THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Unbreakable: A Mother & Son's Fight Against Cancer'

Description:

Join us as we speak with Ashlee and Michael Cramer, the mother-son duo behind the *Michael and Mom Talk Cancer* podcast. Diagnosed at 19 with a rare and aggressive type of lymphoma, Michael endured intense treatments while Ashlee became his full-time caregiver. Together, they turned their pain into purpose—creating a platform to support other young adults and caregivers navigating cancer. In this episode, they open up about diagnosis, survivorship, and the unbreakable bond that grew from their shared experience. Tune in for an inspiring conversation about finding strength, hope, and beauty in life's hardest moments.

Transcript:

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

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

Elissa: Today, we will be speaking to Michael and Ashlee Cramer. Michael was diagnosed with a rare and aggressive cancer, hepatosplenic T-cell lymphoma, in 2020 at 19 years old. His mother Ashlee quit her job to be a full-time caregiver to Michael following multiple treatments, including chemotherapy, radiation, and bone marrow transplant, along with many complications and side effects. Michael is now in remission and has turned his pain into purpose.

Michael and Ashlee started a podcast titled, *Michael and Mom Talk Cancer* and soon after added a website, blog, and YouTube videos. Their theme is beauty in pain, and they seek to inspire other cancer patients and caregivers to keep moving forward. Welcome, Michael and Ashlee.

Michael Cramer: We are so honored to be here. Thank you, guys.

Ashlee Cramer: Yeah. Thank you so much for having us.

Michael: Yes.

Elissa: So, Michael, let's start with you and hear more about your diagnosis of hepatosplenic T-cell lymphoma. What were your signs and symptoms? Did something in particular make you decide to go in and see a doctor?

Michael: Yes, something in particular did make me want to go and see a doctor. It was around March of 2020, and I remember feeling just so exhausted for several months at this point. It was nothing too insane, my symptoms. My day-to-day life, I was okay. I was just really fatigued at first. And it really was just night sweats that were the first main symptom. And then I started to notice, I was losing a little bit of muscle and weight; and this was something that I was a little shocked by because I had been working out a lot, and I was trying to eat well, and I had been gaining a lot of weight the previous year. I went from around 145 pounds to about 165 pounds in a year before my diagnosis. I had gained 20 pounds.

Ashlee: Of muscle.

Michael: I was in the gym a lot, and I was really just pushing myself and feeling the strongest I had ever been. I eventually got up to around 175 pounds, and then from there, it started to shed really quickly. I looked at myself in the mirror one day, and I remember just being like, "I look a lot skinnier." It was during COVID when the gyms were closed, so I was like, "It's okay. It's probably just because I'm working out at home, and it's not the same as being in the gym, which is why I'm tired, which is why I'm losing weight." And it's basically summer in Miami in March and April and May. You know, it's really hot, so I'm like, there's some sun coming through the windows in the early mornings; and that's when I wake up with these night sweats. And I'm like, "Okay, it kind of all makes sense."

And then the gyms reopened. It was sometime in May or June, and I went back, and I remember I went and I started doing some bench press. Then I look at my friend, and I'm just like, "I don't feel well." So, I went and I found the closest trash can and just threw up. And I went home that day, and then I went back to the gym the next day. I remember texting with my mom, being like, "I'm so tired. Can you pick me up because I don't want my friends to have to drive me home or wait for me because we just got to the gym." I was like, "Mom, can you pick me up?" And then she's like, "Just try and see like if you can finish the workout." I finished the workout. I was really exhausted. I got home, and I remember I was just not feeling well. I started to get fevers and that was when we knew something was wrong because it had been months where I was tired, I was losing weight, and then I started to get the fevers. I was like, "Okay, we need to go and see our family pediatrician."

So, we saw our family pediatrician, and she decided to do some bloodwork. She saw me before the bloodwork and said, "I looked good," and after the bloodwork came back, she called us a few days later and told us to go and meet with her friend who was a specialist who knew all about this blood stuff and could help me. And we went as soon as she called us. She squeezed an appointment in for us that day on July 13 of 2020. I did some bloodwork, and the doctor there asked me to spend the night in the hospital and do a bone marrow biopsy.

And at that point I wasn't thinking anything. I didn't even know what a bone marrow biopsy was. I was just like, "Whatever this is, hopefully this is going to get this 'tired' situation figured out, and I'm going to be back in the gym, and I'll be fine in a few weeks or even tomorrow." I don't know what I was thinking and not a lot of experience with doctors in my life because I was very healthy growing up and just never had to go to the doctor a lot.

And, the next day I come in, because I didn't want to spend the night in the hospital. I was like, "Can we just come in the next day and do the bone marrow biopsy?" He's like, "Sure." So, we came in the next day. I did the bone marrow biopsy, and it was under anesthesia, and I never had anesthesia before, so it was really interesting to get the anesthesia. And I remember waking up from the anesthesia super tired, super groggy, like very out of it. And it's still a blur to me, but my mom tells me that the first thing the doctor said was that what I have is treatable. It's a form of leukemia or lymphoma. And then I just remember being taken up to the oncology floor of the hospital, getting a port placed in the next day, and I was going to start chemotherapy right away. But then they couldn't figure out my exact diagnosis, so we spent a week in the hospital; and then after that week we went home but thankfully the doctor put me on steroids because no matter what cancer I had, steroids, dexamethasone specifically, was going to be part of my regimen.

So, my doctor put me on those steroids. I went home on dexamethasone, and going home I was so weak already. It was crazy. One week of being in the hospital and being told I had cancer, I had lost like 10 pounds in probably a week. I could barely get out of the car when we went home. It was like the cancer had hit me at the right time because as soon as I got admitted, that's when I really started to feel the cancer. And then three weeks later on August 3, I was diagnosed with hepatosplenic T-cell lymphoma; and that was when the doctor told me do chemo, radiation, and then a bone marrow transplant.

Elissa: Wow, I would imagine you'd be like, "What is that?", because I think most people have not heard of that type of lymphoma before. I know you're fairly young at 19 but, did you talk to your doctor then about what this is and how it's different from other lymphomas?

Michael: We did, but honestly at that point, to me, I didn't really care about if it was different than other lymphomas. All I knew was that I had to do chemo, get into remission, and get a bone marrow transplant. And I knew because he explained to me that chemo and then bone marrow transplants were fairly common at this hospital. So, to me, the diagnosis at that point didn't matter. All that mattered to me was, okay, I need to get into remission. I need to get the bone marrow transplant, and then I'll be okay. I didn't want to think too much about the cancer or why it happened or dive into any of that. I didn't think it would benefit me in any way. All I thought was, this is what I'm given. I have to find a way to just deal with it and survive and move forward, and that was it.

Lizette: Yeah, you kind of go into like autopilot at that point.

Michael: Yeah, I definitely did. It was like I needed to just get this done. I was like, "Okay, I just have to do this."

Lizette: Yeah. And Ashlee, the whole process of being diagnosed must have been difficult for you as well. I mean, what were you going through at that time? What were you thinking?

Ashlee: So, Michael touched on a lot of things, but it is true. Ironically, Michael's dad had large B-cell lymphoma and he passed away in 2016. It was very quick. His symptoms were different though than Michael. He had a tumor. It was a very different kind of diagnosis.

And so, it's true, when the doctor said come back tomorrow and do the bone marrow biopsy, you would think I would have thought cancer, but I didn't even think cancer because I was like, Michael was 19. He was so young. He was so healthy. His symptoms were really fatigue and a little fever. I really thought, I'm a vegan mom, I'm not giving him the red meat in his diet. He's working out at the gym, and maybe I'm not giving him enough iron. Seriously, that's what I was thinking. I was like, we just need to change his diet. That's going to fix this, and maybe he needs supplements.

But, when he said, "This is treatable. It's a form of leukemia or lymphoma," literally, I think like everything stopped for me for a moment. I was like, "What? Four years ago, we just went through this with my husband, and how is this possible that my son has a blood cancer?" I was completely taken aback and also taken aback that I hadn't even considered the possibility.

And that week we were in the hospital, you could see that we really did go at the right time. That was the blessing in this is that as soon as Michael started to really get sick, we did go to a doctor because the cancer started hitting. We found out afterwards that it's a very aggressive cancer, and what happens often is that people don't get diagnosed in time. There's a 15% survival. There's like less than 200 documented cases, so that means about 30 people have survived, if you want to put it in numbers, right? But a lot of times it's because they don't get diagnosed in time. So, we were blessed that Michael was diagnosed.

And the other thing is when the doctor said, "hepatosplenic T-cell lymphoma," I still have it. He and his nurse practitioner, they handed me a piece of paper that said the name on it. And they also said, "Don't Google it." And at that moment, I think I knew. And the truth is, we did not. Later I did. But the truth is at that moment we did not. We really listened to them. I actually did speak to someone at LLS that spoke to me about getting other opinions. But his doctor was already linked in with five other doctors that helped to diagnosis Michael. So, around the country there were six doctors that diagnosed Michael.

And so, I felt very secure, and they all came up with a very similar treatment plan, but there is no protocol for Michael's cancer, which is another thing. Large B-cell lymphoma, we knew what we were getting into with my husband. There's a very specific protocol. With Michael, there was not. So, I remember, his fifth day of chemo the doctor comes in with a piece of paper, and he's like, "Oh, my God, Ashlee, look what I found. There's this study that someone that added this chemo into this regimen, it helped them get into remission," because we really did know that the goal was get him into remission, and that would be the hardest piece. And if we could get into remission, he could get to his BMT (bone marrow transplant).

We kind of felt like he was going to be home free. That was what we understood about this cancer. I'm not going to tell the end of the story. He's still alive, but that's not been the case that the BMT was the home free. But that was like what Michael says. We just were like, "Okay, we're just going to attack this." And it's true, you have a moment of grief; and then right away you kick into, "I will do anything in the universe. I will move mountains for my son, and you just do it. You just do it."

Lizette: Yeah, as a parent, I totally understand. First, you're a caregiver to your child, and then all of a sudden you're a caregiver to Michael that has cancer.

Ashlee: Yeah.

Lizette: And you were already a caregiver to your husband-

Ashlee: Yes.

Lizette: -who also had lymphoma.

Ashlee: And I saw him die, and so you can't get rid of that PTSD. But then, at the same time, Michael and I talk about this all the time, I feel like it gave us so much more knowledge. And we knew so much more, and we had more to fight for. We don't like the battle terms, the fight. But I think more to live for, I should say. We've been through this, and so with Michael, I think we had even more like, "Okay, maybe we can make it right somehow."

Lizette: Yeah. I know Elissa doesn't like the battle terms either, right?

Ashlee: We don't either. We don't like "fight" and "hero" because it's not really a choice, and there's a lot of reasons we don't like those terms. Are we saying that my husband lost and Michael won? That's a terrible way to look at it, you know?

Michael: Totally.

Ashlee: So.

Michael: Totally.

Elissa: Yeah. That's a very common sentiment, I think, in the AYA cancer community that, it's like, "Hey, we didn't choose to go through this." And if we didn't make it, it wasn't our fault either. And so, we don't need to be blaming people that didn't make it when it was the treatment that failed us, not that we failed, that we lost.

Michael: So true, so true.

Ashlee: And the whole warrior thing. I mean, Michael, okay, he is so strong and beautiful and wise and wonderful, but he didn't say, "I want to be a warrior." It happened to him. He's chosen how he's reacted, but it wasn't a choice either.

Michael: Yeah.

Elissa: Now, you were treated at the Children's Hospital then?

Michael: So, I went through cancer treatment at the Children's Hospital, and then once I had my bone marrow transplant and developed chronic graft-versus-host disease (GVHD), I went over to an adult hospital. It was weird because when I first developed graft-versus-host disease in December of 2020 and then chronic in April of 2021, I was still at the Children's Hospital. I was going to both, actually. I started seeing a doctor at the adult hospital; and then when I would be admitted, I would be admitted to the pediatric hospital up until 2022. And then after 2022, that's when I was like fully transitioned to University of Miami Sylvester Cancer Center.

Elissa: Okay. I'm curious, when they were talking about it being so rare and not very many cases around the country, what was the general age range because we hear about a lot of blood cancers that are generally a lot of older patients versus young adult patients. And so is Michael's age common for that??

Ashlee: Average age is about 30.

Elissa: Okay

Michael: Yeah, it's something like that. I was 19. It's not like I was 8.

Elissa: Yeah, it's about right in there.

Ashlee: But there's been different ages. We've met people that have been-

Michael: Yeah, and then people younger than me and people way older than me.

Elissa: Now, Michael, you were 19 at diagnosis. What were you doing during that time? Were you in college, working? What was it like for you to then get diagnosed with cancer? I assume that all of that got put on hold.

Michael: Yeah, so I was in college. I'd just gotten home from my first semester in college; and I didn't have the best time at the college I went to, so I was actually taking a break, a semester off. I was getting my personal training certification, and I was about to become a lifeguard at the beach near me because I was like, "Okay, I want to get a job while I'm working on my certification." I'd just finished my course for the certification. I was going to take the test to become a personal trainer and then everything closed down. All the testing centers closed down, and I started to not feel well. And then I was diagnosed.

So, it was crazy because I literally got the job as a lifeguard. I was going to start working. I'd done my physical and everything. It was going to be an interesting point for me in life I never experienced, but I guess it wasn't meant to be. And now I don't do that stuff anymore, but, yeah, I was living a pretty interesting life. I was in great shape, just trying to figure my life out when all this happened. And, I feel like it put me on the right path because I was kind of lost at that time. And, now I know what I want to do with my life. So, in a way, it was a blessing to go through all of this.

Elissa: That's good. It almost feels harder, right, if you're really healthy and things are going well. Then you're thinking to yourself, how did I possibly get cancer when I'm very healthy?

Michael: Yeah, yeah. Definitely. I mean I have a few theories, but I don't know. There was a power plant next to our college that I went to. And my doctor thinks that, because I had mono a year before my cancer diagnosis. That mono, it affects your liver; and it's possible that the cells just kept fighting the mono and replicated and turned into lymphoma, so who knows?

But yeah, when you're healthy, it's kind of a shock. I mean, the thing is, now it's not that much of a shock, now that I've been in the cancer community for the last few years because I see it all the time now. We're so involved with the AYA groups around the country here in America and seeing so many people in my same position who were healthy college students and got cancer. Now, it's kind of normal. I don't know if there's more cases. Are we just seeing more because we're in the cancer community?

But when I was first diagnosed, it was weird because all my friends, they'd never seen anyone go through cancer; and for them, I'm sure it was so weird because I was hanging out with them still; and I didn't look sickly. I was just tired, and then I'm like, "Yo, I have cancer." So, I'm sure it was weird for them as well.

Ashlee: We have a shirt that I made, and it says, "There is no why." And sometimes, I think it helps to say, "Okay, there is no why, or at least it's above my pay grade."

Elissa: Yeah.

Ashlee: But that does not mean that you can't make a purpose out of it. And I feel like, that's been a really big difference for us in this is, you know what, we gave up looking for the why. I don't know why my husband, he was healthy, he didn't drink, he didn't smoke, he got cancer. They say it's not genetic. Michael ended up with a different blood cancer. Didn't drink, didn't smoke, was an athlete, ate healthy food, didn't eat sugar – all the things. We say he checked all those boxes for someone that should not get cancer. And he ended up with cancer. And we know so many young people, as Michael said, that are athletes, that take care of themselves that end up with it. So, we said, "Don't ask the why. Don't waste your time on it. But you can take what you've been through, and you can do something with it, and you can make a purpose out of it." And I think that's been the key for us.

Michael, at the time, says he was a little lost. I don't know if he really felt lost at the time. I think maybe it's hindsight because now he's so motivated, and now he really does know this is my purpose in spreading awareness and spreading hope. It's not just spreading awareness. It is spreading awareness about cancer, but I think it's also spreading hope for people.

Michael: 100%.

Ashlee: For humans because we all are going through something. Maybe it's not hepatosplenic T-cell lymphoma, but we've all got something. And I think it is so hard for AYAs , because that is an age that, what 19-year-old do you know that's not just a little bit lost? I mean let's be real. When you're 19, none of us have a clear path that we know exactly what we're going to do.

And, so maybe there was that blessing, I think, for Michael in that he did have an idea; and this gave him a curveball; and he's adapted, and he has another idea. And me too. I had a different career. Now I do something else, but it's beautiful and it's helping people. And I think that's been a huge piece for us, the helping people, the advocating and seeing that there is a lot in the AYA community.

Lizette: Yeah, you've been a real big support for others.

Ashlee: Yeah.

Lizette: Now, Elissa mentioned that you did quit your job to be a full-time caregiver for Michael. Where did you find your support throughout that time?

Ashlee: We have been so blessed with a community of people that have just reached out and just been so kind to us. I was an early childhood educator, so I had a community of families and children that I taught. And when this happened, I just had people reaching out to me. I think it has been challenging because Michael was diagnosed during COVID. So, it was July of 2020. There were no events. There was not cancer support services happening in his first two years of diagnosis. And so, I think that was a challenge, but then actually I started my own support group.

Michael did the same thing. He started a support group for AYAs, and I started a support group for caregivers. And I think that support group has also been my support because, first, it started out initially in the community. People were just so kind, and I felt like I wanted to give back. And giving back started volunteering at the hospital. And then, it just snowballed into us speaking. They would say, "Hey, can you tell your story?" So, Michael and I'd be like, "Yeah." And I think that we both felt that giving back, because we felt so supported, and the hospital did support us so much. When people could not come visit, the nurses and the doctors, they were like family. I think maybe that was a blessing is being at a pediatric hospital first is that there was that pediatric care of so much love and support.

And there's something about oncology. Because you're there all the time, we were in the hospital, admitted for like two years. Not a joke, and so they became family.

And then our transition. I've heard about other AYAs that have had such a hard time transitioning from pediatric to adult. For Michael, it was kind of seamless, but I think part of that seamlessness was because we had that base at the Children's Hospital. So when we walked into the adult hospital, I was like, "Hi, we're *Michael and Mom*." And I used to talk to the doctors, and I talked to the nurses like family. And I think it also set the tone for our relationship that we have at the adult hospital. Because with my husband, it wasn't like that. It was so dry. It was not a family feeling. I felt like he went in, did treatment, left, that was it.

And with Michael, it's been the opposite. I think that that's been part of our story as well, connecting not only with other people and other AYAs and other caregivers, which has been important, but connecting with the nurses, connecting with the doctors.

I think that's important too. I think AYAs and caregivers, we sometimes feel like we're told what to do. But often you can have a conversation. With my husband I didn't feel like I could have a conversation. He was given a protocol. We followed it. With Michael, I felt like we would talk about things, like understand things. Maybe that was a blessing of having a diagnosis that was unusual, as well. But I think it was, us. We just talked to people like they were people, and I think that's a really big message for caregivers and AYAs.

Lizette: Yeah, definitely.

Ashlee: Yeah.

Elissa: So Michael, you briefly went over some of your treatment. Chemotherapy, radiation, then you got the bone marrow transplant. And then, you mentioned that you got GVHD, or graft-versus-host disease. Could you tell us a little bit more about that?

Michael: Yeah, graft-versus-host disease is basically exactly what it sounds like. It is, when you get a bone marrow transplant and the graft, which is the donor's stem cells, start attacking you, the host. It's like the curse of surviving a bone marrow transplant can be graft-versus-host disease. It's like, you survive this cancer, you got your cancer into remission. You get your bone marrow transplant. You're so excited, and then you get this thing called graft-versus-host disease, which about 50% of people who get bone marrow transplant experience graft-versus-host disease. So, it's actually fairly common and it can be very, very detrimental. And for me for the first two years of it, it was extremely debilitating; and it was very, very hard. It still is something I live with to this day, chronic graft-versus-host disease; and I deal with it every single day.

I do mouth rinses every day. I take medications every day. I'm still doing treatments for it in the hospital, so, it's been a journey. It's like getting cancer in remission and then you get another cancer after it. It felt like that at first, because I struggled more with the GVHD than I did with the cancer. After I was in remission and I got graft-versus-host disease, it was so aggressive in my liver that I was so yellow, so jaundice, and for basically a year we were just trying to figure out any way to get my liver to get better. We tried every single graft-versus-host disease treatment that was available. We were in the hospital all the time. I had a drain in my liver. I had to get my gallbladder removed. There was so much that went into graft-versus-host disease treatment. And thankfully, in the summer of 2022, after a year and a half of dealing with graft-versus-host disease, somehow my immune system just calmed down and was like, "Okay, we're going to be okay." And I don't know how I survived.

Ashlee: There was a lot of medication and immunotherapies that went along with that.

Michael: Right, yes, of course. But it was a lot of just luck.

Elissa: Yeah, so you mentioned it affected your liver. Did it affect any other body parts?

Michael: Yes, I have it now in my liver, my skin, my mouth, and my GI (gastrointestinal) as chronic, so-

Elissa: Okay.

Michael: -it's affected a lot of my organs, and it does every day. I do mouth rinses every single day, twice a day. I take immunosuppressants, and every time I brush my teeth, and I am bleeding. Like I spit, and there's just a sink full of blood because of the mouth sores that I have that just don't go away and the sensitivity in my mouth. So, kind of gross, but that's just life with graft-versus-host disease.

And I have a lot of marks on my skin; and my skin is very fragile to the sun and can get irritated very easily and my stomach is very sensitive and I've had lots of issues with my GI over the years. The liver enzymes are still elevated. My kidney function is still elevated as well because of everything. GVHD affects your whole body; and I have to go to ENTs, which is ear, nose, and throat doctors, every few months to check for mouth cancer because it's very common to get mouth cancer with chronic graft-versus-host disease. I had a biopsy in my mouth a few months ago. So, GVHD is another beast just like cancer.

Elissa: Yeah, we recently spoke to a doctor all about GVHD, and thankfully it sounds like they're coming out with more and more treatments, so

Michael: Yes.

Elissa: I do hope that they'll come out with something that works for you and helps it go away or at least be significantly more manageable.

Michael: Oh, it's been so much more manageable the last year though.

Elissa: Good.

Michael: Like, my numbers are still elevated, but I'm alive, and I'm doing very well. I've been back to surfing this year.

Elissa: Yay!

Michael: Back in the gym. Not like before because there's still so many limits and restrictions on the things I can do. But I am living and adapting every day to living with graft-versus-host disease long term.

Elissa: Wonderful. And then the cancer is in remission?

Michael: Yes, the cancer's thankfully in remission.

Elissa: Wonderful. That is so great.

So, another question to both of you, actually, tell us what you've been doing since those initial treatments. It sounds like you've been really busy with your podcast and website and social media, and other speaking engagements like CancerCon®, Young Adult Cancer Conference. So, tell us what you've been doing?

Michael: We have been doing a lot of that stuff. We just go everywhere we can that people want us to speak, anyone that tells us, "Hey, do you guys want to speak at our event? You want to speak at CancerCon? You want to speak at CureFest®?" Any cancer event, we're going there we're speaking. Anyone asks us to be on their podcast, we're on their podcast. We have our own podcast, and I'm not going to say everything. I want my mom to talk as well because I know I can just steal all the words and say everything. But, yeah, we do a lot of stuff.

Ashlee: You're so funny, because he knows he likes to take all the words out of mouth. But that's because we share so much. It has been amazing to see because it's true, after the BMT, everyone that's been through a bone marrow transplant knows the goal is get to Day 100. And you get to Day 100 and then feel like you're home free. And I think for us, we're like, let's get to Day 100, and then you're home free. And on his Day 100, happened to also be my birthday, and we were like, "That is a sign, wahoo!" And actually, that was the same day he was diagnosed with the chronic graft-versus-host disease, with all of these other things that were just so complicated.

But that was also the moment that we're like, you know what, okay, this isn't going to go away. It's not like after Day 100, we thought we're going to bounce back. You're going to get back to college or maybe it's going to be getting back and being a personal trainer. I'm going to get back to teaching, and we're like, "Not going back." But that's, I think, when we realized, not going back but going forward and changing and, as Michael said, adapting. And I was like, "You know what, Michael, we're in this for the long haul." And that's when we're like, "Let's do the podcast. Let's just share this story because it seems like if we are going to be in this, let's use it for the good." And the podcast was just organic and like it's really funny. We've done rap videos in the hospital, and outside of the hospital, we have them on YouTube, and we want to do one for GVHD, that's the next one. But we've done like eight of them.

And, it was a way, I don't like to say distract, but to do something positive with what we are going through and fun. People talk about mindset; and I think for us, we've always said, the best way to help yourself is to help others. I'm a middle aged woman. I don't know, 56, so maybe above middle aged. At the time, he was-

Elissa: No.

Ashlee: He was 19, well, 20 at the time, but he was willing at 20 to like do a podcast with his mom and make YouTube videos with me and make up rap songs, be on this podcast with you, and we do speak together, and we do share a lot. And he has his own voice. He 100% has his own voice and so do I for caregivers. But I love the fact that we also come together, but I think our voices together, it's even more impactful.

So, that's been really beautiful as a mom to see, and he does have two siblings; and they have been so supportive as well. Sometimes we don't talk about them enough. They have their own lives too. But they've also been so incredibly supportive. And when their dad died, my three kids got so close. Of course, they were already close; but it brought them even closer. I always feel like they didn't have their bad teenage years because in the bad teenage years they were huddled, watching their dad pass away.

And when Michael went through this, I was like, could they get closer, and they did. And so, that's been a really beautiful side to cancer is that vulnerability perspective. And I know I went off the topic, because I was supposed to be saying like what are we doing now. But I think what we're doing now is just trying to share our perspectives because it's been such a gift. And I hope that people don't have to go through cancer to get this perspective that we have. That's our goal.

Lizette: And we want to thank you because a lot of people feel isolation.

Ashlee: Yes.

Lizette: And they feel like they're alone. And just you and Michael sharing your story is really helpful for people to know that they're not alone. Not alone with getting treatment for cancer and not alone as being a caregiver.

Ashlee: Yeah, it's ironic, right? Is that we're going through this really hard thing. I always feel like it's such an irony, and we tend to isolate ourselves when we're going through this really hard time. And that's when we need the support. So, I think it is important just to remind people.

And sometimes it is hard because, like Michael was saying, his friends couldn't quite relate to him. And so maybe it's that you don't diss your friends, but maybe you add other friends that do understand, that are in the AYA community. I have a new circle of friends that are caregivers that, gosh, I just love them so much. Every Saturday we're talking. And it's changed my life, and I think it changes their life. It doesn't mean I don't love the friends I had before. But I think in this community, sometimes we need to talk to someone that you don't have to explain. They just, get it.

Lizette: Right. And Michael, you said that now you have a clear focus after all of this.

Michael: Yes, 100%.

Lizette: Yeah.

Michael: It's just doing what we do and trying to speak everywhere that we can and help as many people as we can and do our social media posts, and do the YouTube, and do the podcasts, and it's advocacy and it's just helping others. I think that's our purpose is to help others because we were given this gift that I'm surviving and I'm here and I'm able to share messages of hope with other people.

And I know it helps people. I know how important it was for me to see other people doing well after cancer and see other people online with graft-versus-host disease living as well. So, I'm sure that I can use my situation to help others who are lost like I once was and show them that there is life after cancer and there is life with GVHD, and it's not over just because you have this illness that feels like it defines you sometimes; but it really doesn't define you. You define you, and you can adapt to your situation and that's what we're doing.

Elissa: I think that's a particularly important thing. We talk a lot about life after cancer, so life after treatment, but we don't talk a whole lot about living with GVHD and still being able to have a life and be able to thrive and go back surfing if that is what you would like to do.

Michael: Yeah.

Elissa: And so, it's really good to hear that you have started to build, essentially, a new life around what you still have to live with, with the GVHD. And so, I think that, in particular, is very, very good for people to hear that they can still thrive, even if they're still dealing with these things.

Michael: Yeah, I think it's so important to try and do what you can because when I was first diagnosed with GVHD, I found out I had vascular necrosis in my elbows and my knees. And what that basically means is the bones have deteriorated, and there's lack of blood supply to them, so there's pain. I can't really lift heavy weights anymore, and there's so many things at first I just thought I would never do again. And I thought I would never be back in the gym or surfing because of this condition.

So, I had my knee replaced, and I haven't done anything for my elbows, but I have just modified the way I work out, modified the way I exercise, modified the way I surf, modify everything to what I can do. I think it's really important that people understand that you can still find ways to do things you love. You just have to adapt and modify it because when I was told I couldn't go in the sun because of GVHD, which I still can't, when I was told that my knee was basically collapsed, I was like, "How am I ever going to surf again?" There's no way because the surfing is in the sun. You need your knees, and you need your elbows to stand up. So, I thought I could never do these things again, but now I go surfing early morning or late evening. I had my knee replaced, and I worked in physical therapy for years to be able to just walk normally. And then, it became going on a Stairmaster, and then it became surfing. ””You just have to keep going is my message to anyone listening to this because if you give up, you'll never know. You just have to keep going and keep trying. You never know how good things can turn out. You never know how things can change for the better.

I didn't know that I would ever be happy again, because I was so depressed at one point. So, it's just finding out that you have to just keep living, keep moving forward, and eventually you will come to a better place.

Lizette: Yeah. And Michael, how has this whole experience really shaped your relationship with your mom and your siblings?

Michael: Yeah, so it's like my mom is not my mom, just like someone I live with.

Ashlee: I'm just someone you live, I'm just your roommate? Wait a second.

Michael: No, it's more like a friend.

Elissa: I don't know if she wanted to hear that.

Michael: No, not what I mean. It's like a sibling more than my mom. It's more like someone that I'm bonded with because some people are like, "Oh, my mom wants me to do this. My mom wants me to do the dishes or whatever." You know how people have relationships with their parents, and it's just like, "Yeah, that's my parents." But for me, it's really my best friend and my mom and someone that I'm with every day, someone I'm very close with. And it's a very deep relationship, and I'm very grateful for it.

Ashlee: Whew, you got yourself out of that one.

Elissa: How do you feel like the relationship has changed, Ashlee?

Ashlee: I thought I'd be an empty nester at this point, first of all, and here I am. And we are roommates; but he is one of my best friends. I literally was saying this to someone just yesterday. She said, "I wish our kids were still young and little." And as moms, sometimes we want the little baby age. And I was like, "You know what, I would not trade any of my three kids; but I wouldn't trade this relationship for any baby moment." It's like I love that he talks to me. I love that I can talk to him. You know, I've been next to him when I wasn't sure he was going to wake up. And more than once. We don't always talk about that very much, but I've sat next to him when I really thought I might not see his eyes open again.

And so, being so close to him, and I think that shaped our perspective; and there's a part of me that was like, "Well, when he gets better, I hope we can hold onto this perspective." And I have. I've been watching him, next to him, supporting him and loving him. And I do see like he is surfing again, and he is doing many things. He's doing different things than he did before, and I feel like we're still even closer than we were before.

Yesterday, we were at a celebration of life together for someone, a young AYA that we knew. And the two of us sat there, and we were like, we're so blessed that he's alive and that I'm alive. But so blessed that Michael is still here, and I think that that's a perspective that I hope we hold onto. It is a daily practice. You have to think about it sometimes when traffic gets to you, dumb things, and you have to remember, "Oh, yeah, we're alive."

But it's been so beautiful to see how he's grown from this, and I feel like, Michael, and I don't want to say this and sound the wrong way, he has not put this behind him and neither have I. I think it's part of who we are. And as he said, not defining who we are, but it is part of who we are. We can't deny that, and I think if we denied that and tried to live being like, "Ah, we're just going to go back to who we were before, then what would be the point?" We went through all of this, and I love how it's changed him. I love how it's changed his siblings. And I always say that I feel like we have a cha-cha. We go back and forth, but what's consistent is I feel like our relationship is deeper and wider. I feel like Michael is a human, I see him deeper and wider.

We joke about his bones being 80 years old with the AVN (avascular necrosis), but it's not just the bones. It's also his wisdom, and it's very beautiful, and I think that's one reason we're good friends because probably he's older than me. In fact, Michael, you think you're my kid, but I'm pretty sure you're older than me.

Michael: I am. You don't have AVN in your knees, your elbows.

Ashlee: No. You don't have my gray hair and wrinkles, but you know.

Michael: Younger bones. I'll take the gray hair and wrinkles. I don't care.

Ashlee: I'll just, I'll just take my relationship with him. It's beautiful and we're blessed. We've seen people that cancer has been really hard for their families. And I understand that. But I think we've been really blessed, that opposed to pulling us apart, it's brought us together. And I think it's just a reminder to everyone. The hard things should bring us together. Don't let them take you apart.

Elissa: That is beautiful advice, and I'm so glad that you have built up such a wonderful relationship with each other as friends and, not seeing her as just your parent. And so, that's wonderful.

Now, our final question for you today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would each of you say to other patients and caregivers to give them hope after a diagnosis of cancer?

Ashlee: I think my hope is that it's kind of what I said earlier. It's that, even if you've been through cancer, there is hope for a beautiful life. It might not be that path that you envisioned, but for us it's been even more beautiful, it's been even more fulfilling because you do get that perspective; and I think the hope is the connection with other people that are out there. And the hope is when you go through something like this, you do have a choice in how you react. And I think we forget that we do have some control because cancer feels like it takes control away. And I hear that from caregivers all the time.

But in fact, you do have control, and that control is how you move forward. And that's always just my biggest message is moving forward, not trying to go back to who you were before; and that hope is that your new future, so often it's just richer. It's just richer.

Michael: Yeah, there is hope. There is life after cancer. I am an example of it. I've seen so many others who are examples of it as well. There's also, so much support out there. There are so many resources when you are diagnosed with cancer. I mean, like LLS, CancerBuddy®, all these apps and organizations that are there for cancer patients. And this journey, it's not going to be something you have to go through alone. A lot of times when we get diagnosed with cancer, we don't know many people who have been through it. But there is a community of people out there, and once you become part of that community, you're going to be so happy because the community of cancer survivors, patients, and caregivers is so beautiful. And it's like way better than any other community I've been a part of.

Ashlee: Best club you never wanted to be part of.

Michael: Exactly. So, getting diagnosed with cancer is sometimes a blessing because you get these amazing friends and connections and perspectives. So, it's not all just a struggle. It is a struggle, yes, but there is good to it.

Elissa: Yes, I agree. There is so much support in the cancer community and so many other resources that patients and caregivers can get to be able to navigate through a cancer diagnosis and beyond, navigate through GVHD and survivorship issues. And so, thank you both so very much for joining us today. It was wonderful to hear how you're thriving after this such rare diagnosis and how you're continuing to give hope to others, which is so needed, particularly in the adolescent and young adult, or AYA community.

And Ashlee, thank you for sharing what it was like for a caregiver of a young adult to go through all this as well, especially since you had lost your husband to a lymphoma. And so again, thank you both so very much for being here with us.

Michael: Of course. We were so honored to be here and be part of this amazing podcast.

Ashlee: Thank you. Such a pleasure. Thank you so much and everyone listening. Thank you so much. But thank you both.

Thank you both for really listening.

Michael: Yeah, thank you guys.

Lizette: Thank you.

Elissa: 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.

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