

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Not Cashing In My Chips: Living with Cancer'

Description:

Join us as we speak to Mousa Ghannam, who was diagnosed with chronic myeloid leukemia (CML) at the age of 24. He shares his ups and downs over the past 20 years and how he has persevered to become the happy and healthy husband and father he is now.

Don't miss this inspiring episode of a blood cancer survivor who chooses to bet on life and not cash in his chips.

Transcript:

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

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

Elissa: Today, we will be speaking to Mousa Ghannam, who was diagnosed with chronic myeloid leukemia, or CML, in 2004 at 24 years old after excruciating pain in his knee brought him to the doctor. He was initially misdiagnosed and then finally received his CML diagnosis. He started his daily treatment and now, 20 years later, is a happy and healthy husband and father. Welcome, Mousa.

Mousa Ghannam: Hello and thank you for having me on today.

Elissa: Thank you. So, let's start with your diagnosis of chronic myeloid leukemia, or CML. Could you tell us more about having that knee pain and that eventually bringing you to the doctor? Were there any other signs and symptoms that you had noticed?

Mousa: There might have been a few at the time. I had lost a lot of weight, probably two years prior to my diagnosis; but it's because I had taken it upon myself to work

out, to start living a healthier lifestyle, exercising, and I was biking and hiking, and I took a lot of yoga classes. And once I had lost so much weight and had so much energy, I think at one point, I was losing a little too much weight. I started looking at myself in the mirror, and I said to myself, "Wow, I am as thin as a fiddle. I have never been that thin in my entire life." But I never thought, it would be a diagnosis of a type of cancer. Nobody ever thinks that.

The pain in my knee I can never forget. It was the worst pain I have ever felt. Something told me inside to go and get yourself checked out. Don't waste time because you know your body better than anyone else. I thought maybe I might have injured it, sustained some type of thing during yoga or when I was running outside on the bike trail. But little did I know, there was some really bad news coming my way.

Elissa: So then, that knee pain brought you into the doctor; and I mentioned in the introduction that you were initially misdiagnosed. Could you tell us about that?

Mousa: Correct. They had diagnosed me with ALL at the time.

Elissa: Oh, okay. So, that's acute lymphoblastic leukemia, for those that are listening that don't know.

Mousa: Correct. And I didn't know much about it, hardly anything. Nor did I know about CML or all the other blood cancers. I did quick research though, and it's not a walk in the park. It's not an easy cancer to deal with and to overcome. So, after a week, I made an appointment, and I went and saw a specialist in Baltimore. And the good news was that they told me you have a chronic type of leukemia, CML, which at the time, I was diagnosed in the earliest of three stages. Very, very early they told me, which was very good news, promising.

I was already very healthy. I took very good care of myself. I wasn't stressing over things in life. Wasn't drinking, wasn't smoking. I did the best I could. Was I perfect? No. Nobody is, but you do the best you can with what you have. It made it easy for

me to put things in perspective, what I needed to do, the direction that I needed to move forward in. And I knew I had the best supporting cast you could possibly ask for – a loving mother and father, my siblings. I wasn't married at the time, but I had my grandmother who still lives with us today. She's 94 years old. She is one of my true inspirations in life. I just, I love her dearly – her and my late mother. So, I tell you, it wasn't easy, but nothing ever is.

Holly: So, Mousa, you were diagnosed at the ripe old age of 24 when you're just coming into adulthood. What were your thoughts going through your head being diagnosed as a young adult?

Mousa: You know, you start questioning what it was maybe you were doing in life that might have caused this. I started questioning God, who I'm a big believer in. What did I do to deserve this? Nobody really deserves it, of course. I was young. I was traveling a lot, and I wasn't ready for this type of responsibility to take upon in life because, it's either you take it and you fight it and you put it in your mind and you beat it, or you just cash in your chips and you let it take you out. I was strong-minded, and I had the will and the desire because I loved life so much at the time. And I still do today. I have so much now, more than ever to live for. My four beautiful children, my beautiful wife, and again my grandmother who's still living strong.

But when you're in your early 20s and they tell you, "Hey, kid, you've got cancer." And they tell you this when you're at the peak. I felt like I was in the prime of everything, physically, mentally. I was a rock. I didn't think I could have been broken or beat. There's just no way. But when they tell you something like this, I mean you want to talk about a gut check. Hey, here's reality knocking at the door. You either face it and deal with it or...I had no choice. I put in my mind I was going to beat it, that there were still so many things in my life that I wanted to accomplish; and I'm still heading down that road. I haven't cashed in my chips.

Elissa: I love that. So, after you're diagnosed, you're put on treatment. Could you tell us a little bit about your treatment?

Mousa: Absolutely. So, there was the miracle drug at the time on the market. It was called Gleevec®, and it was just whoa, buddy. It was taking people and putting them in a full remission. And it helped people, depending on what stage your cancer was in. And it had certain side effects. It did affect people differently.

Luckily for me, I remember I think the only thing that I had issues with it would make my stomach a little upset; and I don't think I was eating properly at the time because I think with medication like that you were supposed to eat a good meal with it.

They had told me take two pills – one in the morning, one in the evening. They were each 400 milligrams, so, I was putting into my system 800 milligrams a day. My body reacted so well to the Gleevec after a year that my oncologist reduced the dose to only one pill. It's a blessing. And I'm so thankful. So, I take the one pill still today, 400 milligrams, and it's a generic brand called imatinib. I take it during the evening hours with dinner and I don't have any side effects at all. I think a lot of people who do take this type of medication, it makes them tired. It can really take a lot out of you. But, of course, look what it's doing for you.

Elissa: Yeah, Gleevec was very, very new around the time that you were taking it. I believe it was approved in 2001. We actually did a podcast about two or three years ago with the developer of Gleevec, Brian Druker. And it was really neat to hear how it was developed.

I remember before Gleevec came out, really the life expectancy was only a few years; and not many people were making it past that after a diagnosis of CML. Has your doctor talked to you about the possibilities of really living a very long life with CML? I mean, you've made it 20 years, so what has been the conversation with your doctor about that?

Mousa: He's told me before in the past that, like you commented on, the life expectancy before Gleevec was a lot different than what it is now. And now that I have lived 20 years with it, we're both hopeful. I'm hopeful that I can live the rest of my life. I can live another 20 or 30 years. If my body continues to react well to the medication, and who knows, maybe one day I can stop taking it. But for now, I'm very hopeful that I still have a long life ahead of me.

Holly: What was the emotional impact of being told that you have a chronic cancer that currently isn't curable?

Mousa: It was tough. I was going through withdrawals, denial I should say, just not knowing sometimes what was going to happen early on when I was diagnosed. You know, the fear of not being able to make it. The fear of my body not accepting the medication. There was a lot of doubt and fear. I just kept remaining very positive and optimistic and listened to the professionals around me and, again, I always had the best supporting cast you could possibly imagine, which made it a lot easier at the end of the day for me.

Holly: Yeah, and it's been a long journey. It's been 20 years, and through that experience, it's an emotional rollercoaster of highs and lows. So, do you ever have those lows come up; and when you're thinking about it, how do you manage your feelings?

Mousa: I used to, early on, within the first couple of years when I was diagnosed in the mid-2000s, I used to go to support groups, people that had CML like me; and it really helped that you can talk to people who have the same type of cancer. And we just could relate to a lot of different topics. But then I think what really helped me was remaining busy in life. The responsibilities grew. I got married in 2012. I have four beautiful, healthy kids. It's not that you forget that you're diagnosed. You never forget. There's no way. It will live with me for the rest of my life. It makes it easier

to deal with. You just don't have time to sit down and think of those uncertainties that you used to think about.

I have so many other things that are on my plate. It makes it easier for me now to live my life the way I always wanted to. I kind of put it behind me in the past, but it'll never be separated from my heart and my body.

Holly: It sounds like you lived a lot of life since your diagnosis. You just mentioned your beautiful wife, your beautiful children. Is there anything else that has been just life-changing since your diagnosis?

Mousa: Well, I actually, have had several near-death experiences.

Elissa: Oh.

Holly: Oh no.

Mousa: Oh, yes. I was involved in three car accidents I could have died in. There was a drowning incident. I almost drowned in Hawaii. My brother's best friend saved me. We were cliff jumping, and I wasn't a good swimmer at the time. So, I decided to climb down the side of the cliff on these rocks. This wave came and just nailed me. It was terrible.

What didn't kill me in life made me stronger, whether it was the car accident, whether it was the diagnosis with cancer, the list goes on, and that's life. You've just got to roll with the punches. It's not going to be rainbow and sunshines everyday. I get it.

Holly: And every time you've chosen to fight and not cash in your chips.

Mousa: Absolutely. I love life so much. I love people. I love interacting with people on a day-to-day basis. Just being here on this podcast with you both today, this is a dream come true. I will never forget this as long as I live, and I'm so blessed and so fortunate. And this is who I am every day. I'm so thankful. I get up in the morning. I have so much energy, and it's like this throughout the entire day.

Because not everyone has the opportunity that you and I might have every day. Not everyone is physically able to continue to roll with those punches like we are. So, I don't take any of that for granted. I'm just one of those people who I say thank you. I say thank you every day for everything I have.

Holly: And looking backwards now that it's been 20 years, can you look more forward into the future? Can you see 20 years from now? Can you see 40 years from now?

Mousa: Without a doubt, absolutely. I envision things. I see myself tomorrow where I'm going to be next week, where I'd like to be next year. I set goals for myself. I think it's important because it keeps my mind running. It keeps my battery on a high. And I've never been more ambitious in my entire life.

Elissa: That is so good. Okay, Mousa, so our final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your own cancer experience, what would you say to patients and their loved ones to give them hope after a diagnosis of CML?

Mousa: I would look at them directly into their eyes, and I would tell them sincerely that it's something that you have to grasp mentally, physically. You've got to take it, you have to be strong, you have to be willing to fight the biggest fight ever in your entire life. Will it be easy? Absolutely not. But take it from me, someone who's lived the experience, who is continuing to live it. You've got to get up, give it your all, and go with it. Don't ever stop believing. Don't ever quit. You have to believe in your mind that you will make it out on top, that you will beat this, you will be better than it, and that you will learn from it.

Elissa: That is absolutely wonderful advice. I love it. I hope that that will really give some hope to patients and their loved ones that are listening because they might be early in their diagnosis, right? They might be scared and-

Mousa: Yes.



Elissa: -not knowing what is ahead for them 20, 40 years down the line or just a few years down the line. And you've had all of these ups and downs through this, yet you have persevered, and you have shown so much resilience through this diagnosis. We are so happy to hear that you are doing so well in your life and you have continued to move forward, push forward. So, thank you so much, Mousa for joining us today. We loved having you and really appreciate you.

Mousa: Thank you.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

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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 LLS staff, please email TheBloodline@LLS.org.

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