the long hours, the stress, the quotas, always wanting to outdo the month before and that pressure that goes with it.

So, what was it like working during your treatments? Did you have any time that you took off from work? Was your employer supportive and accommodating during that time?

**John:** Yeah, they definitely were. 2019 was the CML. So, two years of that, and every Wednesday, I was getting checkups, getting blood drawn; and I was an



outbound salesperson. So, I had my clients, and I was also a sales manager at the time.

**Jesse:** Oh, a lot.

**John:** So other people stepped up. Yeah. One of my friends would just step into my shoes on the client side in managerial; and I never felt pressure to get back to work. I also felt great, so that was a very different time.

When it comes to the AML, I feel like I came back to work from the stem cell way too fast. I remember going to my checkups, and they're like, "Are you working?" And I'm like, "Yeah." And they're like, "Full time?" And I was like, "Yeah."

**Elissa:** Ooh!

**John:** Yeah.

**Elissa:** And how fast after your transplant?

**John:** I was back January full time, and my transplant was in October.

**Elissa:** So three months?

**John:** Yeah.

**Elissa:** Oh, wow, so pretty much right after your 100-day mark.

**John:** Yeah.

**Elissa:** You're like, "I'm going back right now."

**John:** Yeah. I was remote because we had a very hybrid remote model with COVID and everything. And the reason why I kind of felt the pressure to go back is because of the way that my commission was structured was, once you come back full time, we'll give you the full commission versus while you're out, you're only getting a smaller



percentage. So, I was kind of leaving money on the table by not coming back; and like I said, I came back a little bit too soon I would say. But that was me putting pressure on myself.

**Jesse:** Yeah, which makes sense.

**Lizette:** Yeah, but did you work with your doctors? Did they give you the green light to go back to work?

**John:** Not really, no. They were like, "Go back in April, dip your feet in." But I was looking at four walls for 150 days. You know what I mean? So even me jumping on a Zoom meeting with my colleagues was so refreshing.

And I had been at that company for six years; so, I had my repeat customers. I wasn't heavily cold calling when I first came back. I was maintaining relationships more than anything.

**Elissa:** That's crazy. You and I had different treatments; but I think I took six months to even go back even part time, and I was exhausted after four hours.

**John:** Yeah.

**Elissa:** Barely driving home afterwards. That's, wow, full time after three months.

**John:** Yeah, and like I said, I would do that differently; and I would advise that differently.

**Elissa:** Lesson learned, so hopefully all the young adults listening right now don't do that.

**John:** Yeah. And retention on information was very challenging for me-

**Jesse:** Yeah.

**John:** -throughout the whole time. I remember when I went into stem cell, I had all these plans of like, "I'm going to ride a bike. I'm going to read books." A lot of people gave me books. I was going to write movie reviews. I was going to maybe write a journal, and that just goes out the window when you're just like fighting for your life.

The two things that I would give advice on for the stem cell that was very helpful for me, a nurse told me to dress normal every day. Put clothes on. I'd wear jeans and a T-shirt, polo, sweats, and sneakers and try to walk every day. Those were my goals. Those are the biggest things that I was trying to get accomplished and talking to people over the phone as I could.

**Elissa:** Yeah, it's kind of the same mindset of when we were all told to work at home during COVID, right? "Get dressed every day; and get out, do things, go walking, even if you can't be around people." It's important to still have that normalcy in your life and still feel like you're doing something rather than just laying in bed or sitting on the couch or things like that.

**John:** Yeah. My friend's dad asked me, "What was the biggest thing that we take for granted?" And I answered very fast, "Fresh air." I had no fresh air when I was at MGH. I couldn't open the window, and I remember thinking, when my mom picks me up to take me home, I'm going to stick my head out the window like a dog in this car. Now, every time I'm outside, I'm like, "Oh, my gosh, thank God that I'm able to do this." And I think that that's something we take for granted on a day-to-day basis.

**Jesse:** Absolutely.

**Lizette:** Yeah, and you had two totally different types of treatment. You had an oral medication that you could take at home, and then you went all the way to a transplant, which, your immune system is at a place where you do have to be housed because we don't want you to get any type of infection. And then this was going on through COVID.



**John:** Yeah, no one could visit me. I had my mom and my dad and then my friend, Nick. Those were the only three people that could visit me, and it wasn't as frequent as it was when I had done my ten days in 2021 and then my ten days in 2019. It was a man and his thoughts for sure.

**Elissa:** Wow. Now you just celebrated your one-year rebirthday post-transplant, which is so exciting. So, you returned to work, obviously, very early. And so how is life now though? You returned to work almost a year ago by this point. So how is life?

**John:** Life is good. I'm thankful for a lot more. I have a very different perspective and initially coming back, that perspective, I think like my leadership team had to adjust to that. I wasn't just motivated by the carrot that you are in sales. And I definitely wasn't motivated by the stick. So, it was like, I want to feel something. You don't have to get up every day and say, "This is awesome." But I want mentorship. I want to inspire someone. I want to coach someone. I want to feel fulfillment in what I'm doing on a day-to-day basis. Less about the financial gain, but more about how you feel and helping other people.

And also, if I want to walk the dog. I was able to see the benefits of exercise and vitamin D and factoring those in every day. Like working out, I was 210 when I went in; and then I came out at 150, so that's a lot of weight.

**Jesse:** Oh, wow.

**Elissa:** Wow.

**John:** Yeah, a lot of weight. I was like slowly walking farther and farther. Started out with one pushup. Slowly getting to be able to work out. I never want to lose those things. Factoring that into my day and finding a company and leadership that is, "hey, I'm going to take a half hour to walk or walk the dog". What is important? What are we working towards? What's the why? How am I spending my time?



**Elissa:** Yeah, it's amazing just what we take for granted, particularly when we're young. And then, something happens that throws you in a different direction; so that's really important.

Now one final question. On our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." Based on your experience with two leukemias and a bit of a roller coaster for your career during treatment, what advice would you give to fellow patients who are of working age to give them hope after a diagnosis of cancer?

**John:** Like I said, get dressed and walk. That's advice for anyone. I'm an only child. I always wanted to be the strongest person. I felt like I needed to tell everyone, "I got this, I got this," because I didn't want my friends to worry. I feel like I'm always the person that my friends go to when they need something or they're down. And it's okay to just show some vulnerability, I think. Talk to someone, seek people out that are going through what you're going through. And it's okay to rest. Don't jump back into things. Focus on your health.

And then, plan on being okay. I think that the effects that your mind has on your body we don't know enough about. And I think me staying so positive all the time and setting goals of I'm going to walk and different things like that really helped me. Music really helped me. Just listening to music. I remember I had expectations of reading. That wasn't information that I could retain, but music inspired me to move forward. And I found a newfound faith in prayer.

Just talk to yourself in a positive way. Don't let negative things impact you. Gravitate towards people that are positive. I remember a nurse was my age, and she came in and she would talk to me like I was a normal person, like we were friends. And we caught up on stuff that had nothing to do with treatment; and that went a long way.

I feel like when I came into this podcast, I was like, "Okay, there's three audiences, medical professionals, family members and friends, and people that are going through

this. So, I hope that if I can provide any advice or inspire someone, then it's all worth it.

**Elissa:** That's wonderful.

**John:** One thing I just wanted to say too. One person that really inspired me, obviously, my parents. My mother lived with me for the 150 days. I got a two-bedroom in the West End which is walking distance from MGH. She had her own bedroom, her own bathroom. She did everything. If I got up and I fell, I mean everything, grocery shop, sanitized the house, helped me with my pills. You need somebody like that; and, I had money coming in financially; but I never had to log into everything. She logged into everything. She made sure the payments were good. Everything was business as usual. My dad was checking in like crazy. You know, would have been here if he could; but, yeah, it was hard. I spent holidays alone. I spent New Year's Eve alone, and that's actually, one thing that is really important from a young adult perspective with Instagram and everything; you're constantly seeing everybody out and about.

I mentioned New Year's Eve, and that's what made me think of it is like the world's moving so fast. And when your life's on pause, it's so hard to be like, "Oh, is that person thinking of me?" So, if you're a friend or family member, just calling that person goes such a long way. And that was really hard. That felt like forever to me, that time where I couldn't leave the house.

So that would be other advice is look to someone to, that you want to emulate. And for me, that was Chadwick Boseman from *The Black Panther* and, when I found out that he passed from colon cancer, that was the most shocking thing to me, from a celebrity death I would say, that had the most impact on me.

And biggest thing that it had was, even if he didn't pass away from cancer, he'd taken on these roles for the African American community, the first real superhero that's the main focus, Black Panther. And to go about your business that whole time knowing

that you're fighting this and executing grace. What he did for the Children's Hospital, speaking at the HBCUs [Historical Black Colleges and Universities], that to me is how I want to conduct myself. I always want to conduct myself with grace, strength, and I don't want anyone to look at me like, "Oh, he was sick" or "That's great that he did that because he was sick." This is the person I am. Sickness is part of it, and I'm thankful for it from the perspective. But he had a very, very big impact on me.

**Jesse:** Thank you for sharing.

**Elissa:** Well thank you so much, John, for joining us today. We really appreciate you sharing your very interesting story with CML and AML on the brain that just turned out to be so rare. So, we really appreciate you and, of course, sharing all about what it was like working with cancer, what you learned, what you could share with others, and the way that it has changed your life.

**John:** Right.

**Elissa:** So, thank you again for being here with us today. We really appreciate you.

**John:** Yes, absolutely, and thank you, guys. Thanks for everything you do; and I can provide my contact information should anybody need it. Like I said, that goes a long way, talking to peers and everything, so I appreciate what you guys do.

**Elissa:** Absolutely, thank you.

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 or at [TheBloodline.org](http://TheBloodline.org). 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.

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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](https://LLS.org/PatientSupport).

You can also find information on chronic myeloid leukemia or acute myeloid leukemia at [LLS.org/Leukemia](https://LLS.org/Leukemia). You can find information on work and school after a cancer diagnosis at [LLS.org/YoungAdults](https://LLS.org/YoungAdults). All of these links will be found in the show notes or at [TheBloodline.org](https://TheBloodline.org).

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