The Bloodline with Blood Cancer United Podcast

A podcast for patients and caregivers

Episode: 'Chronic Myeloid Leukemia (CML): Four Olympics, One Unexpected Diagnosis'

Description:

In this episode, four-time Olympic downhill skier AJ Kitt shares his diagnosis of chronic myeloid leukemia (CML) and how revolutionary medical advances transformed an unsettling diagnosis into a manageable part of his everyday life.

AJ opens up about the initial shock of the news, the emotional toll it took on his young family, and how finding CML pioneer Dr. Brian Druker restored his confidence amid deep uncertainty. The conversation dives into his treatment with tyrosine kinase inhibitors (TKIs), the vital importance of self-advocacy, and how he continues to thrive as both an athlete and a ski coach. Tune in to hear why AJ believes that access to reliable information is the ultimate game-changer for anyone navigating a new CML diagnosis.

Transcript:

Elissa: Welcome to *The Bloodline with Blood Cancer United*. I'm Elissa. Thank you so much for joining us on this episode. Today, we will be speaking with AJ Kitt, a four-time Olympian downhill skier who was diagnosed with chronic myeloid leukemia in 2016. Under the care of Dr. Brian Druker, who developed Gleevec®, he went on treatment immediately and has been on two different tyrosine kinase inhibitors, or TKIs, since his

diagnosis. Though he is now retired from skiing after four Olympics, 12 World Cup podiums, and four national championships, he has been able to thrive while living with leukemia and still coaches in Colorado during the winters. Welcome, AJ.

AJ Kitt: Good morning. Thank you. I'm happy to be here.

Elissa: Well, thanks for being here with us. So, let's start with your diagnosis of chronic myeloid leukemia, or CML. Could you tell us how you ended up being diagnosed? Did you have any signs or symptoms that brought you into the doctor?

AJ: Well, probably like everyone that's diagnosed with something like this, it came unexpectedly. I probably was experiencing some symptoms but didn't know it. I obviously wasn't looking for anything like that. It was purely by accident. I mean, I had gotten sort of the typical, you know, winter flu symptoms one winter and because I hadn't been to my family doctor in so many years, they couldn't just squeeze me in right away. They had to set me up for a whole new patient exam, which takes longer. So, the appointment was further out. I had to wait, like, six weeks. I got in there and met with the doc and he did all the examinations and interview, and he kinda noticed something unusual in my abdomen, and he felt like my spleen might be enlarged. And so, we did the typical blood work, and then he sent me out for an ultrasound on my abdomen to find out what was going on. I mean, at the time, I would call myself probably a moderate level drinker, maybe a little bit more, depending on if we were celebrating something or whatever.

Elissa: Yeah.

AJ: And so, I thought, "It's gotta be my liver. But it turns out that he brought me back in later that week for the results and he said, "Everything in your blood looks great except you've got leukemia." And he pretty much put it-

Elissa: Wow.

AJ: -that way. It was matter of fact, and it was a total shock. And yeah, I mean, that was the moment when everything changed.

Elissa: I feel like that's really common. You go in when you're thinking it's something else, anything else, and then they're like, "You have a blood cancer."

AJ: Yeah. Yeah. I was expecting anything and everything, but that didn't include cancer, to be very honest with you. You know, I wasn't anticipating that at all.

Elissa: Yeah.

AJ: But yeah, there's no doubt there was a lot of things spinning in my head, all the what ifs. But that was nothing compared to the way my head spun after I got the diagnosis because it was a Friday afternoon, he basically gave me the diagnosis, told me that there's a hematologist here in our small town of Hood River, Oregon, who I could call on Monday and set up an appointment to go get further evaluated and discuss treatments. Meanwhile, I'm thinking leukemia, I'm a dead man. You know, I've never heard of anybody surviving-

Elissa: Oh, yeah.

AJ: -leukemia, which didn't mean anything 'cause that wasn't like I studied leukemia patients. And so, I went home, told my wife. Total shock, of course. And it wasn't really

very easy getting in to see the local hematologist. I believe we called them on Monday, and they said, "Oh, we don't have a hematologist that works in our hospital anymore." We're a small town, so a-

Elissa: Yeah.

AJ: -small hospital, probably one hematologist in the entire town. And they said, "Oh, they've been reassigned to Portland."

Elissa: Oh, gosh.

AJ: So, I called the-the Portland clinic and that woman was there that said something to the effect of, "We can't get you in," I was just shaking the trees trying to figure out what to do next, talking to everybody I could talk to and trying to learn as much as I could.

Elissa: Yeah. That's a lot when you're trying to figure out where to go next and not having a whole lot of guidance.

AJ: Yeah. Yeah, yeah. And in the age of-of the internet, that's a dangerous undertaking to go and try to-

Elissa: Yes.

AJ: -find out what CML is all about on the internet.

Elissa: Oh, yeah.

AJ: I have a close friend who's retired now, but who's a physician in town, and I leaned on him a lot, and he explained to me that there's this doctor in Portland at OHSU (Oregon Health & Science University) who developed a drug about 20 years ago, and

it's been pretty successful. But he didn't know a whole lot about it either because he was an ER physician, so his-

Elissa: Yeah.

AJ: -specialty and focus wasn't on blood cancers. And so, I was ski coaching in the wintertime, and one of the athletes that I was coaching, her mother is close friends with Dr. Druker's wife.

Elissa: Oh.

AJ: And a couple of days into this whole thing, she approached me and gave me a number and said, "Here. email your labs to Dr. Druker. He's expecting to see your labs." And so I did, not really knowing what I was getting myself into. At this point, I knew who he was. He was the guy that developed the drug.

Elissa: Yeah.

AJ: But I didn't know I was getting a backstage pass, so to speak. And he responded immediately. He called me, and he said, "Listen, I've got your labs here. I've seen where you're at, and I set up an appointment for you this Wednesday at my office. See you then. We're gonna take great care of you."

Elissa: Great.

AJ: I was like, wow. I felt like I was getting a hug suddenly, but I still didn't really know much about what any of it meant. I didn't know was I in stage one, stage four. Were there even stages to leukemia? I still didn't know anything, so we were still on that journey of-of figuring stuff out.

Elissa: Yeah. So, you and I had met a few weeks ago at an event held by OHSU, the academic research hospital in Portland, Oregon, where Dr. Druker is, and you were speaking with Dr. Druker to celebrate the 25-year anniversary of the Gleevec approval. And I remember that you got kind of choked up when you spoke about how your children were young when you were diagnosed. What was that emotional impact for you and your family after hearing that you had leukemia?

AJ: Well, I mean, I can't really overstate it, to be honest. Like I said before, you think death sentence.

Elissa: Yeah.

AJ: You know? It's like how long do I have? What do I need to do to get my affairs in order? And I certainly did a lot of that stuff. But my kids were little. They were, like, 10, and I wasn't sure how to tell them. In the end, my wife and I decided we weren't gonna tell them right away because, A, we didn't really know what we were talking about.

Elissa: Yeah.

AJ: We didn't know what the prognosis was.

Elissa: Mm-hmm.

AJ: And-and they were 10. We didn't know what they knew about cancer, right? The C word. How they were gonna react, and we didn't want them to react in a way that was unnecessarily severe. So we just waited to talk to them about it. But I mean, personally, it was really tough. It's like the last thing you wanna do is leave your kids behind. I mean, when you're a father, you know-

Elissa: Yeah.

AJ: -your primary job in this world is to prepare your kids to be independent and to love and nurture and all that kind of stuff, and at 10 years old, my job wasn't done, and I didn't feel like it was gonna be okay for me to leave them behind and leave that job unfinished. So, that was really hard.

Elissa: Mm-hmm.

AJ: -Obviously, there's a ton of things that your kids go through after age 10, between then and when they become, adults and, you know, college, marriage, kids maybe, all that kind of stuff. And on a personal level, I didn't wanna miss that, but on the other side of it, I didn't want my daughters to, walk down the aisle without me. I didn't want my grandkids to grow up without a grandfather or, you know, that kind of stuff. So yeah, all that stuff just bombards you.

Elissa: Yeah. Did that help once you met with Dr. Druker and found out more of the realities of what CML was and what the treatment looked like and the prognosis? Did that help with the emotional impact and also talking to your children?

AJ: Well, yeah, of course. We went through this when my wife was pregnant. We have triplets, so we had a high-risk pregnancy. And of course, doctors don't wanna give you false hope. It's all, "Here's what the clinical research says your chances are of, you know, making it to full term with triplets or surviving CML."

Elissa: Yeah.

AJ: So, none of it was guaranteed, but at one point Dr. Druker said to me, "You're gonna die from something else." And that was good enough for me. You know what I mean?

Elissa: Yeah.

AJ: It kinda said, "You're gonna live probably a normal lifespan. This leukemia is gonna affect my day-to-day a little bit, but it wasn't something that I was really gonna suffer terribly from. And that sorta changed everything as far as my long-term outlook. When we did finally decide to tell the kids, when they got into middle school age, we thought, "Okay, there's enough people around town that kinda know about this, adults, friends of mine who've got kids that they're in school with."

Elissa: Yeah. They might hear it.

AJ: We don't want them to hear about it from somebody else, and they be like, "Wait a minute-

Elissa: Mm-hmm.

AJ: -my dad doesn't have leukemia. He would've told me." So we sat them down, and we told them, and we did it at dinner one night. My wife and I talked about it, we planned on it. And so we were, like, in the middle of dinner, and I said to the kids something to the effect of, "Hey, you guys, you know when I gotta go to Portland every once in a while and go see a doctor, or I gotta go get my blood drawn?" I've talked to them about that part of it, but they never asked why. I said, "Do you know why I do

that?" They're like, "No, why do you do that, Dad?" I'm like, "Well, 'cause I have leukemia."

And nobody said anything, and I thought, "Okay, this is the moment where they're all kinda trying to figure out how they're gonna react." And I said, "I've had it for, at this point it was five or six years, and I'm getting really well taken care of. There's medicine for it, and it's not really affecting me day to day." And again, pause, and one of them was like, "Hey, pass the ketchup."

And I don't know if that's exactly what they said, but it was something to the effect. You know-

Elissa: Yeah.

AJ: -it let me know that they were more interested in what they were eating for dinner than whatever this leukemia news was all about. Because I think they felt like we conveyed the information in a way that they knew that it wasn't something that was dire. And so, we were glad we waited.

Elissa: Yeah.

AJ: But, you know, they did not hear about it from anybody else, so that was good.

Elissa: That's good. And especially as they're seeing over the years that you're seeming healthy-

AJ: Yeah.

Elissa: -you're doing well, and so they can already see that this is an okay thing that they can-

AJ: Yeah.

Elissa: -deal with.

AJ: Yeah, yeah, exactly. I think all that information lined up, and it wasn't like I was down to 120 pounds and looking really unhealthy when I told them, which would've probably closed the loop on a bunch of questions that they'd had. They were, um, pretty-pretty sure that I was healthy at that point, which I was.

Elissa: Good. So, let's go then into after the diagnosis. So, you met with Dr. Druker. What treatment were you put on and how often do you have to go in for checkups?

AJ: Yeah. So, he put me on Gleevec right away. My blood counts were, like, 180,000, which is high.

Elissa: Yeah.

AJ: I don't know if that's super, super high. I know normal's around, I think 4,000 or 5,000 or 6,000. So it was, you know, high. And, they were looking for my numbers to come down to, like, under 20,000 pretty quickly. And they didn't. My numbers came down a little bit, and they continued to come down, but it wasn't like they jumped all the way down to 20,000 or less. And they let me know about it. At this point, I was probably getting my blood done every week or two for the first six months or so, and then it transitioned to more, like, monthly, and now I'm quarterly. I do a blood draw every-

Elissa: Okay.

AJ: -three months and get on the telephone with Dr. Druker every three months. But, yeah, the numbers came down and got better. I don't know if I ever got below, like, a zero number. I may have been down in, like, the below one, which at this point they're not looking for my white cell count, they're looking for the actual leukemia number to be down below a certain point.

Elissa: Yeah.

AJ: The presence of leukemia cells. And all of a sudden my numbers started going back up.

Elissa: Oh.

AJ: And at that point, Dr. Druker knew what was going on, he'd seen it before, that the cancer had sort of developed a resistance to Gleevec.

Elissa: Yeah.

AJ: For a certain number of patients, the cancer sort of mutates and it creates a resistance to Gleevec. So, they've got another drug-

Elissa: Mm-hmm.

AJ: -that they've developed because Gleevec was originally developed for this. They were like, "Oh, here's a way we can improve this to make it better." And so, they put me on the next level of drug which, bam, I mean, immediately my numbers were below zero, below 0.1. And now I'm undetectable.

Elissa: Very good.

AJ: So SPRYCEL® or dasatinib, is this-this second drug that I've been on. I know people that are CML patients that have been on Gleevec, and it's worked for them great, and they've been on Gleevec for 20 years.

Elissa: Yeah.

AJ: And I know others that are like me that-that were on Gleevec and it didn't work, and they've been on SPRYCEL for 20 years now. And I know that there's cases where they have to keep putting people on more and more extreme and sophisticated, drugs that have a little bit more side effect risk with them, and I'm fortunate that my side effect risk is pretty low and I don't really notice it much in the way of side effects.

Elissa: Oh, that's good. So, you're not really having any or just kind of some minimal ones that don't really bother you?

AJ: It's hard to know if it's a side effect or if it's just aging.

Elissa: Oh.

AJ: So, that's how minimal that I feel like it is. I mean, my back hurts and my eyes are getting worse.

Elissa: Yeah. Yeah.

AJ: Sounds like aging, right?

Elissa: Yes, that does sound like aging.

AJ: Yeah.

Elissa: Well, that is good to know. So, was there a discussion with Dr. Druker when you were in there about how treatment and monitoring will go for the rest of your life, and what that will look like?

AJ: Yeah, I mean, the optimal scenario is that we take me off of the therapy altogether and see if the leukemia will sit and stay. He tells me that with about 50% of patients that they take off of therapy, it works and they stay off of therapy indefinitely. And for other 50%, the numbers go back up, put them back on the therapy, and the numbers go right back where they're supposed to be. So, I figure worst-case scenario, if I've gotta stay on it, it seems like it's working okay, and it's not hurting me, so-

Elissa: Yeah.

AJ: -I'll take it if I have to.

Elissa: How do you feel about the possibility of going off? Do you feel like that's something that you want to try?

AJ: Mixed. Oh, yeah, I wanna try it, but I'm still of mixed emotions.

Elissa: Yeah.

AJ: It's gonna be a scary time. It's probably like a little kid who's learning to swim, and he's got his little swimmies on his arms. Everything's great, and he's swimming around and everything's cool. He can't swim as fast as his friends, but he's still swimming.

Elissa: Yeah.

AJ: And they take the swimmies off, and it's like, okay, can you swim or do you need your swimmies back on again? You know what I mean?

Elissa: Mm-hmm.

AJ: That's kinda how I feel.

Elissa: Would you have extra monitoring if you had to go off?

AJ: Probably. I can only assume. We haven't really gotten into it. We talk about it every month, quarterly call we have, we talk about going off, and I start to anticipate, "Ooh, we're gonna go, you know, next time." And we don't, you know?

Elissa: Yeah.

AJ: He's keeping an eye on the numbers, and when he thinks we're ready.

Elissa: Yeah.

AJ: -but, yeah, I'm sure when we have the discussion of, "Okay, here's how this and this," and that when we get really into it, I know we're pretty close. But-

Elissa: Mm-hmm.

AJ: -at this point, it's all promises.

Elissa: Yeah. Yeah. We'll see how that goes. And I assume that your numbers probably just have to be pretty stable for a while before he feels comfortable with really looking into that.

AJ: I think so, and I don't know what that exactly means.

Elissa: Yeah.

AJ: My numbers have been very consistently below detectable range for a couple of years anyway. And he told me from the beginning, "I want you to be undetectable for several years before we try this." So-

Elissa: Yeah.

AJ: -maybe I'm partway there. But yeah, I mean, I'm ready for it.

Elissa: Good. All right. So let's move on to living with leukemia. Do you think about it often, or ever feel like it holds you back from living the way you want to? I know you've been so active as a skier all of your life and now as a ski coach.

AJ: Yeah, I don't think about it at all. I mean, I think about it every morning when I-

Elissa: Have to take a pill.

AJ: Yeah, I guess it's morning. Uh, yeah, I take it in the morning. Take my pills in the morning. But that's really the only time I think about it during the day because there's no other reason to think about it. I mean, I don't have any side effects hat remind me. I haven't changed my lifestyle because of it.

Elissa: Mm-hmm.

AJ: I quit drinking four years ago just for health reasons. But I always check with-with Dr. Druker. I'm like, "Hey, should I quit drinking?" He's like, "It's not gonna change anything with the way the medicine works with leukemia. It doesn't make leukemia worse if you drink." So, he was honest and fair with me about that, so that was a lifestyle change I made on my own. But otherwise, nothing's really changed. I don't really have a day-to-day thing which is great.

Elissa: That's really good, though, that you're talking to your doctor about potential lifestyle changes and if that would make a difference with the leukemia or with your situation. So, that's really good that you're communicating with him.

AJ: I mean, I think you have to, and if you don't, you're not being your own best advocate. -

Elissa: Exactly.

AJ: The most poignant thing that I was told by my buddy that's the ER physician, when I was like spazzing out trying to gather information, he's like, "Start a book. Get a three-ring binder, put all your reports in there, every piece of paper you gather," you know, "Be your own best advocate," is what he told me. Like, "Do your own research, keep your own records, carry it with you every time you go see a doctor, and if they're asking you about your medical records, you've got them in your hand," you know? Nowadays with all the online, you know, charting stuff, everything's in my phone anyway, so I don't have the booklet anymore, but I did. If you're not doing everything you can do to be healthy, then what are you doing? You know what I mean?

Elissa: Yeah.

AJ: Like, I'm trying to eat as healthy as I can. I'm trying to get as much sleep as I can. My wife gives me a hard time because I'm constantly paying attention to all these, you know, the latest and greatest dietary supplement that's gonna be good for this or that. And I'm thinking pretty good about filtering out the stuff that's nonsense. But I'm willing to try stuff as long as it's not a major risk. And anything that is, like, I had some injections in my lower back years ago because my back is destroyed from ski racing, and I called up Dr. Druker, and I said, "Hey, I'm about to get PRP or platelet-rich plasma injections in my back. Is that gonna disrupt the dasatinib treatment? He's like,

"Nope. Go ahead and do it." So, I feel like you have to be your own best advocate's the best way to put it.

Elissa: Very good. Always important.

Now, you said you waited several years to talk with your kids. How was that first several years just between you and your wife as you navigated this diagnosis in the beginning?

AJ: Well, I mean, in the real beginning, every week we were looking at numbers. Every week we were talking to the doctor.

So, when I got that diagnosis from my family doc and I went in on that Friday and he told me, "You've got leukemia," he goes, "We're gonna take more blood. We're gonna do some follow-up testing." They've got their own little in-house lab at the clinic, and I went in there, and I was waiting, and the nurse that was taking my blood said, "What are we doing here today?" I said, "Oh, I just got told I have leukemia."

And she said, "Well, oh, that's terrible. What's the diagnosis?" And I said, "Oh, I don't know. It's CML or something like that." And she said to me at that point, she's like, "Oh, you're really fortunate. They've got good medicine for that now."

Elissa: Yes.

AJ: I didn't put a lot of faith in that bit of information, but it was better than the alternative of her saying, "Wow, that's terrible." You know what I mean? She could've said something else. So, from that point forward, I felt pretty confident or at least was

building some confidence that this was gonna be something that I could survive long term with. And then, of course, meeting with Dr. Druker and more and more people. They eventually did assign a new blood cancer doc to Hood River, and I met with that guy, as well, within the first week or so, and, he said the same thing. He's like, "If I was diagnosed with CML, I'd go see Dr. Druker as well," 'cause it's down the road. It's an hour away.

And so, I started building this confidence that things were gonna be okay. So, it wasn't really, like the first weeks and months, Amy and me wasn't touch and go.

Elissa: Yeah.

AJ: We were doing what we were told-

Elissa: Yeah.

AJ: -as far as getting my blood checked and taking the meds and hoping for the right results with the blood tests and all that kind of stuff. And going into OHSU on a very regular basis. It was a journey, that's for sure.

Elissa: Yeah, I mean, 25 years ago before Gleevec came out, CML treatment was a totally different ballgame. So, what your nurse said, what the doctor said is very true that, you're lucky to be diagnosed now, where there is such a good treatment and more TKIs have come out since Gleevec did. So, like you said, if one stops working, you can move on to the next one, and there's so many different options for CML patients that it was just truly groundbreaking treatment for CML and just amazing.

AJ: Yeah, I've talked to Dr. Druker a little bit about those years in the late '90s when he was going through all of that testing and developing and discovering.

And then trying to get it approved and then trying to get the drug companies to actually spend the money to make it and-

Elissa: Yeah.

AJ: -you know, do all that. I mean, he's like Indiana Jones or something with all this because I know that not without— he and his colleagues at OHSU in those days, nothing might have changed, you know? I could have been in the same situation as all those people in the '80s and '90s who would get CML, and nobody knew what to do for them, and nothing could be done for them, and it was horrific, and it was pretty aggressive, I think-

Elissa: Yeah.

AJ: -just from what I've been told, you know? So, it's hard for me to not feel fortunate, which sounds kinda dumb. Not in the sense that I'm fortunate that that development took place, but I'm fortunate that, if you look at the statistics, statistically it's fairly likely that any given human being is gonna be afflicted with cancer in their lifetime. And I'm not saying this is the only one that I might get afflicted with, but this is my one now, and I'm pretty fortunate that it was this and not any number of other ones that are really, really terrible. I feel fortunate.

Elissa: Yeah.

AJ: Which sound silly that this is the cancer diagnosis I got.

Elissa: Yeah. Yeah, and all the work that Dr. Druker and his colleagues did was just amazing. We had him on the podcast a few years back, actually, for our 100th episode, and he shared all about that with, I believe the number two participant on the phase one clinical trial, Mel Mann, who is the longest surviving, CML survivor, to date who started on Gleevec. What was really amazing was that it was just such an incredible phase one trial, and they had just incredible results, which was really helping him get that funding to be able to continue on because he could show these incredible results to show what it was doing with CML patients.

AJ: Yeah, I can't even imagine what it would've been like in those days to just wait for, you know did we strike gold or did we hit the oil pocket? You know what I mean? Just not knowing. I mean, of course they had their tests and their theories and all that, but what an incredible time for them.

Elissa: Yeah. Absolutely. So, our final question today, on our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." What would you say to other patients and their families, particularly those listeners who may be newly diagnosed, to give them hope after a diagnosis of CML?

AJ: Well, I mean, look at me, look at all the other hundreds of thousands or millions of patients in the world who are surviving with it. I think that, like I said before, the building that confidence was something for me that, I think went fairly quickly because I was talking to the right people and because, like I said, I got a backstage pass to talk with Dr. Druker four days after I got diagnosed, which I know is very unusual and very

fortunate on my part. You know, the hard thing is, and this is probably the biggest thing that's come out of being involved in that presentation at OHSU and preparing my remarks and all that, was part of the story here is that when I got diagnosed, there's no playbook, right? My family physician doesn't have a playbook to say, "Hey, you got diagnosed with CML, here's who to call."

"Here's a place to go and get some information." I know they don't wanna give you false hope and all that, and I don't know how this works in the world of medicine, but if I would've been able to walk out the door that day and know, okay, current survival rates are like this, there's a medicine for this, the person that developed this is down the road an hour away, he's seeing patients, he's currently taking appointments. You know what I mean? Like, there's no playbook for it. And I would've been happy to not have gone through a lot of the nasty stress that I went through for the first week or so of all this. Being your own best advocate is the best advice I can give anybody with any healthcare situation, but with CML, the fact that we've got now 25 years of historical data of mostly successful results of treatment from Gleevec and the other TKIs that have followed, I'd like to think that the playbook would be a little bit more like, "Hey, you've got the sniffles. You're not--" You know what I mean?

Elissa: Yeah.

AJ: I'm not saying it's that common, but I think survival is that common.

Elissa: Yeah.

AJ: Survival of CML is now that common. And that'd be really nice to be able to put the next round of newly diagnosed patients into the situation with a little bit less stress and anxiety.

Elissa: Yeah. And I think you're also showing the importance of finding a specialist as well, particularly if you don't live near an academic research hospital or a major cancer center. And for our listeners, you can definitely still work with your local oncologist but also connect with that specialist so they can collaborate together to make sure that you are getting the best treatment possible and also are understanding. It seems to be that you really need to understand the disease better and understand what is going to come, and so you're not in limbo. You're not wondering, what is going to happen.

AJ: Yeah. That's so true for what you said about the rural healthcare infrastructure in our country, is that the further you get away from cities, the harder and harder it is to find specialized care.

Elissa: Yes.

AJ: And for a lot of people, getting from eastern Oregon over to Portland isn't that easy. You know what I mean? I can drive it in a few hours, and I've got the ability and resources to do it, but a lot of people don't, you know?

And they don't know that they should. And so, just maybe, I don't know, spreading the knowledge a little bit more to those rural centers, and allowing people to have the ability to know these things and to know that there's resources beyond where they live.

I mean, if you're listening to this podcast, you probably have blood cancer or know someone that does. So, we're kind of preaching to the choir here, but for those listening today, I don't really know what the move is to make a big change in the healthcare system. But, fortunately for myself and everyone listening to this, more than likely, Gleevec's there, and it's doing its job, and Dr. Druker's to thank for it.

Elissa: Yes. And so all our listeners know what we're doing at Blood Cancer United. We have our professional education team that is working with these community centers and educating them about blood cancers more, and so that they can put together that playbook for patients that come in. And we also just recently recorded a vlog with a community center in eastern Washington, to talk about how patients can get care locally, but also be connecting with that specialist and if they need that extra care, so stem cell transplant, CAR T-cell therapy, they can still get that and still collaborate and stay at home as much as they can.

AJ: Yeah.

Elissa: So, we are working to try to make that better for our rural patients that live farther away. But thank you so much, AJ, for joining us today and sharing all about your CML diagnosis. I am so happy that you are doing well and thriving and still able to do your ski coaching and everything in your life. That is so wonderful. So, thank you again so very much.

AJ: Yeah. Thank you, Elissa. I really appreciate the work you're doing and yeah, knowledge is power and I'm really happy to be part of it. Thanks for inviting me.

Elissa: And thank you to everyone listening today. *The Bloodline with Blood Cancer United* is one part of our mission to improve the quality of lives of patients and their families.

Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. You will also receive an email notification for each new episode. Join for free today at TheBloodline.org/SubscriberLounge.

In addition to the Lounge, we could use your feedback to help us continue to provide 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. 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. However, if you would like to contact Blood Cancer United staff, please email, TheBloodline@BloodCancerUnited.org. We hope this podcast helped you today. Stay tuned for more information on the resources that Blood Cancer United has for you or your loved ones who have been affected by cancer.

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Blood Cancer United

Have you or a loved one been affected by a blood cancer? Blood Cancer United 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 BloodCancerUnited.org/PatientSupport. You can find more information on chronic myeloid leukemia at BloodCancerUnited.org/leukemia. These links and more will be found in the show notes or at TheBloodline.org. 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.